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Community and Wellbeing Scrutiny Committee Supplementary Agenda

Tuesday 3 March 2020 at 6.00 pm
Boardrooms 3-5 - Brent Civic Centre, Engineers Way, Wembley, HA9 0FJ

Membership:

Members Councillors:	**Substitute Members** Councillors:
Ketan Sheth (Chair) Colwill (Vice-Chair) Afzal Ethapemi Hector Knight Shahzad Stephens Thakkar	Aden, S Butt, S Choudhary, Gbajumo, Gill, Johnson, Kabir, Kelcher, Mashari and Nerva Councillors: Kansagra and Maurice

Co-opted Members
Helen Askwith, Church of England Schools
Dinah Walker, Parent Governor Representative
Simon Goulden, Jewish Faith Schools
Sayed Jaffar Milani, Muslim Faith Schools
Alloysius Frederick, Roman Catholic Diocese Schools

Observers
Jenny Cooper, John Roche and Azra Haque
Brent Youth Parliament

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If a Member is aware they have a Disclosable Pecuniary Interest* in an item of business, they must declare its existence and nature at the start of the meeting or when it becomes apparent and must leave the room without participating in discussion of the item.

If a Member is aware they have a Personal Interest** in an item of business, they must declare its existence and nature at the start of the meeting or when it becomes apparent.

If the Personal Interest is also significant enough to affect your judgement of a public interest and either it affects a financial position or relates to a regulatory matter then after disclosing the interest to the meeting the Member must leave the room without participating in discussion of the item, except that they may first make representations, answer questions or give evidence relating to the matter, provided that the public are allowed to attend the meeting for those purposes.

*Disclosable Pecuniary Interests:

(a) **Employment, etc. -** Any employment, office, trade, profession or vocation carried on for profit gain.
(b) **Sponsorship -** Any payment or other financial benefit in respect of expenses in carrying out duties as a member, or of election; including from a trade union.
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(g) **Securities -** Any beneficial interest in securities of a body which has a place of business or land in the council's area, if the total nominal value of the securities exceeds £25,000 or one hundredth of the total issued share capital of that body or of any one class of its issued share capital.

**Personal Interests:

The business relates to or affects:

(a) Anybody of which you are a member or in a position of general control or management, and:
- To which you are appointed by the council;
- which exercises functions of a public nature;
- which is directed is to charitable purposes;
- whose principal purposes include the influence of public opinion or policy (including a political party of trade union).

(b) The interests a of a person from whom you have received gifts or hospitality of at least £50 as a member in the municipal year;

or

A decision in relation to that business might reasonably be regarded as affecting the well-being or financial position of:
- You yourself;

a member of your family or your friend or any person with whom you have a close association or any person or body who is the subject of a registrable personal interest

Supplementary Agenda

Introductions, if appropriate.

Item		Page
4	**CCG Review and Proposals for Local Palliative Care Services**	1 - 140

To receive and consider a report from Brent Clinical Commissioning Group (CCG) providing an update on the review and proposals for local palliative care services in Brent and three other north-west London boroughs.

Date of the next meeting: **Monday 16 March 2020**

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- The meeting room is accessible by lift and seats will be provided for members of the public.

Brent	**Community and Wellbeing Scrutiny Committee** 3 March 2020
	Report from Brent Clinical Commissioning Group

Community Specialist Palliative Care

Wards Affected:	All
Key or Non-Key Decision:	Non-key
Open or Part/Fully Exempt:	Open
No. of Appendices:	9: Appendix A - Summary of the Penny Hansford review Appendix B - The Penny Hansford Review Independent Review Palliative Care Report Appendix C - Palliative Care Review Workshop findings Appendix D - Palliative Care Services Involvement document Appendix E - Palliative Care letter to stakeholders – 3 January 2020 Appendix F - Palliative Care letter to stakeholders – 17 January 2020 Appendix G: Mortality rates and preferred place of death Appendix H: Current spend by Brent CCG on palliative care services Appendix I: National Guidelines on End of Life Care
Background Papers:	None
Contact Officer:	Jonathan McInerny Senior Commissioner Manager Brent CCG jmcinerny:@nhs.net 07940 297544

1.0 Purpose of the Report

This report provides an update to the Committee on the engagement on re-designing services for people with incurable illness or in their last phase of life in Brent, Central, Hammersmith and Fulham and West CCG areas.

The current engagement process has resulted from an independent review by Dr Penny Hansford, of specialist palliative care services commissioned by Central, Hammersmith and Fulham and West CCGs.

Brent CCG was not included in the Hansford Review. However, Brent CCG commissions some of the community specialist palliative care reviewed by the report and since its publication has been working closely with other CCG's in engaging local patients and stakeholders on the outcomes of the review and the development of commissioning policy for all four CCGs.

The Hansford Review was prompted by the suspension of the In-patient unit at the Pembridge Palliative Care Service, run by Central London Community Healthcare NHS Trust (CLCH) on 1st October 2018. This was as a result of the resignation of a specialist palliative care consultant in July 2018 and the inability of the provider to recruit a registered specialist palliative care consultant to lead the unit.

The Pembridge In-patient Unit is jointly commissioned by Brent, Central, Hammersmith and Fulham and West CCGs with Central London CCG being the lead commissioner.

Neither the CCGs nor CLCH could be assured that the in-patient service being delivered at the Pembridge was clinically safe without a lead suitably qualified specialist palliative consultant in post.

CLCH has been unable to recruit a suitably qualified consultant to lead the Pembridge in-patient unit since October 2018 and patients have been supported by alternative in-patient units commissioned by the CCGs. Whilst the in-patient unit is suspended, the Pembridge Palliative Care centre continues to deliver palliative care services to local people through its day centre and community services within people's homes.

Interim arrangements have been in place since 1st October 2018 to ensure patients who would normally be expected to be an in-patient at Pembridge are transferred to other available hospices commissioned by the respective CCG. For Brent CCG that includes St John's Hospice, St Luke's Hospice and Marie Curie Hampstead Hospice.

Total in-patient bed nights have remained relatively stable before and after the Pembridge in-patient hospices was suspended (see 5.0 below for details). In addition, there has been an increase of 1,441 hours provided by the Hospice at Home service to provide end of life care in peoples' homes.

The aims of the Hansford Review were to review national strategy, policy and best practice alongside local context and report recommendations to Central London CCG (the co-ordinating CCG) on options for a new commissioning model that provided the highest quality of care for patients, their families and carers at the best value.

For the purpose of engaging stakeholders and local people the CCGs have described four potential scenarios for the future delivery of palliative care. These have been discussed at a series of well-attended workshops.

Patient engagement meetings were held in the Hospices in Brent in March and April 2019 and workshops were held across the boroughs to understand the experience of the end to end pathway covering ‘Access’, ‘Care’, ‘Bereavement/aftercare’. A public and patient working group’ was formed with representation from across the 4 CCGs, to work with us on this programme and review our scenarios.

Currently further public engagement workshops are being held until 13th march 2020 on potential scenarios for the future delivery of community palliative care.

The results of this engagement period will be presented to CCG governing bodies for consideration of the next steps. The CCG governing body meetings are likely to take place in early spring. The CCGs would like to update the public with the outcome of these meetings after they have taken place.

Should any recommendations be classed as ‘substantial’ change to the existing specialist palliative care services by our governing bodies (the CCG boards) and associated NHS bodies, these changes will be subject to a public consultation.

2.0 Update on Specialist Palliative Care work

The CCG presented a paper to the Committee in July 2019 updating members on Community Palliative and End of Life Care (EOLC) services in Brent and the work being done to consider the Strategic Review of Palliative Care (the Hansford Review).

2.1 The Strategic Review (Hansford Report)

The Strategic Review was launched on 14th December 2018 on behalf of three Inner North West London CCGs – Central London, Hammersmith & Fulham and West. It was led by Penny Hansford and overseen by a Specialist Palliative Care Clinical Steering Group.

As part of this review, the Clinical Steering Group invited experts, local stakeholders and patients, their families and carers to submit written evidence to support the development of its recommendations.

The Hanford Review provided a comprehensive assessment of the current local service provision, a review of best practice and made a number of recommendations for commissioners to consider for the future model of service. The review identified a number of challenges across the services in the areas of:

- inequity of specialist palliative care services in the three boroughs

- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services;
- 70% of patients would prefer to die in their own home but are unable to; and
- inequity of funding arrangements for the services from the CCGs.

The full report can be found in the appendices.

2.2 Engagement on the Strategic Review

Between September 30th and October 24th 2019 all four CCGs ran a series of public engagement workshops. The role of these engagement events was to involve patients, local people and health and care professionals in the development of plans to address the challenges facing palliative care services across Westminster, Kensington and Chelsea, Hammersmith and Fulham and Brent.

The workshops were attended by local residents, patients, health and care professionals and local councillors. The events were well attended and enabled local people to talk about their experience and to hear feedback on palliative care services across the boroughs. Details on the three workshops are set out below:

- Workshop One: Theme - Access to Care, held at Wembley Centre for Health and Well-being, Brent CCG, number of Workshop Attendees was 23

- Workshop Two: Theme – Palliative Care, held at St Paul's Church, Hammersmith and Fulham CCG, number of Workshop Attendees was 22

- Workshop Three: Theme - Moving between settings and bereavement and aftercare held at Al-Manaar – The Muslim Cultural Heritage Centre – number of workshop attendees was 42

In summary, across the three workshops it was noted that:

- Care works well once a service or pathway has been accessed with inpatient hospice services offering peace of mind for family, friends and carers.
- Care is not standardised across different areas in the four boroughs
- There is inequitable access to information and support to access and navigate available services
- Care planning should be transparent with family, friends and carers and start at an earlier stage
- More could be done to ensure that minority groups are aware of palliative care services and ensuring that these services are personalised for a diverse range of communities
- Travel times to hospice services have a significant impact on carers and families. This should be a key consideration for any future model of care.
- More could be done to improve integration and coordination between services.
- Bereavement services need to be planned earlier in the patient journey and be promoted better for friends, family and carers

The information gathered is being used to inform the future design of palliative care services across Westminster, Hammersmith and Fulham, Kensington & Chelsea and Brent. The CCGs are now working on a future plan for palliative care services. With this in mind a letter has recently been sent to Chairs of Overview and Scrutiny Committees setting out plans for further engagement. This is attached in the Appendices.

The CCGs have also established a Patient and Public Working Group to help the CCGs formulate their ideas. The Group has met on four occasions. Made up of a wide range of local people with a range of experiences, the Group is a valuable part of the process of determining how services are commissioned in the future.

Understandably, there has been a lot of local interest in the future of the Pembridge Unit since the temporary suspension of inpatient services.

The CCG fully acknowledges the importance of the beds at the Pembridge unit to local residents. It is important to remember that the beds were suspended because it was not possible to recruit to the consultant post. There was, therefore, no choice other than to suspend the service in order not to put patients at risk.

Comment has been made that the workshops held in September and October did not provide any opportunity to discuss the situation with the Pembridge Unit. The workshops were not set up to look at the specific issue of a single element of the palliative care provision. They were designed to seek peoples' views on the totality of a specialist palliative care service and to help commissioners determine what should be included within a future model for palliative care. Participants wishing to talk about the Pembridge unit were offered the opportunity to talk about this element of the service separately.

2.3 The Pre-Consultation Engagement Process

The 4 CCGs have now shared their current thinking on how to address the challenges faced by palliative care services in these areas.

Working with local hospice providers and from the information we have gathered from our working group and the local community, the CCGs proposed some potential scenarios that we would like to hear local people's views on. These were published on the CCG's websites on 14 February and mark the start of a 4 week engagement period that ends on 13th March 2020. An online survey on the proposed scenarios can be found here: www.surveymonkey.co.uk/r/2JJKP8J

A Patient Focus Group for Brent patients and other stakeholders was held on 25th February in Brent to give local people the opportunity to comment and discuss the 4 scenarios. The CCGs have set up a dedicated mailing list for anyone interested in keeping up to date with the progress of the palliative care services review The address to register for the mailing list is: nwlccgs.triborough.palliativecare@nhs.net

2.4 The Four Potential Scenarios

The 4 scenarios are described on the following page. The first 3 scenarios were developed with the feedback received from the information gathered at the three workshops in September and October 2019, as well as the service specification developed by the clinical reference group. The fourth scenario has been developed following feedback from the public and patient working group.

While the group agreed with the direction of travel and the need to change and recognised that scenario 3 allowed the best opportunity to do that, there was concern about the potential impact on patients who live alone and require nurse-led specialist palliative respite care that does not require a consultant. Scenario 4 was therefore developed to reflect this feedback.

The scenarios were also developed using evidence from the National Council for Palliative Care Services 2017 Report ‘Best Practice in Care Co-ordination for Palliative and End of Life Services: Information for Commissioners’. The recommendations from this report include:

- Clinical triage 24/7 with a single phone number and the availability for face to face home assessment with a short response times for clinical situations that are urgent
- Rapid response mobilisation of health and social care that is able to stay with patients for prolonged periods including overnight
- Availability of medication and equipment
- Skilled and competent practitioners
- Integration with all other service providers in the area, evidence of joined up services with acute care and discharge
- Evidence of electronic record sharing
- strong links with local community groups/ the voluntary sector
- Consideration of the needs of hard to reach groups and building links with local communities

Potential Scenario 1

This scenario would keep all specialist palliative care services as they are including the reopening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant.
In-patient, day and community care services would continue as they are.

Potential Scenario 2

This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge palliative care centre subject to the appointment of a palliative care consultant.
Community and day services would be standardised across the boroughs.
This scenario would lead to some but limited improvements in the co-ordination of out of hours advice.

Potential Scenario 3

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.
This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Potential Scenario 4

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Patients who do not require specialist inpatient care but cannot be supported at home or have a preference to die in a hospice environment, can access respite and end of life care in their local area via a nurse led in-patient service.

Scenarios 2-4 have been developed to reflect the recommendations of the report, as well as the issues raised within the independent review. The main issues raised included:

- inequity of specialist palliative care services in the boroughs;
- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services;
- 70% of patients would prefer to die in their own home but are unable to; and
- Inequity of funding arrangements for the services from the CCGs.

The relevant engagement documents can be found in the appendices. They include:

- Summary of the Penny Hansford review
- The Penny Hansford Review Independent Review Palliative Care Report
- Palliative Care Review Workshop findings
- Palliative Care Services Involvement document
- Palliative Care letter to stakeholders – 3 January 2020
- Palliative Care letter to stakeholders – 17 January 2020

2.5 Next Steps Following Engagement

The results of this engagement period will be presented to CCG governing bodies for consideration of the next steps. The CCG governing body meetings are likely to take place in early spring. The CCGs would like to update the public with the outcome of these meetings after they have taken place. Should any recommendations be classed as ‘substantial’ change to the existing specialist palliative care services by our governing bodies (the CCG boards) and associated NHS bodies, these changes will be subject to a public consultation.

3.0 Demographic data on palliative care patients in Brent

Please refer to the appendices for demographic data and graphs in the following areas:

- Number of deaths in Brent
- Place of death
- Mortality rate by borough
- Projected increase in deaths up to 2030 for England and Brent

4.0 Overview of existing palliative care services

The Brent population is supported by care from multiple providers across the sectors. The main providers of acute health services in Brent are London North West Healthcare NHS Trust (LNWHT), Central and North West London NHS Foundation Trust (CNWLT) and Imperial Healthcare Trust (IHT).

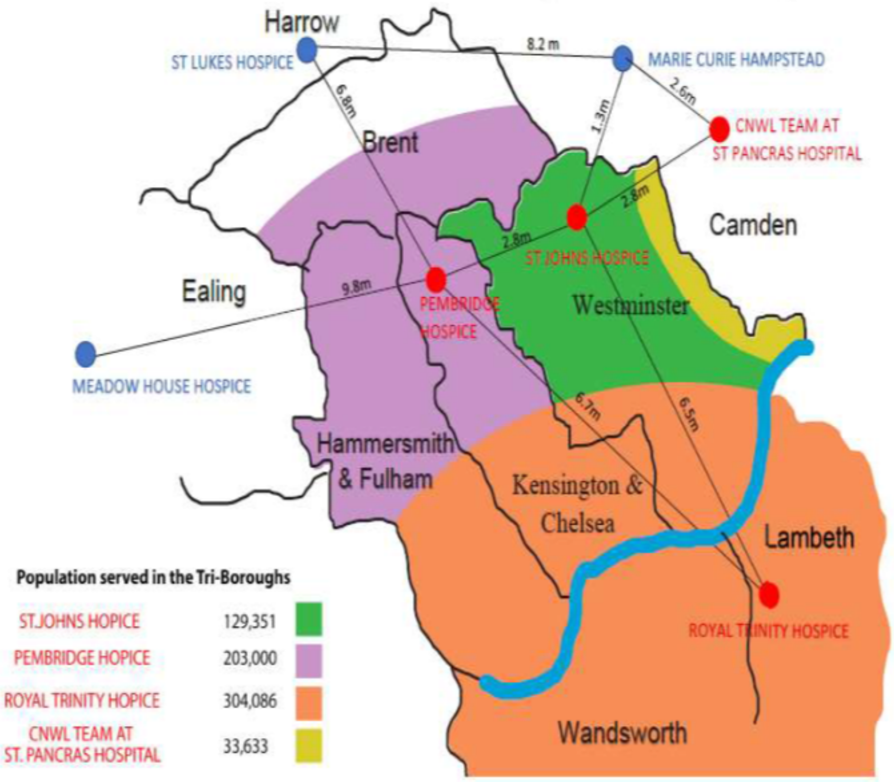
Specialist palliative care is mostly provided for Brent patients in the following hospitals: Northwick Park and Central Middlesex Hospital (London North West Healthcare NHS Trust), Charing Cross and St Mary’s Hospitals (Imperial College Healthcare NHS Trust) and the Royal Free Hospital (Royal Free NHS Foundation Trust).

Specialist Palliative Care teams in acute setting are made up of specialist nurses and therapists led by a Specialist Palliative Care consultant who work alongside other specialist teams to control physical or psychological symptoms, ensure a smooth discharge from hospital and support families and carers.

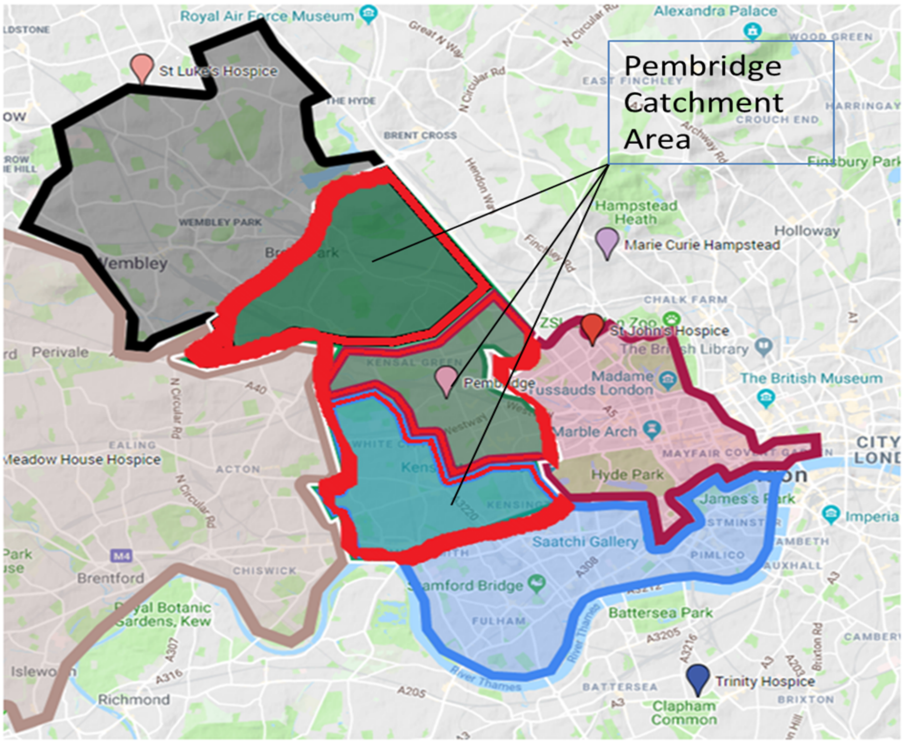
Community specialist palliative care is provided by services are provided by St Luke’s Hospice (StL), CLCHT Pembridge Hospice (PH), St John’s and Elizabeth Hospice (StJ) and Marie-curie Hospice Hampstead (MC). The 6 main elements of community hospice provision are described below:

- In-patient Unit – Consultant led 24/7 in-patient beds for terminal care, symptom control and palliative rehabilitation. (All except PH since 1st October 2018)
- Hospice at Home – 24/7 specialist palliative care in patient's homes for a maximum of 2 weeks that supports admission avoidance, respite care, facilitated discharge from acute care (StJ & StL)
- Community Specialist Palliative Care – Support and care to patients in their own homes delivered Monday to Friday between 9am and 5pm (StL and PH provide Sat-Sun)
- Daycentre– Therapy and peer support in a day centre delivered during the week including complimentary therapy (StJ, StL & PH and MC)
- Outpatient – Consultant or nurse led clinics at the hospices delivered 5 days a week (All)
- Bereavement/Counselling for carers and families (all)

The location of the main hospice providers in North West London is set out in the map below:



The catchment area for services provided by Pembridge Palliative Care centre is outlined in the map below.



Pembridge primarily delivers services to the south of Brent, with significant cross-over with the St John's Hospice and Marie Curie Hampstead hospice. St Luke's Hospices primarily covers the north of Brent.

With the suspension of the In-patient Unit, the Pembridge continues to provide the following services:

- Day Centre
- Community Specialist Palliative Care service

Interim arrangements have been in place since 1st October 2018 to ensure patients who would normally be expected to be an in-patient at Pembridge are supported by the other available hospices commissioned by the respective CCGs and taking into consideration patient's preference. For Brent CCG that includes St John's Hospice, St Luke's Hospice and Marie Curie Hampstead Hospice. Between October 2018 and January 2020, 25 Brent in-patients (who would normally be expected to be an in-patient at Pembridge) have been admitted to the other three hospices for a total of 582 Bed days.

5.0 Community Specialist Palliative Care Activity Data

The tables below shares the activity data over the last 5 years for Brent patients use of all commissioned community Specialist Palliative Care Services. The 2019/20 date is forecast outturn and mostly based on the activity data from Quarters 1 to 3.

It shows that the total in-patient bed nights have remained relatively stable before and after the Pembridge in-patient hospices was suspended. They also show an increase of 1,441 hours provided by the Hospice at Home service.

In-Patient Bed days for Brent patients

Hospice	2015/16	2016/17	2017/18	2018/19	2019/20 FOT
St Luke's	1,110	888	729	983	1400
St Johns	341	310	154	284	757
Marie Curie	860	147	236	291	253
Pembridge	1533	1,404	1,118	992 (FOT)	n/a
Total	**3844**	**2749**	**2237**	**2550**	**2410**

Hospice at Home for Brent patients – home visits

Hospice	2015/16	2016/17	2017/18	2018/19	2019/20 FOT
St John's (hours)	2,115	3,186	1,683	1,242	2,665

Day cases for Brent patients - attendances

Hospice	2015/16	2016/17	2017/18	2018/19	2019/20 FOT
St Luke's	528	632	557	516	392
St John's	610	686	830	765	1307
Marie Curie	288	213	145	105	185
Pembridge (contacts)	2781	2,557	615	2,862	3065
Total	**4,207**	**4,088**	**2,147**	**4,248**	**4,949**

Community Specialist Palliative Care Service for Brent patients – home visits

Hospice	2015/16	2016/17	2017/18	2018/19	2019/20 FOT
St Luke's	781 visits	947 visits	1228	995	1345
Pembridge (contacts)	4171	4,380	5,415	6,840	7304
Total	**4,952**	**5,327**	**6,643**	**7,835**	**8,649**

6.0 The Role of GPs and Nursing Homes

GPs and primary care professionals are key stakeholders in delivering End of Life Care. GP's deliver care in line with their General Medical Contracts (GMS) Quality and Outcome Frame work (QOF). For palliative care the GP is required to establish and maintain a register of all patients in need of palliative care/support irrespective of age. This indicator is focused on identifying these patients – a critical first step in addressing the key elements of good medical practice identified by the General Medical Council. Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care are the key steps in the provision of high quality care at the end of life in general practice.

This year 2019/2020 saw the introduction of a new QOF Quality Improvement (QI) domain for End of Life Care.

In Brent, local GPs are increasingly using the Co-ordinate My Care (CMC) digital care planning record system to improve the quality of care for patients in the last stages of life to supports patients achieve their preferred place of care and place of death. The percentage of CMC's created by GP's in June 2017 was 12%. This has now increased to 67%. GPs also play an important role in referring and coordinating patients to appropriate services, prescribing medications to support patients in their last phase of life, identifying and supporting carers and patients through personalised care planning.

Care homes are key End of Life Care stakeholders and play an important role in the care of older people at the end of life. National data can be found at this link:

https://www.gov.uk/government/publications/the-role-of-care-homes-in-end-of-life-care

All care home residents must be registered with a GP. The care of these patients will be delivered in line with the GP GMS Contract referenced above. Services available to care home residents are the same as for all patients registered with a GP in line with local commissioning; this includes Specialist Palliative Care.

Care homes are assessed and inspected by the independent regulator of health and social care in England, Care Quality Commission (CQC) in regards to delivery of End of Life Care.

7.0 Financing of Palliative Care

Please refer to Appendix H on current spend by Brent CCG.

8.0 Equality Implications

The four CCGs evaluated the impact of the emergency suspension of the inpatient care at Pembridge Palliative Care Service and provision of additional NHS commissioning inpatient palliative care services at other locations. The evaluation was a retroactive review of any potential impacts on Equalities and Health Inequalities which may have occurred as a result of the emergency suspension. The retroactive evaluation identified potential impacts on some protected characteristics.

The evaluation suggested that patients over the age of 60 would be more affected by changes to palliative care services than patients from other age groups. Patients may have to travel further to receive inpatient care as a result of the suspension of the Pembridge Palliative Care Service. Increased travel time would potentially be more complex for patients who are aged 60 and over, than other age groups and for patients with a disability. In some cases the impact was mitigated by arrangements in place such as Hospice at Home or other palliative care support in the community.

If the Governing Bodies approve an option that would lead to significant changes to local services, a full EQIA will be published by the CCGs.

Appendix A

Palliative care services

Executive Summary

Review of provision in Kensington & Chelsea, Hammersmith & Fulham and Westminster

Penny Hansford - June 2019

Background

Central London Clinical Commissioning Group (CCG), on behalf of West London CCG and Hammersmith & Fulham CCG, commissioned Penny Hansford of PJH4 Consulting and former Hospice Director at St Christopher's Hospice to independently review palliative care services in the area, commencing November 2018. The aim being to deliver a report which provides a set of recommendations for a sustainable, clinically effective and cost efficient commissioning model for delivering Specialist Palliative Care Services (SPCS – both bed based and community provision), in order to achieve national strategic outcomes and best value.

Context

The review came as a result of the recognition that there were multiple providers of 'specialist' palliative care in three small boroughs with differing services and service specifications. It was also prompted by the temporary closure of the Pembridge Hospice In patient unit which occurred in October 2018, where adequate medical cover was unable to be recruited.

The current landscape

The tri-borough CCGs commission three specialist palliative care providers: Central London Community Healthcare Trust (CLCH) The Pembridge Hospice (PH), Royal Trinity Hospice (RTH) and St Johns Hospice (SJH). Central North West London (CNWL) deliver a community service to North East Westminster commissioned by Camden CCG. Marie Curie Hampstead deliver care for a very small number of patients (non-contracted). St Luke's Hospice is a peripheral part of the review as patients from Brent CCG also access the Pembridge Hospice.

Methodology.

The review included an analysis of national strategy and policy alongside local policy and context, a review of current service provision alongside what will be needed in the future. Investigating views of stakeholders via interviews with key professionals and groups and a public call for evidence via local groups and the media was central to the review.

Key findings

The review highlighted the following:

The most consistent feedback from professionals and the public was inequity of service provision across the boroughs and in the services, poor co-ordination and communication between services, lack of ease of access to services at the appropriate time and the lack of urgency of response of most services. Also consistent was the high levels of satisfaction of patients and families once they were being cared for by a specialist palliative care service.

Patients, families and carers report high satisfaction rates once they start receiving a specialist palliative care service.

There are variations in services, contracts and performance across all providers.

There is no one commissioner with oversight of all specialist palliative care provision across the tri-borough.

The NHS contribution towards the care costs varies across providers.

(range 18%-100%)

There is a variation across providers in the ratio of specialist palliative care nurses in the community per head of population.

The involvement of the community based palliative care teams significantly improves the likelihood of dying outside the hospital setting which is what patients say they want.

The palliative care services in the tri-borough reach approximately 48% of patients who have an expected death.

Getting a rapid face to face assessment from the specialist palliative care provider in the community is problematic.

Access to a senior a specialist palliative care clinician to aid decision making for a GP or community nurse can be problematic and inconsistent.

The Community Independence Service (Rapid Response team) are regularly called to patients who on initial assessment are in need of end of life care.

The model of daycare varies: Traditional model by St Johns and Pembridge saw a 47 new patients in 17/18. Trinity has a modernised day care and rehabilitative approach.

District Nursing services feel aggrieved that the Specialist Palliative Care services see themselves as advisory and not interventionist.

Specialist Palliative Care nurses perceive District Nursing to be task orientated, not holistic and personalised.

74% of the public who responded to the online survey reported poor co-ordination and communication between services for people at the end of life.

The percentage of deaths at home is higher in all 3 boroughs(28.2%) than London (23.8% or England

(23.5%)

Deaths in hospital for the boroughs(48.9%) are higher than England(46.9%)but lower than London(52.8%)

Referrers who interface with more than one provider for inpatient care have a perception that hospice A is better able to cope with complexity than hospice B and refer accordingly.

The specialist palliative care services different IT systems that have no interoperability with primary care or the hospitals (exception Pembridge)

Based on the number of inpatient bed days available across the tri-borough, there is capacity in the system to admit more patients or close some beds.

Length of stay is above the London average of 14.6 days:

- *St Johns Hospice: 17.8 days*
- *Pembridge inpatient unit: 17.8 days*
- *Royal Trinity: 16 days*

There is a lower ratio of nursing care home beds in the tri-borough compared to the London region which may impact on the length of stay.

The palliative care services still predominantly deliver care to people with a cancer diagnosis but this is steadily changing. (Average 70/30)

The balance of palliative care medical time is heavily weighted to inpatient beds and not the community

The occupancy of two of the three units is low:

63% St Johns Hospice - 67% CLCH Pembridge Inpatient Unit (2017-8 figures)

The recommended model

The recommended model and options are derived from the views of key stakeholders, including – patients and carers, and clinical and managerial professionals and the professional experience of the reviewer.

The delivery of the model needs to be integrated with the multi-speciality provider models (MCP) being developed in other parts of the CCGs. The reconfiguration of services ae progressing at different rates within the CCGs and it has not been possible within this review to describe the methodology for integration.

Implementation of the recommendations will deliver a clinically and cost- effective commissioning model for palliative and end of life care, ensuring equity and service resilience for the future. For individual services it carries a level of risk.

A model fit for the future

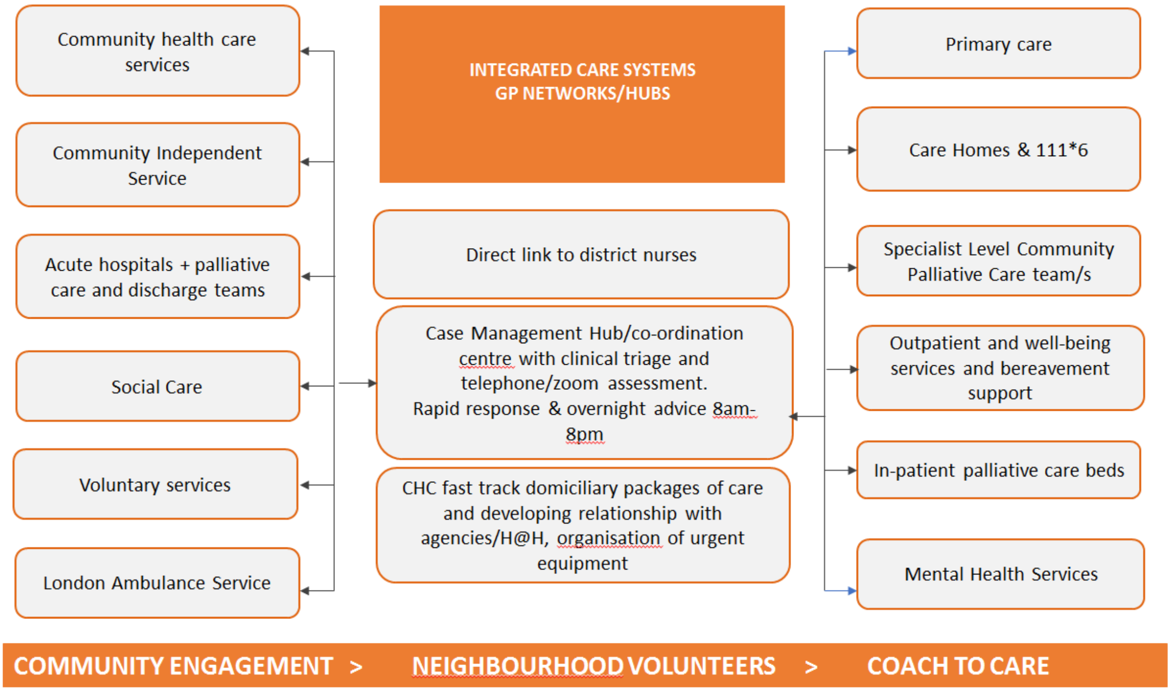


Figure 1: New model of community palliative and end of life care

Overarching Recommendation by Penny Hansford Independent Strategic Reviewer

In conducting this review it has become clear that the three major challenges for the CCG's commissioning services are:-

- inequity of specialist palliative care service provision in the three boroughs
- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services
- inequity of funding arrangements for the services from the CCG's which ranges from 18-100%

Once in contact with a specialist palliative care service patients and families report high levels of satisfaction. In order to significantly improve the specialist community service I have suggested a 8am-8pm palliative care hub with skilled clinicians that can ensure patients get the right repose by the right person at the right time. The hub will also have a rapid response service. I have also recommended that the community services are retendered with a lead provider model to enable better co-ordination and accountability.

I am also recommending a reduction in specialist palliative care beds. These are not currently fully utilised. Bed modelling in appendix L has demonstrated that there is some capacity in the system and that more could be created by extra provision of continuing healthcare beds.

Since the Pembridge Hospice inpatient unit has been closed the majority of patients have been successfully admitted to surrounding hospices. This, combined with the block contracting arrangement that the CCG's have with CLCH who manage the Pembridge Hospice leads me to recommend that the Pembridge inpatient unit is decommissioned and the monies used to purchase provision in other local hospices and in the re tendering of enhanced community services.

Recommendations based on seven key areas identified in the review:

Area	**Recommendations**
1. Case Management	• To co-ordinate care from a central hub that operates from 8am-8pm, seven days a week, with access to advice outside of these hours. • Clinical triage and assessment and reassessment with competent senior staff to manage routine and urgent referrals. • Joint decision making and coordination of care between District Nursing and the Specialist Palliative Care teams. • Rapid response service, a key element of case management. • Response times from specialist level services should be in line with the degree of urgency and of patients need; this should be measured. • Bridging care packages to be offered until a continuing heath care package can be mobilised. • Rapid accessibility to equipment. • The integration and coordination of fast track care and placements (including night care). • An agreed End of Life Care plan should be implemented across the tri-borough with all health and social care providers including the acute sector. This should include the patient's wishes and preferences for care and guidance for deterioration (escalation plan) • The service provision is the patients GP and not where the patient resides. • Joint visits with the GP in complex cases (home/care home). • For specialist community providers to be equipped to respond to the nursing needs of patients if they have a planned or unplanned visit. • Link service with the 111*6 care home initiative.

2. Planning	• To have a single End of Life Care commissioner for the tri-borough CCGs. • To commission specialist palliative care services to include the case management/care co-ordination model. • To better understand bed provision in hospices across the tri-borough including; reasons for the long length of stay, issues with transfer to a care home settings and patient complexity and intractable problems. • To reduce the numbers of specialist beds that are not being utilised and reinvest the money into the community provision which will further reduce the need for as many beds over time. Bed modelling in appendix L of the main report suggests that it may be possible to close between 4 and 10 beds. This modelling is however based on a series of assumptions and is linked to further work that needs doing regarding the adequacy of CHC fast track care home bed provision. • To better understand the need for CHC fast track beds for the future as it seems likely that increased bed provision in this area would allow for better patient acuity. • Specialist palliative care provision is targeted at complex patients and hard to reach groups (mental health, homeless and learning disability). Their work should be episodic where possible, but they should be case managed even when they are not directly involved, in order to recognise when their involvement is needed and to support GP's and community nurses. • The provision should include coaching and training for the wider community teams and this should be a major focus. • To commission new community palliative rehabilitation health and well-being services to replace traditional day care. • To integrate the community specialist palliative care provision with integrated care systems (including co-location). • To better utilise IT programmes like e-shift which enable a senior clinician to supervise a group of nurses/care workers via video link. • Hospices to review the balance of community and hospice work; moving to support the wider system including some bed management to be led by senior nurses. • When recruiting, consideration should be given to the balance of medical staff with some consultants, doctors in training to be palliative care consultants, speciality doctors as well as GP's with a special interest in palliative care. • Staff work across the communities and cross cover for one another. • CCGs to review the provision of nursing care home beds across the tri-borough. • CCG's within the NW London 'Sustainability & Transformation Partnership' (STP) footprint should ensure similar models of service provision are standardised and implemented throughout. • There should be an agreed mechanism for medical staff to cross cover 24/7 to ensure service resilience in the tri-boroughs.

IT systems	• To ensure IT systems that have interoperability across the central co-ordination hub, Community specialist palliative care provision, primary and nursing homes. • CCG's to ensure the prognostic indicator tool (SPICT) is embedded in SystmOne to aid patient identification at end of life.
Funding	• To ensure that core aspects of community provision are fully funded to address inequitable funding between providers. • To review the operation and expenditure of the Continuing Health Care team and the care home contracts. • To have a common understanding of the cost of a bed day and an inpatient bed tariff between the providers and the CCG.
Outcome measures	• To ensure Community specialist palliative service specifications are standardised across providers. • To ensure Community specialist palliative services reach 75% of expected deaths either by direct provision or case management or advice. • To ensure there is a reduction in hospital admissions for those in their last 90 days of life. • To ensure more patients die at home or in their care home. • To ensure all patients at the end of life have an accessible care plan e.g. CMC as it can be shared across providers. • To ensure specialist palliative care services include a rapid response that is measured. • To increase attendance at primary care multi professional meetings and assist GP's in the identification of patients in the last phase of their life. • To implement the Outcomes Assessment and Complexity Collaborative (OACC) in all palliative care settings. • To ensure that the patient feedback is collected using a validated tool as part of the outcome measures. • To develop measures for the delivery of education and training.

Training and Review	• To ensure that education and training is a core part of the provision with adequate time and resource. This should particularly include the social care workforce in domiciliary care and care homes. This should also include the development of a 'coach to care team' that will be part of the rapid response and work with domiciliary care agencies. • To maintain and develop multi professional forums (including social care and eventually the voluntary sector) in primary care to review patients in their last year of life and on the palliative care registers. • To develop joint operational guidance to ensure that there is understanding of roles and responsibilities between community specialist palliative services, GP's and district nursing. • The tri-borough CCGs and NW London STP to agree the palliative care nurse responsibilities and skill sets to work as advanced nurse practitioners.
Other	• To include joint working with the voluntary sector in service specifications. • To collaborate with the local authority to commission a lead provider to integrate and standardise the many small bereavement services that exist in the tri-borough and a new model developed. • To ensure re-commissioned community nursing services include rapid response. • To standardise models of service provision across the tri-borough and the NWL footprint. • CCG's to work towards a lead commissioner for palliative and end of life care across the NWL STP footprint. • To review nursing care home provision to ensure it is fit for purpose now and in the future. • To invest in an advance care planning programme in the memory clinics to capture the wishes and preferences for care and death at an early stage • Primary Care contracts to include monthly multi professional reviews for people at the end of life. • Referrals for the hospice inpatient care should also be directed to the care co-ordination/case management centre and forwarded to the appropriate unit. (or a joint in box for hospices to access) • Changes in operational policies of the specialist palliative care providers to enable anyone to refer to their services. • Subcutaneous fluids should be available in the community and not require a hospital admission.

Commissioning options

Option One

- Tender a new community service with one lead provider.
- This would not preclude subcontracting arrangements.
- To provide an 8am-8pm co-ordination/case management centre.
- Out-patient, rehabilitation and well -being services should be easily accessible to patients and be located within the boroughs.
- Renegotiate bed-based care with separate providers.

Option Two

- Tender a new service and reduce the number of providers to two.
- All providers to have the same service specification and contract.
- The service specification should stipulate a partnership to provide a 24/7 co-ordination/case management centre.
- Out-patient, rehabilitation and well -being services should be easily accessible to patients and be located within the boroughs.

Option Three

- Tender the service based on one community service per borough with the same service specification (including a co-ordination centre/case management centre per borough).

Summary

The recommended option from the options above is number one. The rationale for recommending option one, to have one lead provider in the community, is due to the significant transformational change needed in the specialist palliative care services to enable them to use their resources in a focussed way, acting in a consultative and training capacity to the wider care system whilst managing a small number of highly complex patients themselves, alongside case management for all expected deaths. Achieving the recommended outcomes for the new model of care will be challenging and most likely achieved with a systems leader 'driving' change.

There is also an imperative to become part of the emerging integrated care systems in the tri-borough CCGs and to provide an equitable service throughout. The reviewer believes this is best achieved by an overall lead provider, accountable for the change needed. The integrated care systems are progressing to different timescales and slightly different models in each CCG and so it has not been possible for the reviewer to make a recommendation on how the palliative care co-ordination centre will integrate, only that it will need to.

The idea of a co-ordination centre, single point of access with extended hours and rapid response was consistent feedback from many of the patients. 76% of public respondents (n46) rated co-ordination and communication between the services as very poor to fair and 64% of the same group (n42) rated access to services as fair to very poor. Rapid access to care both in and out of hours were also marked with similar scores by the public.

Contracting the beds separately to the community contract is a pragmatic approach as the provision of care in this setting requires less change management. Since the closure of the Pembridge inpatient unit it appears that patients have been successfully admitted to other units who have had capacity. There does appear to be a lack of continuing health care (CHC) fast track provision across the boroughs. Although further work needs to be done it is likely that there could be a reduction in commissioned hospice beds and consolidation on less sites with a greater provision of CHC fast track beds for dying people to improve patient flow and the correct level of acuity.

Contracting the specialist palliative care beds separately is likely to reduce the instability, both financial and operational to the provider services.

All of the recommendations in this review are in line with the vast majority of feedback from both the public and professionals.

Policies guidance and reports underpinning the recommendations

NICE Quality Standard for End of Life Care for Adults[1]
One Chance to Get it Right: Improving people's experience of care in last few days and hours of life, One year on Report[2]
Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020[3]
Cost Effective commissioning of End of Life Care[4]
Shifting the Balance of Care [5]
Specialist Level Palliative Care, Information for Commissioners[6]
Enhanced End of Life Care in the Community[7]
Business Care for Specialist Palliative Care Provision Across London[8]
Joint Strategic Needs Assessment (JSNA) for the Royal Borough of Kensington and Chelsea, Westminster and Hammersmith and Fulham End of Life Care: Key Themes and Recommendations[9]

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[1] Nice Quality Standard for End of Life Care for Adults (QS13) November 2011 https://www.nice.org.uk/guidance/qs13

[2] Department of Health (July 2015): One Year on Report to the 'Once Chance to get it Right : Improving People Experience in the Last Days and Hours of Life.' https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/450391/One_chance_-_one_year_on_acc.pdf.

[3] Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-20 http://endoflifecareambitions.org.uk

[4] Public Health England, Cost Effective Commissioning of End of Life Care (2017) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/612377/health-economics-palliative-end-of-life-care.pdf

[5] Nuffield Trust, Shifting the Balance of Care (2017) https://www.nuffieldtrust.org.uk/files/2017-02/shifting-the-balance-of-care-report-web-final.pdf

[6] NHS England, Specialist Level Palliative Care, Information for Commissioners. April 2016 https://www.england.nhs.uk/wp-content/uploads/2016/04/speclst-palliatv-care-comms-guid.pdf

[7] RM Partners, Enhanced End of Life Care in the community. August 2018 http://rmpartners.nhs.uk/wp-content/uploads/2017/03/Enhanced-EOLC-community-project.pdf

[8] RM partners, Business Case for Seven day Specialist Palliative Care Provision Across London , June 2018 http://rmpartners.cancervanguard.nhs.uk/wp-content/uploads/2018/09/7daySPCReport_Final_060918.pdf

[9] Joint Strategic Needs Assessment (JSNA) for the Royal Boroughs of Kensington & Chelsea, Westminster & Hammersmith and Fulham. End of Life Care , Key Themes and Recommendations , October 2016 https://www.jsna.info/endoflifecare

Appendix B

Palliative care services

Independent review - full report

Review of provision in Kensington & Chelsea, Hammersmith & Fulham and Westminster

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Penny Hansford - June 2019

Preface

This was a complex review to carry out. Dying is not something most of us think about until it touches us personally. When it does, it often evokes strong and sometimes unfamiliar feelings. The health and social care professionals that I have met in the course of this review also had strong feelings and a desire to deliver the very best of care to dying people and their families. The clinical reference group that worked with me on this review also demonstrated a desire to get the system of support for dying people more equitable and more co-ordinated than it is at present. I am grateful to their support, challenge and robust discussion. Thank you to the many who submitted evidence, particularly bereaved carers who took the trouble to 'tell their stories' which for some will have been hard. These are the voices to which we must listen.

I am also grateful the group within the CCG's that have supported this review. Benjamin Smith, Project Manager, Central London CCG, Lena Coupland ,Delivery Manager for Integrated Care, NHS West London CCG , Ray Boateng, Head of Integrated Commissioning and Continuing Care , Joint Commissioning Team and Sarah Flynn, Communications officer, NW London CCGs.

With thanks to the Clinical Steering Group

Steve Barnes -St Johns Hospice, Ray Boateng- Joint commissioning, Jackie Bennett- Marie Curie Hospice, James Benson- CLCH, Olivia Clymer- Healthwatch, Lena Coupland- West London CCG, Sarah Cox -Chelsea and Westminster Foundation Trust and Royal Trinity Hospice, Jo Dedes -St Luke's Hospice, Jennifer Karno -Imperial College Health care, Molly Larkin NW London CCG's, Sam Lund -Royal Trinity Hospice, Farukh Malik GP, Jo Medhurst CLCH, Clare Montagu-Royal Trinity Hospice, Neil Nijhawan -Charing Cross Hospital, Alex Rogers -St Johns Hospice, Michelle Scaife NW London collaboration of CCG's, Benjamin Smith -Central London CCG, Paul Trevett Central North West London.

Penny Hansford

Independent Reviewer
PJH4 Consulting

Contents

Background & rationale

Central London Clinical Commissioning Group (CCG), West London CCG and Hammersmith & Fulham CCG (the tri-borough) commission their palliative care services together for the boroughs of City of Westminster (WCC), the Royal Borough of Kensington & Chelsea (RBKC) and the London Borough of Hammersmith & Fulham (LBHF).

Current provision is commissioned via three contracts. Two are with independent charitable hospices, St Johns Hospice (SJH) and Royal Trinity Hospice (RTH) and one is with an NHS provider, the Central London Healthcare Trust (CLCH) who delivers services at The Pembridge Hospice (PH). There is also a community service provided by Central and North West London NHS Foundation Trust (CNWL), for patients in North East Westminster. This is a small part of a larger service which provides care to South Camden, Islington, UCLH and HCA and commissioned by Camden CCG.

Context of the review

On October 1st 2018, the inpatients beds at the PH were suspended, as there was inadequate medical cover for the inpatient unit. A consultant registered on the specialist register for palliative care is required to cover inpatient care. This event, combined with commissioners desire to ensure palliative care services are fit for the future, meant the tri-borough CCGs decided to review the current provision of specialist palliative care.

Central London CCG, on behalf of West London CCG and Hammersmith & Fulham CCG, commissioned Penny Hansford, former Director of Nursing at St Christopher's Hospice, South East London; as the independent reviewer in November 2018. A 'Call for Evidence' was launched on 14 December 2018 and a clinical steering group was created, with representatives from GPs, acute trusts, community trusts and hospice providers, all with an interest in specialist palliative care.

Timeline

The process for the review followed this timeline:

Event	Date
Suspension of inpatient admissions to the PH	1st October 2018
Penny Hansford commissioned to review palliative care services within the tri-borough CCGs	26th November 2018
First clinical steering group held	29th November 2018
Call for evidence launched	14th December 2018
Engagement with providers, stakeholders and patient groups	1st December-14 February 2019
Call for evidence closed	14 February 2019
Publishing of review	14 June 2019

Figure 1: Timeline of palliative care review

The review was launched on the 26th November 2018 and concluded on February 28th 2019. The review included extensive consultation with health and social care professionals, and a public and patient consultation via available communication channels, the media and patient/public engagement groups (see appendix A). A literature review was undertaken of key national policies and recent research evidence was included, to ensure that any recommendations were evidence based.

The review also looked at a number of new models of palliative and end of life care being developed in the UK aimed at improving inequalities in access and to modernise services. All of the recommendations are included in this report and summarised in the Executive Summary.

Defining specialist palliative care
This strategic review of 'specialist' palliative care services has caused some confusion in terminology.

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Traditionally, services called 'specialist' as opposed to 'palliative care' services, which has included hospices, would define themselves as caring for people with the most complex physical and psychological symptoms. However, given there is no standard definition of 'complexity' it is not possible to distinguish in any standardised way those people who need specialist input. Furthermore, the needs of a patient and family are not linear and most people will have episodes or situations where review and advice will need to be sought from the experts who specialise in palliative care.

This review concentrates on the 'specialist' palliative care services delivered by SJH, RTH, PH and the CNWL service. However, as palliative care is 'cross cutting' the review has needed to consider how the wider system works together with community nursing, primary and social care. All of whom are also delivering palliative care as part of, rather than the entirety of their role. The term ‘specialist palliative care’ and ‘palliative care’ are used interchangeably in this report.

Statistics - End of life in the boroughs

The boroughs

- The total population of the tri-borough CCGs is 583,525. (Hammersmith & Fulham 182,998, Westminster 244,786 and Kensington & Chelsea 155,741) (2017)[1]
- The average number of deaths per year in the tri-borough is 2,815 between 2014-2017. In 2017-18 there were 2,777 deaths.[2]
- Of these 2,222 are said to be 'expected' deaths.
- On average there are 844 (30%) deaths per year due to cancer, 768 (27%) due to circulatory disease, 341 (12%) deaths due to respiratory disease and 863 (31%) deaths due to other causes.[3]
- In England there was a 1.6% rise in deaths since last year and this is expected to rise by 10% by 2030. However, in the tri-borough the number of deaths is not expected to significantly rise, therefore no recommendations have been made specifically about forecasted capacity for the next three years.
- The population of over 65's is projected to grow by 20.4% in England over the next 10 years. However, the tri-borough has a lower than average population of over 65- year olds compared to 16.3% for England. (RBKC 13.6%, WCC 10.6% and LBHF 10.3%) The predicted rise of this age group is negligible with only LBHF predicting a 6.7% rise in the ten-year period.[4]
- Almost two thirds of deaths occur in the over 75 age group in the tri -boroughs, which mirrors the national picture.
- Care home provision across the three boroughs is among the lowest in England 3.1 beds per 100 of the population over 65, compared to 4.3 for London and 4.9 for England. (appendix B)

Place of Death (Appendix C)[5]

- Deaths by percentage in care homes is also correspondingly low 11.9% compared to 14.3% for London and 21.8% for England.
- The percentage of deaths at home is significantly higher in all three boroughs (28.2%) than the England average (23.5%) and the London average (23.8%) in LBHF (28%), WCC (29%) and RBKC (27.6%).
- The percentage of deaths in a hospice is slightly higher (7.7%) than the average for England 5.7% and the region 6.6%. 213 people from the tri boroughs died in a hospice in 2017-8.
- Deaths in hospital (48.9) are slightly higher than England (46.9) but below the London average (52.8%).
- A person in their last year of life with cancer can expect 3.49 admissions and use 18.25 bed days. With non-cancer conditions this is 3.01 admissions and use 18.45 bed days. The percentage of people who have 3 or more admissions in their last 90 days of life is 7.8% for the tri-boroughs, 9% for the NW London area and 6.9% for England (Appendix D).
- The number of completed 'Co-ordinate my Care' (CMC) care plans for the calendar year 2018 was 788 representing a 35% CMC completion rate (see appendix E). Use of CMC is

important as it guides professionals to a patient’s wishes and preferences, especially in urgent situations.

The Impact on Place of Death when one of the 4 specialist palliative care services are involved

- Home deaths increase by 4.1%
- Hospital deaths are reduced by 23.5%.
- Care home deaths increase by 7.7%.

The literature on place of death

It is often quoted that more than 70% of people would prefer to die at home. In a systematic review looking at peoples preferred place of death, home preference estimates ranged from 31%-87%for patients, 25%-64% for caregivers and 49%-74% for the public. 20% of 1395 patients changed their preferences.[6] Dying at home is however associated with a greater sense of peace and less intense grief for the bereaved.[7]

Cost of Care

- For every 1000 living people, nine will die within the year and seven of these will have end of life care needs prior to their death and be disproportionately high users of hospital care; consuming an estimated 27% of hospital spend.[8]
- The cost of hospital care for the over 65 age group in their last year of life is £2 in every £10.[9]
- There is also a growing body of evidence that the provision of specialist palliative care services results in improved experience and reduced costs at the end of life. Benefits include doubling a person’s chances of dying at home, reducing patient symptom burden and reducing costs by between 18 and 35 per cent, when compared with usual care. [10]

Recommendations for Commissioning Outcomes:

- Decrease the numbers of admissions in the last 90 days of life.
- That more people are supported to die at home or in their care home.
- Increasing the ‘reach’ of the specialist palliative care services to reach 75% of expected deaths either by direct provision or by case management/advising.

Local & national policy on palliative and end of Life Care

There are nine key documents that have been published between 2015 and 2017 that have been used throughout the development of the recommendations found within the review, (appendix F):

- ‘Specialist Palliative Care, Information for Commissioners’ 2016 [11]
- ‘Ambitions for Palliative and end of life care’ 2015 [12]
- Review of Choice in End of Life Care’ 2016[13]
- Commissioning Person Centred End of Life Care: A toolkit for health and social care. 2016[14]
- ‘Actions for End of Life care 2014-16 [15]
- ‘What is important to me-a review of choice in end of life care 2015[16]
- Shifting the Balance of Care-March Nuffield Trust 2017[17]
- Independent Review of the Liverpool Care Pathway 2013 [18]
- Introducing the Outcomes Assessment and Complexity and Collaborative Suite of Measures. Kings College London University 2015[19]

North West London STP Priorities[20] [21]

The boroughs of RBKC, Hammersmith & Fulham and Westminster sit within the footprint of the North West London Sustainability Transformation Plan (STP). In June 2016 the STP was published; one of the key objectives was to improve the overall quality of end of life care.

In 2015/6 a steering group was formed as part of the NW London STP plan - to improve care in the last phase of life. The recommendations of the group include:

- Implement a 24/7 telemedicine co-ordination, advice and support line for care home staff and their residents.
- Build on St Luke’s Hospice experience of a single point of access co-ordination centre for people at the end of life
- Align GP’s more closely with individual care homes and develop enhanced care services.
- Develop robust and consistent identification of patients in the last phase of life and avoid unplanned admissions work in primary care
- Support specific extensions and adjustments to existing Hospice@Home /rapid response /community pharmacy services.
- Build on schemes such as homeward, STARS, CIUS to avoid acute admissions and support greater co-ordination of health, social and voluntary sector services.
- Develop training and education for GP’s, Care Home and LAS staff.

Some of the above is yet to be implemented. Each CCG within the NW London STP footprint has to mandatory commission a new dedicated care home advisory service, called 111*6. This provides urgent clinical advice for care home staff. A NW London pilot provides an enhanced version of this service, with a dedicated team of advance nurse practitioners who give clinical advice.

A care home manager leadership programme has been commissioned by NW London CCG’s with funding from Health Education England NWL. A NW London care home dash board, initially focusing on unscheduled hospital service utilisation was created to enable the sharing of intelligence between health and social care, support learning and promote best practice.

Other priorities for palliative and end of life care is to work with commissioners and services to reduce the gap in variation in service delivery and to develop comprehensive standardised data sets and metrics for multiple stakeholders. The STP is clear that palliative and end of life initiatives need to be linked to advanced frailty initiatives and the development of integrated care systems.

Recommendation:

- For the CCG's within the STP footprint, ensure similar models of service provision are standardised and implemented throughout.
- For the CCG's to work towards a lead commissioner for palliative and end of life care in the STP footprint.

JSNA for the Tri-Borough CCGs[22]

In 2016, a Joint Strategic Needs Assessment (JSNA) was published but there has been a lack of leadership and structure to implement the recommendations. It has five key recommendations:

- Maximise choice, comfort and control through high quality effective care planning and co-ordination.
- Promote end of life care as everybody's business and develop communities which can help and support people.
- Identify clear strategic leadership for end of life care across both social care, health care and the independent sector.
- Develop a co-ordinated education and training programme for practitioners, the person dying, carers and for family members.

Tri Borough CCG Priorities

The individual CCG's are in the process of setting up integrated care partnerships (ICPs). These are alliances of NHS and other providers that work together to deliver care by agreeing to collaborate rather than compete. These providers include acute hospitals, community services, mental health services and GPs. Social care and independent and third sector providers may also be involved. In the tri-borough CCGs, these are at different stages of development.

Hammersmith & Fulham Integrated Care Partnership have been working together since February 2018. This partnership has three clinical workstream areas of initial focus.

- Proactive prevention and management of frailty.
- Improving the diagnosis of dementia and early advance care planning.
- Improving end of life care, including care homes.

The members of the partnership have signed an alliance agreement to work together which includes the local NHS acute trusts, the community trust, the mental health trust and the GP Federation. The local authorities attend but haven't yet signed the partnership agreement. Hammersmith & Fulham have access to a range of specialist palliative care providers, including the RTH and CLCH who operate their services from PH. CLCH are represented but RTH are not part of the partnership agreement. This leaves part of the hospice sector outside of the developing integration.

West London CCG (which includes the Royal Borough Kensington and Chelsea and the wards of Queens Park and Paddington) has developed its own integrated care strategy 2018 - 2020. The current strategy is an enhancement of the 2015 'My Care My Way' (MCMW) programme. MCMW is targeted at over 65's and provides case management and health and social care navigation. It also funds a programme of support for people with long term mental health problems. 'Community Living Well.' The current strategy aims to deliver a fully integrated community health team serving the whole populations health and social care needs by April 2019. The outcomes are based around the proactive maintenance of good health and disease management. End of Life Care is one component of the programme. A co-design group was established in 2018 to understand the challenges and develop a model for patients. This work has been paused to focus on this review.

The proposed Integrated Care delivery model will be through clusters of GPs working together in five 'Primary Care Networks'. Each Primary Care Network will have an integrated care team built around it. A reorganisation of estates is desired to enable the teams to be co-located. The longer -term vision is to develop a multi-speciality community provider (MCP), a form of accountable care system, meaning that all providers will eventually share a single capitated budget with a co-ordinated model of care.

Westminster

Central to the transformation plans for Central London CCG is their Primary Care Strategy 2017-20. GP's will be promoted as the systems leader and practices will work together in the concept of "village" working within small groups of GP practices, adult social care staff, care co-ordinators and others working together as a multi professional team referred to as a 'primary care home'. Larger more sustainable delivery models in the community between the primary care homes have already been developed. From April 2019 Central London CCG will be creating a new structure, the multi-speciality community provider (MCP) based on the system of accountable care aimed at promoting integration of care services with joint responsibility and accountability – one system, one budget and better outcomes.

Going forward and as these new structures emerge in all three boroughs the specialist palliative care service must integrate into the new models and not sit outside of them. The responsibility and thinking about how this can be implemented sits with both the commissioners and the palliative care providers. The hope of this happening will be helped if, as a result of this palliative care review the numbers of providers are rationalised to two or one lead provider for the community palliative care services.

Recommendations:

- In the planning of the integrated care services and development of primary care, the tri-borough CCGs must ensure that the community level, specialist palliative care service is fully integrated into developing systems, including the concept of co-location.
- Work with the integrated care systems to deliver care to groups that are 'hard to reach' particularly the homeless and those with a learning disability and those with mental health problems.
- To ensure primary care have regular multi professional meetings to review their palliative care patients.
- To standardise models of service provision across the Tri-Borough and NWL footprint.

National Models of End of Life Care[23] (appendix G)

In response to the changing demography and needs of dying people, nationally enhanced models of end of life care are being developed and evaluated. This enhanced care can demonstrate quality improvements and cost savings with reduced emergency admissions, reduced length of hospital stay and increased achievement of choice around place of death. Evidence suggests there are a number of overarching components that are necessary to ensure success. A published report reviewed 66 palliative and end of life care co-ordination systems with the aim of identifying best practice, improving people's experience and choice at the end of life. The components of service models from the report combined with other components from research include the following:

1. Clinical triage 24/7 with a single phone number and the availability for face to face home assessment with a short response times for clinical situations that are urgent. This is paramount as there are often multiple professionals and organisations involved as someone whose death is expected deteriorates, leading to fragmented disorientating experience for patients and families (Ombudsman report 2105).
2. Rapid response mobilisation of health and social care that is able to stay with patients for prolonged periods including overnight.
3. Availability of medication and equipment.
4. Skilled and competent practitioners.
5. Integration with all other service providers in the area, evidence of joined up services with acute care and discharge care.
6. Evidence of electronic record sharing. EPaCCS- for the tri-borough CCGs this means at the very least the formation of a CMC record.
7. The building of strong links with local community groups/ the voluntary sector.
8. Consideration of the needs of hard to reach groups and building links with local communities.

There are three excellent examples of palliative and end of life care co-ordination centres in the London region. All have been developed and run by a hospice service working as the lead organisation but in partnership with others and can be seen in Appendix H.

The provision of Specialist Palliative Care in the tri-borough

The four providers of specialist palliative care in the tri-borough CCGs, are located close together, a unique feature of the geography of London. A small number of non-contracted patient activity, goes to Marie Curie Hospice Hampstead (6 inpatients and 28 outpatients for 2017-8).

According to the 2017 CQC report hospices deliver an extremely high standard of care. 70% are rated as good and 25% are rated as outstanding. This is considerably higher than any other CQC regulated sector where only 6% of NHS acute hospitals' core services and 4% of GP practices were rated as outstanding and, within adult social care, 2% of domiciliary care agencies, nursing homes and residential care homes were rated as outstanding. [24]

SJH, PH and RTH all received an overall 'good' rating in their most recent CQC reports. The PH were inspected as part of an overall CLCH inspection as a large community provider, SJH as part of the private hospital. Only RTH received a stand-alone inspection.

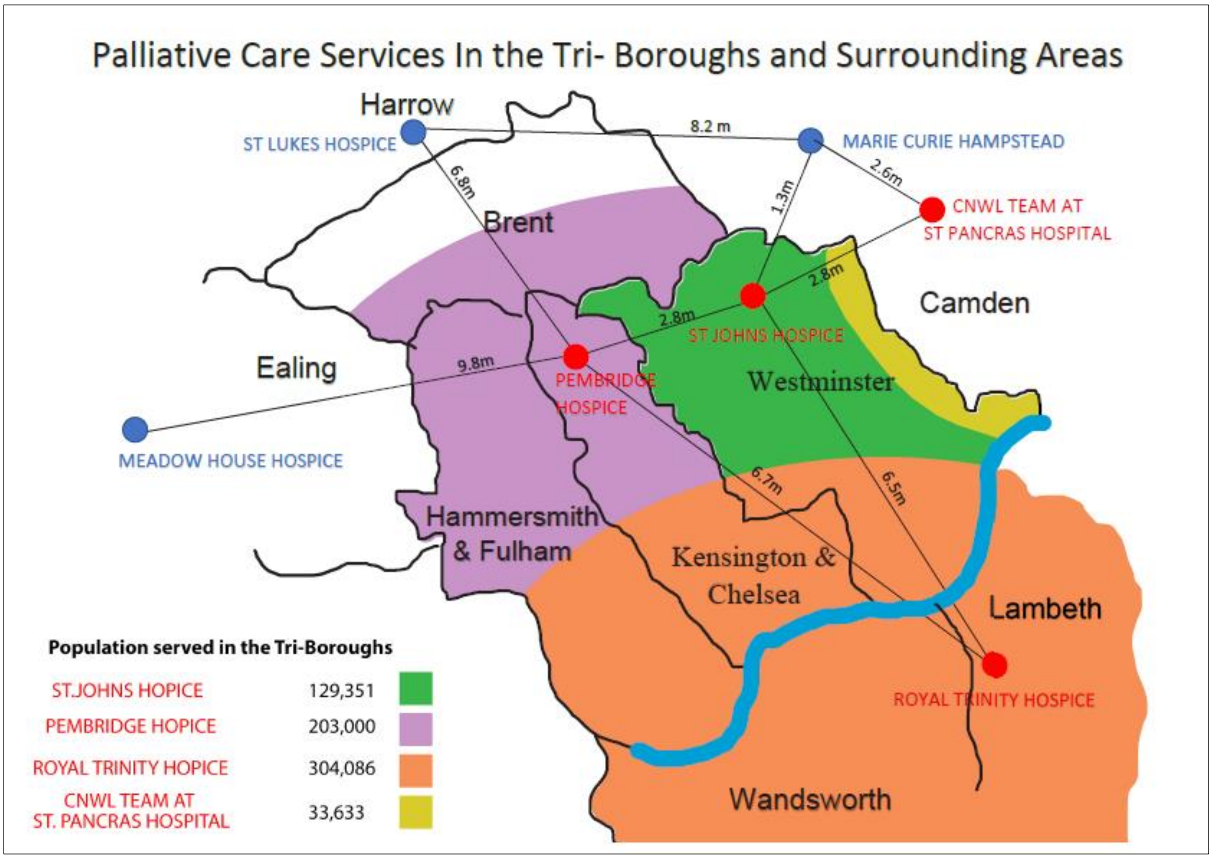
The hospices have significant variations in their service provision particularly in their community services. For example, the SJH finishes at 5pm with advice available from a ward nurse overnight. PH community specialist palliative care nurses also finish at 5pm, but the clinical nurse specialists are available to give telephone advice overnight. At RTH, the CNS's finish at 8pm and are on call until the next morning for telephone advice. At CNWL, they operate a Monday-Friday 9am-5pm visiting service with on call support outside of these hours. At these times advice can be obtained over the telephone and clinical visits provided at weekends or at night if necessary. Contact is made via the hospital switchboard. The ratio of specialist palliative care nurses per head of population also differs.

RTH have a 1:47,000 ratio, PH 1:48,000 and SJH 1:23,000. RTH has one independent nurse prescriber and PH has two and SJH have none.

Although NHS Central London CCG is the lead commissioner for CLCH and the PH, palliative and end of life services are commissioned by the Joint Adults Commissioning team, held by Hammersmith & Fulham CCG. No single CCG is responsible for all palliative and end of life services in Westminster, Kensington & Chelsea and Hammersmith & Fulham.

Both RTH and SJH deliver an in-depth quality analysis of their services to the CCG's. The PH does not. Commissioners stipulate what is required of the providers but some hospices produce quality reports as part of their governance which they share with their commissioner. A community palliative care service, continues to operate in North East Westminster and is provided by CNWL, based at St Pancras Hospital Monday-Friday 9am-5pm. This service is commissioned by Camden CCG.

Figure 2: Location of palliative care services



The Pembridge Hospice

Overview
Pembridge Hospice (PH) is part of Central London Healthcare NHS Trust (CLCH). The Hospice is one of a small number of NHS Hospices in England. CLCH is a large provider of community healthcare managing 78 different services across 11 London boroughs and in Hertfordshire. It employs 3,500 staff. Pembridge Hospice is the only specialist palliative care service in its portfolio.

Workforce
Pembridge Hospice has 69 staff representing 60 full time employees (FTEs) and 45 volunteers. At any one time it supports approximately 400 patients. As part of the CLCH CQC inspection that took place in 2017, the trust which included the PH was rated as ‘good’ in all domains.

Finance, contract and monitoring
PH is commissioned as part of a block contract. The commissioner has not specified any palliative care key performance indicators in the contract for the service. However, the trust reports to commissioners on the number of admissions, number of community and day care contacts/attendances. Quality of care is reported on a monthly basis to the CCG Quality Group in terms of patient experience and clinical care. As well as the tri-boroughs it also delivers services to Brent CCG.

CLCH operates a registered charity with a number of named funds within the overall CLCH charity. The largest fund is ‘The Pembridge Hospice Charity’. The accounts for 2017-8 show a balance in the Pembridge Hospice Charity Fund of £2.069m, which aims to support the entire trust. The Pembridge Hospice Charity funds 4.97 FTE posts. These posts support the wellbeing of patients, families and carers and are not clinical posts. This equates to £187k funding. Additionally the charity provides £50k per year to support patient activities such as a reading service. The total annual charitable contribution of £238k represents 7% of the overall running costs.

Strategic plan and progress
The Trust End of Life Care strategy is a broad strategy and incorporates all end of life services e.g. Community Nursing and the specialist palliative care services provided by the Pembridge. The overarching aims of the End of life Care strategy 2017 to August 2019 are:

- To enable integrated, co-ordinated end of life care.
- To promote the early identification of people at the end of life and delivery of compassionate end of life care by the CLCH workforce and other partners.
- To improve end of life care and experience for patients and their families receiving care from CLCH with advanced, progressive and incurable illness.
- To reduce inequalities, eliminate discrimination and advance equality when developing, arranging and delivering end of life care.
- To improve access to end of life care services, improve the coordination and choice of type and place of care and reduce inequalities of service provision across CLCH.
- To increase the proportion of patients who are cared for and die in their preferred place of care.
- To be aware of the role of the wider community in the dying person and other important networks.

Key achievements to date include:

- The implementation of a patient user group at Pembridge and the Swan Song project ensuring the patients voice is heard and listened to when making changes to the services.
- A revised paper and electronic Individual plan of care.
- The implementation of further training on advanced communication, key documentation and the care and use of syringe drivers.
- Competencies related to end of life care for staff which are now embedded as part of existing development programmes.
- The implementation of an Always Event focused on bereavement.
- Trust wide Schwartz round programme.

The strategy is reviewed on a regular basis by the Trust End of Life care committee. This is chaired by the Director of Patient Experience and reports into the Trust Quality Committee, a sub-committee of the Trust Board.

The strategy is currently being updated using patient feedback, latest end of life care guidance, the new Trust Clinical Strategy and the new NHS 10 -year plan with the aim of being launched in August 2019.

The Pembridge business plan

The Pembridge has its own business plan which includes a number of aspirations for the service over the next 3 years. This has led to the development of a communications plan leading to improved communication with relatives and carers. Current work is looking to redesign the Pembridge Day Hospice to include a wider range of clinical treatments.

Recent service developments

The Pembridge Hospice has recently implemented the SystmOne IT system which gives them intra-operability with primary care and the service has begun to implement the Outcomes Assessment and Complexity Collaborative (OACC) suit of clinical outcome measures across ward, community and day hospice. This enables more patient-focussed clinical interventions and provides a real time measure of clinical effectiveness.

St John's Hospice

Overview
St John's Hospice is part of the Hospital of St John & St Elizabeth. The hospital has a charitable status. The Hospice Director sits on the hospital board.

The hospital board oversees the operation of the Hospital of St John and St Elizabeth and St John's Hospice. By volume, the main business of the board is the operation of the hospital where they are about to embark on a huge project to rebuild the operating theatres at an expected cost of approximately £40m.

St John's Hospice employs 72 staff which represents 64.33 FTE's. It also has 150 volunteers which help with patient care on the inpatient unit and in the retail shops. At any-one time it is supporting approximately 850 patients.

They are the only hospice in the tri-borough area that run a Hospice@Home service. This is a service which delivers practical care and support in the last days of life to people at home. They also are the only hospice to run a lymphoedema service in all three boroughs.

The largest element of the Hospice@Home workload is terminal care, with the service also providing respite care, admission avoidance and facilitated discharge. The nurse co-ordinators work closely with the Continuing Health Care (CHC) team and are occasionally asked to assess a patient, to establish the level of need.

The Hospice@Home service provides care for up to two weeks, usually as day care, night care or both. Packages average six days in duration, and average 105 hours in total. Hours of care delivered in 2018 were 21,896, a 19% increase on 2017 (18,394).

Finances, Contracts and Monitoring.
For 2018, the Hospice had annual running costs of £6.9m. The revenue to cover this came from NHS contracts (£2.8m), fundraising (£2.3m) and the surplus made from the Hospital of St John and St Elizabeth (£1.8m).

Accounts submitted to the Charity Commission for the year to 31st December 2017 showed an increase of income to the hospital of 1.2% to £58.2m; and an increase in operating costs of 2.6% to £55.7m. Free reserves are £6.8m and their operating surplus for the year was £2.5m.

St John's are commissioned on a standard NHS contract and performance is measured against bed days, new patients to the community service and day care attendances. The bulk of their specialist palliative care activity is for Central London CCG, followed by West London CCG. They deliver services for patients in Brent, Camden and Islington CCGs with NHS contracts valued at £700k annually.

In total, St John's receives £2.8m from their NHS contracts which represents 46% of their care costs and 40% of their total costs. There has been no uplift in the NHS contribution over the past few years, despite rising costs. They meet their contractual expectations but have capacity to substantially increase their inpatient care as the unit is commissioned for and operated at 63% capacity for 2017-18.

Strategic Plan and Progress
The hospital has published a strategic business plan for 2018-2020. Within the document it has 8 actions required to be completed by the hospice in 2018-2019

- Augment Hospice@Home services.
- Develop outpatient clinics for community/day care patients.
- Achieve growth year on year in numbers of patients.
- Increase uptake of feedback methods for patients and families.
- Demonstrate full compliance with relevant quality standards.
- Perform within annual budgets for revenue and expenditure.
- Develop educational programmes for local health professionals raising awareness of the hospice.

Recent Service Developments
St John's have developed joint working with Imperial College Healthcare NHS Trust for patients with COPD and heart failure, attending a regular multi-disciplinary team meeting with the respiratory and heart failure teams.

The hospice clinical staff have regular contact with the Butterworth Centre, a care home located on the Hospital site.

Forrester Court care home is supported by a Clinical Nurse Specialist in the Specialist Community Palliative Care Team, who attends a monthly multi-disciplinary team meeting with care home staff and representatives from primary care.

The Royal Trinity Hospice

Overview

Royal Trinity Hospice (RTH) is an independent charitable hospice founded over 125 years ago with accounts submitted to the Charity Commission. There is a board of trustees governing the hospice whose sole purpose is the improvement in palliative and end of life care. RTH supports over 700 people at any-one time across central and south west London. They service four other boroughs as well as the tri-boroughs. RTH employs 256 staff and has a well -developed ‘army’ of volunteers who assist in almost every area of the hospice.

Finances, Contracts and Monitoring

RTH have a standard NHS contract in a multi CCG alliance as they service not only the tri-borough CCG’s but Wandsworth, Lambeth, Merton and Richmond CCG’s. Lambeth is the lead commissioner and achievement on the contract activity is based on bed days, numbers of patients seen by the community palliative care nursing team and outpatient attendances.

In 2017-8 they received £718,816 in funding from the tri-borough CCG’s plus a further £227,607, which is a historical sum of money given over ten years ago by central government, originally via the cancer networks to hospices to help them make improvements in line with the End of Life Strategy of 2008.

There has been no uplift to the NHS contribution for many years, despite rising costs, and the NHS core contract contributes only 18% of the hospices running costs. The RTH has to raise £9.5 million each year to close the gap between NHS funding and the cost of providing services.

Forty five percent of independent hospices are reporting that expenditure is now exceeding income, with Royal Trinity Hospice included.

In 2017-18 revenues declined from £12.4m to £11.9 m, due to a decline in fundraised income, although this was partially offset by increased retail income. Expenditure increased slightly by 1.3% to £12.5m mainly due to a 1% salary increase and an increase in retail property costs. The deficit for the year was £0.635m before depreciation. Year-end net assets were £20.9m and year on investment assets were £5.9m, which would cover five months of operating costs at 2017-8.

Strategic Plan and Progress

A strategic plan for 2018-21, has been developed, which aims to:

- Develop impact reporting to identify strengths and weakness in the service;
- Ensure sustainability of their services; and
- Develop their community services to enable the hospice to see 30% more people in three years.

Royal Trinity Hospice has already made considerable progress with their strategy. They have developed an impact report, visit their website www.royaltrinityhospice.london

The published data informs us that 2351 patients were supported by Royal Trinity last year:

- 58% had cancer, 42% did not.
- 93% had an advance care plan, 69% died in the place of their choice and only 1 in 4 people died in hospital.
- 94% of patients seen reported an improvement in their pain.

Ensuring sustainability means increasing fundraising and retail income year on year to support the growth in patient services. The growth strategy has seen four new shops open during 2018/9 with more to come in future years, and an increase in fundraising targets over the next few years.

In developing their community services, they have re organised their model of care in West London CCG, with a 'team around the patient' model of shared competencies. The model is allowing for more proactive and efficient care.

Recent Service Developments

Royal Trinity Hospice have modernised their traditional day care services. The primary service intervention is therapeutic with a range of drop in activities alongside rehabilitative palliative care, enabling them to spread their resource in a cost-effective focussed way. A dementia community nursing service is provided across the whole catchment area. A converted inpatient bay has become dementia friendly, allowing the hospice to offer respite care and all staff have been trained in dementia awareness enabling them to be 'dementia friends.' They have one independent nurse prescriber and plan to develop more. Since 2015, a successful co-ordination service is provided in Wandsworth CCG (see appendix H). The hospice is also pioneering the use of 'Virtual Reality' for patients, through a research study examining its potential therapeutic effectiveness.

Central North West London NHS Foundation trust (CNWL) Palliative Care service in North East Westminster

There is also a small area of North East Westminster whose community palliative care services are provided by CNWL and commissioned by Camden CCG. The approach to the commissioning of palliative care across North Westminster boroughs is a product of legacy commissioning. The service covers 5 GP practices.

The CNWL team is part of a large established community focussed service and is working proactively as part of the North Central STP to deliver on the last phase of life plan (Appendix I). They have a quality improvement plan across a range of markers and offer a high volume of education. An end of life strategic plan is about to be ratified by CNWL which amongst other things will see an increase in the educational offering to health care professionals working in the tri-boroughs.

Many aspects of the last phase of life plan parallel the recommendations within this review. This is the only service which currently delivers a 24- hour advice and visiting service to patients in their own residence.

Services Provided by the Palliative Care Services

	St Johns Hospice	Royal Trinity Hospice	The Pembridge Palliative Care Service	CNWL palliative care team
In-Patient beds	18 beds 24/7 Admissions	28 beds 24/7 admissions	13 beds 24/7 admissions	No Hospice inpatient beds
Day hospice	10-4, 4 days a week	Traditional day care has developed into flexible outpatient, therapeutic and social activities available 9-5pm , 5 days a week	10-4 ,4 days a week	No day care facilities
Community palliative care	Mon-Friday 9-5pm with one CNS working at the weekend 9-5pm	Multi professional team around the patient with a 7 days a week visiting service led by the CNS's.	Mon-Friday 9-5pm with one CNS working at the weekend 9-5pm.	Community services provided Mon-Fri 9-5pm with clinical community visits available if needed outside of these hours
Out of hours advice	Managed through the ward nurses after 5pm. Back up doctor is the RMO on for the hospital. Second on is a palliative care consultant second on call	24/7 specialist clinical /medical advice. A CNS is on the late shift at the hospice until 8pm and then available for telephone advice 8pm-9am. This is supported by two on call doctors: a first on call specialist registrar, and a second on call medical consultant, all available to speak to health care professionals and patients/carers as required.	Usually managed by the ward nurses after 5pm with back up advice from the shared rota with St Johns. Currently a Cis on call to give advice and the medical rota is shared with 3 other consultants from different providers.	Full telephone advice accessible through an 'on call' service' via the hospital switchboard from 5pm until 9am, 7 days a week.
Hospice @ Home	Small service that sometimes bridges CHC packages of care. Not available in H&F	No	No	No

Bereavement support	yes	yes	yes	Bereavement support is delivered via the team social workers
Lymphoedema service	Yes	No	No	No

Figure 3: Provision of services

Recommendations:

- There is one commissioner for end of life care in the tri-borough CCGs.
- That the CCG's address the inequity of current funding arrangements for hospices.
- That service specifications and contracts are standardised.
- That the NHS meets the cost of all core community palliative care services.
- Response times from specialist level services should be in line with the degree of urgency of patient need and measured.
- Measured activity should not solely be based on direct face to face contact with the specialist level provider but their sphere of influence with others. For example, a specialist level practitioner may advise on the management of patients whose service is being delivered by others.
- The service provision should be based on the patients GP and not where the patient resides.
- User feedback using a validated tool should become a routine part of outcome measures e.g. Voices for Hospices (which includes non-bedded service) The CCG's may want to develop a mechanism for feedback for the whole of their integrated care programmes in which case the specialist level palliative care should be incorporated into this.

Specialist Palliative Care Activity

Available data
The review found that data collection for the specialist palliative care services was inconsistent and therefore benchmarking the activity and performance was difficult. Royal Trinity were not able to breakdown their activity into working hours and 'out of hours.' Data on bereavement services and therapy services has been omitted in this report due to the lack of accurate data. Data on the out of hours advice line activity is also missing as none of the providers collect any data in this area. The review was also unable to see data on the different aspects of the non-bedded services at the Royal Trinity, as the data was all recorded under 'home care activity.'

At the time of this report, no data was available for the CNWL service based at St Pancras Hospital. However, the data available shows:

- The reach of the current services impacts on 48% of expected deaths. It is suggested that 60-75% of dying people could benefit from palliative care[25].
- The numbers of patients seen with a non-cancer diagnosis is increasing each year, currently about 30%.
- 23% more people die outside of the acute sector if a palliative care service is involved.
- 458 people were admitted to a hospice bed out of 2,222 expected deaths. Admissions are possible out of hours but only 21 people were admitted to an inpatient bed at this time. (This excludes the RTH which is unable to provide data on out of hours admissions).
- Utilization of available inpatient beds was low in two settings; PH only had a 67% occupancy and SJH 63%. However, SJH met its contractual obligations. The PH have a block contract and the percentage occupancy and target for admissions is not stipulated.
- Insufficient doctor or nurse activity in outpatient clinics, which are a cost- effective setting to assess a patient.
- In SJH and PH, few new patients' access the service (47 for the 2017-8) and both are still running traditional day services rather than a drop in, goal focussed and rehabilitative approach service enabling many more people to benefit from palliative care.
- The length of stay in the hospice beds is amongst the highest in London. 16-17.8 days with a London Hospice average of 14.6 days (Appendix K). This may reflect the paucity of care home beds.
- Hospice@Home receives outstanding feedback for the quality of their care but are only involved in a 3% of expected deaths in the boroughs. Developing this across the boroughs is likely to be prohibitively expensive and similar to the cost of a bed in a hospice or hospital.

Inpatient Hospice Bed Usage
It is generally accepted that hospice beds should be used for patients who have complex and intractable problems that are unable to be managed at home. This should include patients with severe psychological distress but not overt mental health problems as most hospices are not structured to have formal links with mental health services. RTH do have arrangements for psychiatric assessment and management of patients with mental health problems.

All hospices should have the facility to manage complex pain with more acute interventions such as intrathecal blocks and epidural catheters. All the tri-borough hospices are able to seek opinions from chronic pain specialists and manage intrathecal blocks and epidural catheters. The Government's ambition to deliver preferred place of death Commissioning for Quality and Innovation national goals, 'CQUIN's', has influenced hospice admissions, to admit patients whose preference is to die in a hospice, but who do not necessarily require specialist palliative care.

Bed costs

The price for a bed-day within the tri-borough CCGs are:

- Hospice - £750
- Hospital - £411 (based on 800 NW London admissions, April 2017-December 2018, average Length of Stay 13 days)
- Residential nursing home – £111-£301 (CHC contracts)
- National data for final admissions shows that 32% die after a stay of 0-3 days, 18% after a stay of 4-7 days and 50% after a stay of 8 days or longer. [26] [27] [28]

The length of stay in a hospice bed commissioned by the tri-borough CCGs is higher than the London average and slightly more people die in a hospice bed than in other London boroughs. In 2017-8, there were 458 hospice admissions from the tri-borough CCGs and 213 deaths (West London CCG - 84, H&F CCG - 50, Central London CCG - 79).

Hospice beds are an expensive place to die compared to other settings. Although the cost to the NHS is heavily subsidised in the independent charitable hospices, hospice beds should be thought of as "critical care beds" for the highly complex rather than a place to choose to die.

It is unlikely that there will be an increased need for 'critical care' inpatient beds for people who have highly complex symptoms. Given the low occupancy of PH and SJH there is probably enough capacity in the system for the tri-boroughs to operate with less specialist palliative care beds (Appendix L). Indeed, the system has been managing without the 13 beds at PH since October and as far as we can tell the majority of patients requiring admission have been redirected to other units where there has been spare capacity. As far as we are aware, there has only been one patient who refused an inpatient admission to St Luke's in Harrow because of distance.

Only RTH has kept data on admissions requested from the tri-boroughs that were not fulfilled which was 15 patients for the 2017-18 year but even with this data we do not know the reason for non - admission. The hospitals report instances of patients who died waiting for a hospice bed but unfortunately there is no data to demonstrate this.

Every hospice has reported difficulties in discharging people who need a Continuing Healthcare care home bed. Given the low ratio of care home beds to the over 75 age group in the tri boroughs, this is not surprising. This in turn increases the average length of stay in a hospice bed. To ensure robustness of this assessment it will be important to understand the impact of the long stay patients and the reasons why they cannot be transferred out of an inpatient bed. It appears that there is a problem with patient flow at the correct level of acuity. It seems likely that more CHC fast track beds are needed rather than specialist palliative care beds.

The reviewers assessment is that it is there could be a reduction in specialist palliative care beds if :

- There were more CHC beds in the system.
- The hospices ensured that the admissions truly required a ‘critical care’ hospice bed.
- The numbers of patients who require an inpatient ‘critical’ hospice care bed is approximately the same as the numbers of 2017-8 (485)
- Hospices ensured that their discharge procedures worked to NHS guidelines
- The model of specialist palliative care in the community improved in line with the recommendations.
- The number of beds that could be decommissioned is outlined in Appendix L, and is based on the assumptions as outlined.

Recommendations:

- Reduce the number of commissioned beds/bed day activity (see appendix L for modelling and assumptions.
- Reinvest cost savings to improve community palliative care service as outlined.
- Care is co-ordinated from a central hub that operates from 8am to 8pm 7 days a week involving quick and efficient access to care, advice and signposting. This will increase the reach and influence of the specialist services, particularly to those with multiple-co-morbidities in their last phase of life. Included in the co-ordination/casement management centre are:
- A clinical triage and assessment with competent staff of sufficient seniority and authority to get the right care to the right person at the right time with the right service. The district nursing services should be firmly linked into the care co-ordination centre/case management centre.
- Referrals for hospice in-patient care should also be directed to the care co-ordination/case management centre and forwarded to the appropriate unit, or have a shared referral 'box.' This will make it easier for referrers both in the acute sector and primary care.
- The care co-ordination centre/case management centre will need to provide a rapid response service.
- Consultant doctors and nurses should be part of the case management/care co-ordination centre both in an advisory capacity and for urgent assessments for people at home/care home. Joint visits with the GP are to be encouraged.
- Community specialist palliative care provision should be mostly targeted at short term episodic interventions. The majority of their work should be aimed at coaching, training and empowering others. They should take responsibility for case management to recognize when their involvement is needed. This will ensure that the reach and influence of the specialist palliative care provider is greater.
- There should be a joint audit between the CCG and the hospices to better understand the reasons for the long inpatient length of stay and the issues the hospices are raising re transfer to a care home setting.
- The CCGs should review their provision of CHC funded beds.
- Hospices should review their bed provision to ensure admissions are for those with complex and intractable problems. They may wish to develop a mixed provision with appropriate resourcing and pricing.
- Reduce the number of beds that are not being utilised, reinvest the money into the community provision, which will in turn further reduce the need for as many beds over time.
- The hospices work with the CCG's to ensure there is a common understanding of the cost of a bed day and agree a common model for funding inpatient care.
- For Commissioners and Hospice Providers to develop a service specification and pricing mechanism via a tariff to ensure effective use of inpatient beds
- Work should be undertaken with the local authority to commission a lead provider to integrate and standardize the many small bereavement services that exist in the boroughs and a new model developed.

Specialist Palliative Care Medical Provision

Royal Trinity Hospice

Establishment	**IPU**	**Community/OP/day care**
Medical Consultants	1.3	1.05
StR's/speciality Drs	2.0	0.7
Drs in training	3.2	0
Total	6.5	1.75

St Johns Hospice

Establishment	**IPU**	**Community/OP/day care**
Medical Consultants (employed by CLCH)	1.2	1.0
StR's /speciality Drs	2.6	0
Drs in training	0.45	0
Total	4.25	1.0

Pembridge Palliative Care Services

Establishment	**IPU**	**Community/OP/day care**
Medical Consultants	1.0	0.8
StR's /speciality Drs	3.0	0
Drs in training	0.5	0.5
Total	4.5	1.3

Figure 4.

The table above describes the breakdown of where the palliative care doctors are primarily based. For an inpatient bed, the doctor has primary responsibility for the clinical management; in the community this sits with the GP. Doctors in training are always likely to need their primary working practice to be in an inpatient setting as it is the place that they are able to get to see more patients in a shorter space of time. However, there are up to twenty times more patients under the community palliative care team than in an inpatient bed at any one time.

Recommendations:

- The hospices review the balance of their medical work plans and move resource to work with the care system in the community. They could consider some of the bed management to be led by senior nurses.
- When recruiting, consideration should be given to the balance of medical staff with some consultants, doctors in training to be palliative care consultants, speciality doctors as well as GP's with a special interest in palliative care.
- Medical staff in palliative care that deliver to the tri-borough CCGs, have an agreed mechanism for cross cover 24/7 to ensure service resilience.

Stakeholder data & themes

Data collection
The stakeholder feedback was collected in the following ways.

- Face to face or telephone interviews were held with more than 50 key professionals working in the provision of specialist palliative care services.
- A number of focus groups were held with patients, carers and patient representatives. A public ‘Call for Evidence’ which received 101 responses via an online survey (51 public-mostly informal carers and families, and 50 professionals/staff from the care system). Qualitative and quantitative data was captured
- 11 further submissions were received from individuals or larger national or local organisations.

Focus group data is in Appendix M. It is evident that the current hospice patients and their carer’s are very satisfied with the services they are receiving which was largely day care. The BME user group who were not currently accessing palliative care services described feeling ‘lost’ in the health care arena and the terms ‘hospice’ and ‘palliative care’ were confusing. This is important feedback and better data needs to be obtained on the uptake of palliative care services from marginalised or ‘hard to reach’ groups.

Stakeholder themes

The key themes across all groups

Patients, families and carers report high satisfaction rates once they start receiving a specialist palliative care service.

There are variations in services, contracts and performance across all providers.

There is no one commissioner with oversight of all specialist palliative care provision across the tri-borough.

The NHS contribution towards the care costs varies across providers.

(range 18%-100%)

There is a variation across providers in the ratio of specialist palliative care nurses in the community per head of population.

The involvement of the community based palliative care teams significantly improves the likelihood of dying outside the hospital setting which is what patients say they want.

The palliative care services in the tri-borough reach approximately 48% of patients who have an expected death.

Getting a rapid face to face assessment from the specialist palliative care provider in the community is problematic.

Access to a senior a specialist palliative care clinician to aid decision making for a GP or community nurse can be problematic and inconsistent.

The Community Independence Service (Rapid Response team) are regularly called to patients who on initial assessment are in need of end of life care.

The model of daycare varies: Traditional model by St Johns and Pembridge saw a 47 new patients in 17/18. Trinity has a modernised day care and rehabilitative approach.

District Nursing services feel aggrieved that the Specialist Palliative Care services see themselves as advisory and not interventionist.

Specialist Palliative Care nurses perceive District Nursing to be task orientated, not holistic and personalised.

74% of the public who responded to the online survey reported poor co-ordination and communication between services for people at the end of life.

The percentage of deaths at home is higher in all 3 boroughs(28.2%) than London (23.8% or England

(23.5%)

Deaths in hospital for the boroughs(48.9%) are higher than England(46.9%)but lower than London(52.8%)

Referrers who interface with more than one provider for inpatient care have a perception that hospice A is better able to cope with complexity than hospice B and refer accordingly.

The specialist palliative care services different IT systems that have no interoperability with primary care or the hospitals (exception Pembridge)

Based on the number of inpatient bed days available across the tri-borough, there is capacity in the system to admit more patients or close some beds.

Length of stay is above the London average of 14.6 days:

- *St Johns Hospice: 17.8 days*
- *Pembridge inpatient unit: 17.8 days*
- *Royal Trinity: 16 days*

There is a lower ratio of nursing care home beds in the tri-borough compared to the London region which may impact on the length of stay.

The palliative care services still predominantly deliver care to people with a cancer diagnosis but this is steadily changing. (Average 70/30)

The balance of palliative care medical time is heavily weighted to inpatient beds and not the community

The occupancy of two of the three units is low:

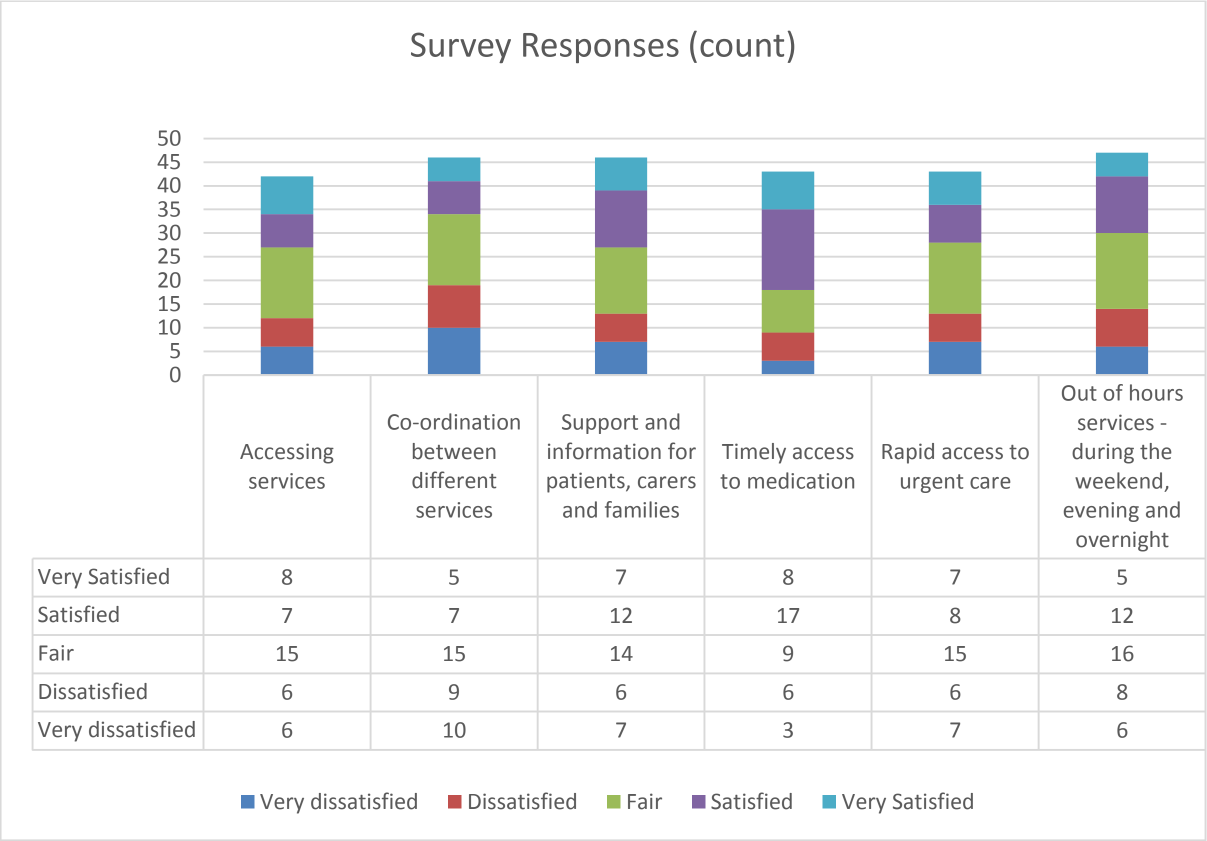
63% St Johns Hospice - 67% CLCH Pembridge Inpatient Unit (2017-8 figures)

The analysis of the survey monkey data is below. The data is split between the professionals which is largely health and social care staff and the public which is largely patients, families and informal carers.

	Numbers of respondents	% who were very satisfied or satisfied
Accessing Services	42	36%
Co-ordination & communication between services	46	26%
Support and information	46	41%
Timely access to medication	43	58%
Rapid access to urgent care	43	34%
Access to services out of hours	47	36%

The vast majority of the feedback from both groups is strongly corelated. The least satisfied are the public where only 26% rate the co-ordination of care and communication between professionals as satisfied or highly satisfied. On every measure there is much room for improvement.

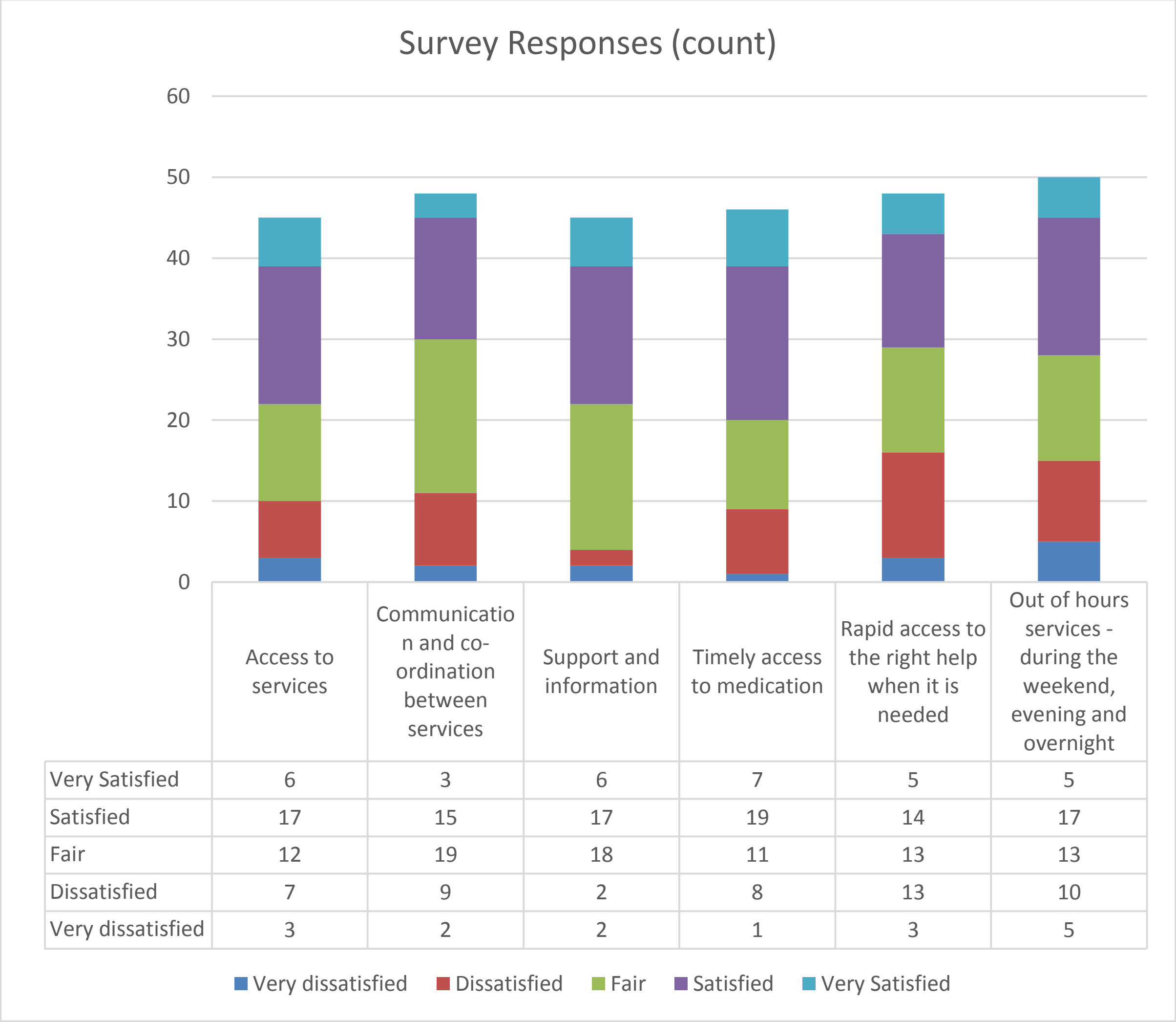
Survey Monkey Responses from the public



	Accessing services	Co-ordination between different services	Support and information for patients, carers and families	Timely access to medication	Rapid access to urgent care	Out of hours services - during the weekend, evening and overnight
Very Satisfied	8	5	7	8	7	5
Satisfied	7	7	12	17	8	12
Fair	15	15	14	9	15	16
Dissatisfied	6	9	6	6	6	8
Very dissatisfied	6	10	7	3	7	6

Responses from Professionals & staff

	Numbers of respondents	% who were very satisfied or satisfied
Accessing Services	45	51%
Co-ordination &communication between services	48	37%
Support and information	45	51%
Timely access to medication	48	39%
Access to services out of hours	50	44%



	Access to services	Communication and co-ordination between services	Support and information	Timely access to medication	Rapid access to the right help when it is needed	Out of hours services - during the weekend, evening and overnight
Very Satisfied	6	3	6	7	5	5
Satisfied	17	15	17	19	14	17
Fair	12	19	18	11	13	13
Dissatisfied	7	9	2	8	13	10
Very dissatisfied	3	2	2	1	3	5

Online survey comments received relating to the review from the public:

" I didn't know how to access the services we needed."

" I didn't know how to get continuing health care funding."I

" I could have done with a fact sheet on palliative care."

" We were really helped by the care at night."

"Palliative care is hugely underresourced in the tri boroughs"

"The lack of co-ordination between medical and social services is a disgrace."

"Communication between serices needs improving."

"Information is not passed from one service to another."

" I have only good things to say about services I received."

" Everyone was caring and supportive."

"Dealing with different departments was fragmented and frayed."

" closer collaboration would help-the hospital presribed a medicine we cojuldn't get at home

"Our hospice is closed, we need good doctors and more nurses- it is an exemplorary service."

" We need easier access to pain relief at home."

"palliative care made no difference."

" We needed more care at an earlier satge when the diagnosis was terminal."

A sad, articulate and detailed submission also came in from a recently bereaved carer. The carer described the difficulties that she had accessing the right care at the right time for her husband and experienced services working in silos. The patient needed urgent equipment, a care package, symptom control and a care plan. The carer and patient felt let down by most of the services and no services responded in a timely manner considering the urgency of the situation. Eventually the patient was admitted to a hospice where he received good care and died a few days later. This is a far too familiar story and serves as a ‘vignette’ of why this review is important.

Feedback from the two Hospice groups:

" I feel safe coming here every week."

" It's a wrap around service and home visits are provided , if needed."

" support for families is excellent."

" Need better cover at the weekends."

" End of life care should be as important as maternity care."

" The hospice helps me navigate the rest of the system."

" They know me well at the hospice."

"It provides me with a support network."

"It's given me a new lease of life."

"They always listen and take my concerns seriously."

" I can get rapid access at the hospice to the right help."

I didn't want to be referred but now I wish it had been earlier."

"The staff are so supportive and reliable."

"Here at the hospice I can easily get sorted."

'It's a strong word but I mean it, I love it here."

" I wish I could come more often."

The future challenges of palliative care

Defining complexity & who requires specialist care

Services have traditionally delivered care to a population of people that were considered to have complex needs. However, there is no standard definition of 'complexity' and in reality, it has been defined by a case mix classification such as disease group, age and physical symptoms.[29] This was in practice limited to those with a cancer diagnosis, younger people, alongside a limited number of those presenting with neurological diagnosis e.g. Motor Neurone Disease. There is an urgent need to define what constitutes complexity.

The specialist palliative care model, delivering a one size fits all, gold standard service to a few is no longer fit for purpose. Published research over the last few years has demonstrated similar symptom burden and distress in other disease groups and the multi morbid frail population.[30]

The trajectories of dying are different in the different groups of people as illustrated in figure 5 and new models of care must take account of this.[31] Specialist Palliative Care providers need to plan these trajectories in parallel with social care.

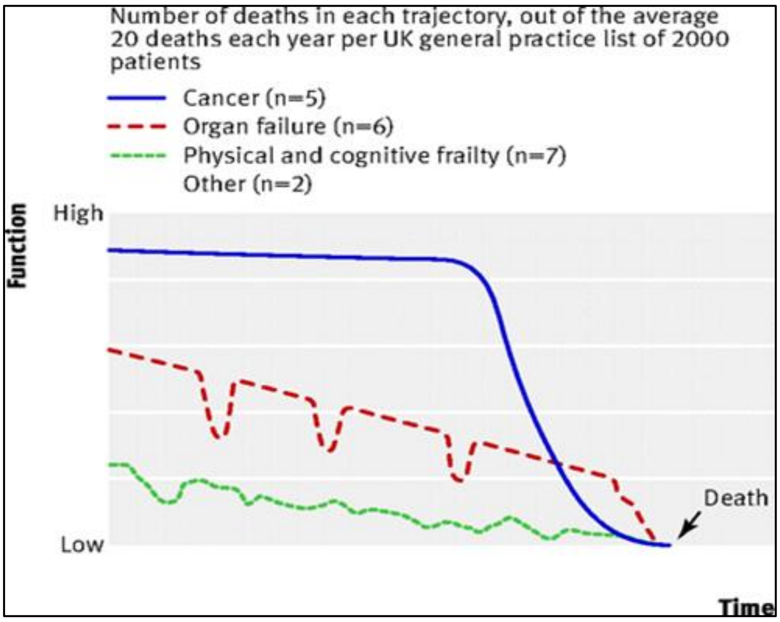


Figure 5

Rapid response

Currently in the tri-borough CCGs the specialist palliative care providers do not see themselves as needing to respond rapidly to urgent situations, the contract for community nursing states that they have up to 24 hours' to respond and so the default position often becomes a referral to the Community Independent Service (CIS). A rapid response service who have a remit to respond within 2 hours or the London Ambulance Service. Neither of whom can currently make a direct referral to all of the specialist palliative care services and most of whom require a referral to come from the GP.

The role of the palliative care nurse specialist

How specialist palliative care services integrate in a meaningful way with mainstream health and social care services is another challenge. Traditionally the clinical nurse specialist (CNS's) has had an expert advisory role within primary and community health care teams. This has led at times to challenges between district nurses and CNS's regarding role and function. District nurses have felt that nurse specialists can be overly precious about their role and are reluctant to be involved in direct hands on patient care should the situation require.

Specialist nurses have also been reluctant to become directly involved in the administration of medication via a syringe driver or for a patient who needs a one off injection. CNS's must take a more interventionalist approach and undertake nursing tasks particularly when with a patient. Palliative care nurses become frustrated when district nurses take a 'task orientated 'approach to care and fail to see and address the needs of the whole person.[32] Specialist nurses sometimes find district nurses reluctant to take instruction from other nurses and depending on the communication skills and experience of the CNS, this may or may not affect the working relationship and also the care that the patient receives.

How specialist and community nurses work together is fundamental to the delivery of high quality specialist palliative care. Where relations fracture, care is compromised and it is important for both sets of nurses to meet together regularly and discuss patients, to acknowledge both difference in practice and also role overlap and to be honest and open about how to best work together.

CNS's need to be highly competent and train to the level of an advanced practitioner These roles are experts in clinical practice, facilitate learning, provider leadership and ensure services are based on best practice. The Nursing and Midwifery Council has not yet regulated these roles but it is generally acknowledged in specialist palliative care that the advanced practitioner would need to be qualified in advanced assessment, independent prescribing and have successfully completed masters modules in symptom control and psychological care.

Recommendations:

- Introducing and using the Outcomes complexity and assessment collaborative tool (OACC) in all settings 33.
- The development of a rapid response component to the specialist palliative care services to better respond to the different trajectories of dying.
- To introduce a tri borough wide care plan that includes wishes and preferences of the patient and an escalation treatment plan.
- For specialist community providers to be equipped to respond to the nursing needs of patients if they have a planned or unplanned visit.
- For guidance to be developed to describe how primary care, community nursing and specialist palliative care clinicians work together.
- For specialist palliative care nurses to work with district nurses to improve the skillset and confidence of community nurses.
- For a borough wide agreement to be developed on the responsibilities and skillset of clinical nurses specialists to be developed into advanced nurse practitioners.
- Ensure that when the community nursing services are recommissioned the specification includes a rapid response element.
- Change in operational policies of the specialist palliative care providers to enable anyone to refer to their services.
- Primary care contracts to include monthly multi professional reviews for people at EoL.

Working with social care

Delivering personal care to patients is now considered to be the remit of the social care workforce, which is most commonly commissioned from private domiciliary care agencies. The Cavendish review (2013)[34] exposed the major difficulties and challenges for this workforce, poor training and supervision, poor terms and conditions and no established links into health services. The separation of activities of daily living from the work of health care and community nursing is particularly problematic for people coming towards the end of their life and deteriorating. It is during this period that there is a serious need for health and social care to be integrated. If they are not, social care workers don't develop the skills and confidence to manage the deteriorating patient with all the anxieties that this incurs for families.

The range of professionals that may be involved in a person's care are extensive and for the patient and family it is of the essential to their experience for professionals to work effectively together. Silo working of services in this phase of life can have far reaching consequences. Dame Cicely Saunders, the founder of the modern hospice movement said, "How a person dies lives on in the memory of those who are left[35]. The professionals involved in care can include the following; GP, community nurse, social care staff, palliative care clinicians, the acute sector, the ambulance service and sometimes mental health clinicians and the ambulance service.

Identification of dying people

This is a challenge and encompasses more complex disease groups other than cancer. Many patients are not identified as reaching the last phase of life, particularly frail older people with multiple co-morbidities and therefore do not have the benefit of assessment and care planning to meet their current and anticipated needs. However, there are now some useful tools to help clinicians identify those at risk of deteriorating and dying. The two most commonly used in the UK are the Supportive and Palliative Care Indicator Tool (SPICT) [36]and the Gold Standards Framework prognostic indicator guidance (PIG)[37].

Recommendations:

- SPICT is integrated into SystmOne for GP's.
- Integration with Health and Social Care

Mitigate silo working by:

- To set up a tri borough palliative care case management/co-ordination centre with one email address and one phone number
- To invest in IT systems that have interoperability.
- To increase the use of the CMC care plan
- For district nurses to have daily video linkage to the CNS's in the care co-ordination centre to plan the daily work for the patients on their caseload with palliative care needs.

24/7 support

Maintaining people in their own home requires appropriate support to be available 24/7. Out-of-hours palliative care is often provided by 'generalists' with no easy access to professionals with specialist level knowledge. The result is that individuals who contact an out-of-hours doctor are at a greater risk of being transferred to hospital at the end of life. An important study synthesized the components of a palliative and end of life service in the community that engendered security and confidence in patients and families at home[38].

Recommendations:

- The care co-ordination centre operates from 8am-8pm.
- From 8pm-8am advice for patients and families is obtained from the hospice advice lines and for out of hours GP's and community nursing, the on-call doctor is available.
- Rapid accessibility to equipment from the care co-ordination/case management centre.

Care Homes

Nationally 20% of the population and 30% of those aged over 75 die in care homes. 71% of permanent care home residents died in a care home and the number of deaths aged 75 years or older in care homes increased by 28% from 2011-2015[39]. Care homes are a major provider of end of life care[40], 80% of care home residents have dementia many also have multiple co morbidities. Goodman (2018) [41] notes that people usually opt to enter or are admitted to a care home when their needs can no longer be managed in their own home and they are unlikely to benefit from curative treatments.

The NHS has recognized the importance of improving end of life care in care homes[42] and there are many different models of specialist palliative care services working with care home staff both in education and training, and in assessing the resident's clinical needs.

There are no specific recommendations regarding the training of care home staff in this report as the NW London STP has a programme that it is implementing and a clinical triage service that it has introduced with telephone support from a clinician. Video consultation is also being introduced.

Recommendations:

- The care co-ordination /case management centre makes direct links to work closely with the 111*6 care home initiative
- The CCG's review their provision of nursing care home beds to ensure it is adequate for the population both now and into the future
- Ideally, each nursing care home should have an identified link to a specialist practitioner.

Workforce Challenges

The other major challenge for both medicine and nursing in palliative care is the number of people available to do the job. The ageing workforce in nursing, combined with the lack of nurses is becoming a national crisis with vacancy rates reaching higher than 25% in some areas and the national vacancy rate at 11%.[43] The numbers of senior district nurses has fallen by 30% with a reduction of 50% in the last eleven years.[44] Together with cuts in the social care budget this has reduced the number of available support staff to provide personal care to people in their last days of life.[45] Macmillan Cancer Support have identified a gap of 3400 CNS's across the UK which they estimate will rise to 7000 by 2030. Alongside of all of this is the lack of standardisation and regulation of the competencies required to function at an advanced practitioner level.

In palliative medicine the headcount of consultants in for the UK was 459 FTE's. In 2015 there were reported to be 53.8 vacancies and 30 new posts in development. Only 40 doctors gained places on the annual specialist training scheme which is inadequate to meet the current and anticipated needs. There are also 58 self-reported retirements due in the next five years.[46]

The 'Call for Evidence' and stakeholder feedback revealed a need for training of community nursing and a need to increase the confidence of some GP's in their management of people in the last phase of life.

Recommendations:

- The development of delegated responsibility in the care system through the use of IT programmes such as the 'e-shift palliative care module', where a senior palliative care clinician supervises a group of care workers via video link.
- Built into service provision and commissioning should be time and resource for the specialist level palliative care providers to train and educate the wider workforce. This should particularly include the social care workforce in domiciliary care and care homes.
- Measures are developed for the delivery of education and training.

Dying of or with Dementia or Advanced frailty

Dementia/advanced frailty has emerged as a key issue for hospices as they consider their strategic direction for the future. Dementia is one of the biggest public health challenges and people dying of dementia often receive the poorest care of our population.[47] For people with advanced dementia acute hospital admissions are distressing, inappropriate and expensive. The length of stay is longer, and a person is four times more likely to die during an admission than anyone else. Most admissions are for infections, which could be treated in a care home.[48]

Palliative care services are now beginning to embrace the needs of people with advanced dementia and taking the opportunity to work closely with both statutory and other voluntary sector organisations such as the Alzheimer's society and Admiral Nursing. Guidelines for services have been produced.[49]

Recommendations:

- To invest in an advance care planning programme in memory clinics as it is important to capture the patient's wishes and preferences at an early stage.
- The rapid response part of the care co-ordination/case management centre will be able to respond to the sudden deterioration of this group and prevent inappropriate hospital admissions.
- Subcutaneous fluids should be available in the community and not require a hospital admission.

Continuing Healthcare (CHC) in the context of the fast track process

CHC is the name given to a package of care which is arranged and funded solely by the NHS for individuals outside of hospital who have ongoing health needs. Packages of care usually involve care worker support in the patient's home or the payment of care in a care home. NHS CHC is free unlike care provided by local authorities for whom a financial charge may be made depending on your income and savings.

The tri-borough CCGs work together to administrate this contract with 12-16 care agencies to deliver this care. These care workers are an enormously important part of the patients experience of care at the end of life. The possibility of specialist providers interfacing, coaching and training these care workers is likely to have a big impact on the patient experience and the confidence of the family to manage the care. The CHC team also organise night 'drop in' services from their contracted agencies to patients if this is needed as part of the care package. Most of the London boroughs have contracts with Marie Curie whose traditional night service is care from 10pm-7pm, usually in the patients last few days of life. The tri-boroughs purchase this occasionally on a spot purchase basis.

In an audit from 1st April-August 31st 2018, 101 packages of care from the tri-borough CCGs were accepted for CHC funding under the fast track process. This process is to meet the needs of those who are rapidly deteriorating and entering the terminal stage of life. Of those accepted, 64% were still alive 3 months later. This implies that either the information on the application was not correct or there was not enough scrutiny of the application.

Recommendations:

- To move the fast track brokerage part of the CHC service into the care co-ordination centre to enable palliative care clinicians to help with difficult decision making and to build a relationship between palliative care services and the care agencies to impact positively on practice.
- To develop a small team of senior care workers as part of the care co-ordination rapid response service who will help to coach and empower the domiciliary care staff and bridge care packages that the agency is having difficulty mobilising quickly.
- To review the operation and expenditure of the continuing health care team and the contracts for care home provision.

Modernising Palliative Day Care

The most notable changes in the care of the dying, apart from the development of clinical co-ordination centres with advisory hubs and rapid response services, has been in the reshaping of day care services with a rehabilitation approach. Traditionally patients attended for whole days and had access to a huge range of both social and therapeutic activities. Patients often attended for months oryears. Whilst there was no doubt that the day care services were of a very high standard, only a small number of patients could access them, leading to gross inequalities. Access was usually based on patient choice rather than a specific need that required an intervention.

A model of rehabilitative palliative care has been developed, defined as:

> *"Rehabilitative palliative care is a paradigm which integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care. It is an interdisciplinary approach in which all members of the team, including nurses, doctors, psychosocial practitioners and allied health professionals, work collaboratively with the patient, their relatives and carers to support them to achieve their personal goals and priorities.*
>
> *Rehabilitative palliative care aims to optimise people's function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness.*
>
> *It is an approach that empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health.*
>
> *Rehabilitative palliative care supports people to live fully until they die."* [50]

Hospices are reforming their day care services taking this approach. Many more patients attend for a specific intervention rather than the whole day. Interventions such a circuit training or management of fatigue and breathlessness are proving popular with proven positive impact of increased mobility, confidence and hope under the guidance of physiotherapists. Many of these activities take place in groups, which both makes them more cost effective and enables patients to get the benefit of meeting other people in similar situations. Many more patients, particularly those with non- malignant conditions are accessing rehabilitative palliative care and hospices are becoming more efficient in spreading their resources.[51]

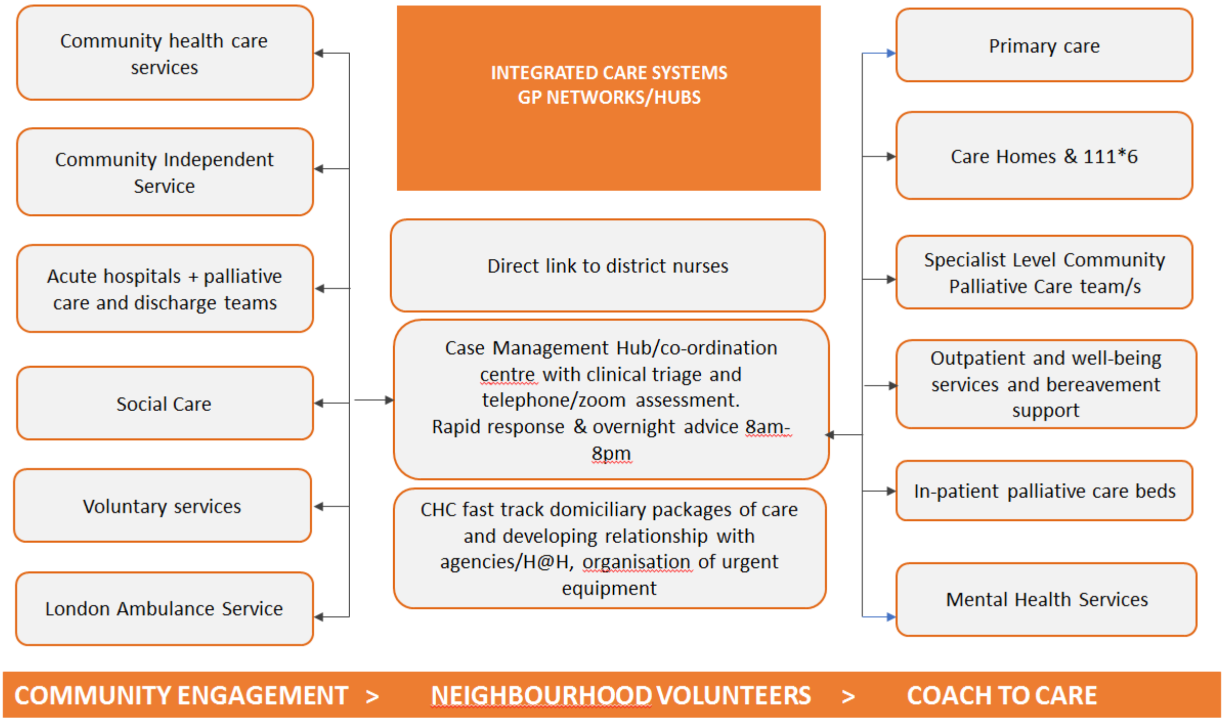
The End of Life Intelligence Network published a Palliative Care Set Clinical Data Set Evaluation Report[52]. It concludes that the use of a suite of outcome measures will drive up quality and consistency of services and help with an understanding of complexity.

Recommendations:

Commission new community-based palliative rehabilitation and health and well-being services to replace traditional day care .Working collaboratively with the voluntary sector, this should also be built into the service specifications.

Recommended model of care

Recommended Model and commissioning options to deliver the recommendations identified:



Overarching Recommendation by Penny Hansford Independent Strategic Reviewer

In conducting this review it has become clear that the three major challenges for the CCG's commissioning services are:-

- inequity of specialist palliative care service provision in the three boroughs
- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services
- inequity of funding arrangements for the services from the CCG's which ranges from 18-100%

Once in contact with a specialist palliative care service patients and families report high levels of satisfaction.

In order to significantly improve the specialist community service I have suggested a 8am-8pm palliative care hub with skilled clinicians that can ensure patients get the right repose by the right person at the right time. The hub will also have a rapid response service. I have also recommended that the community services are retendered with a lead provider model to enable better co-ordination and accountability.

I am also recommending a reduction in specialist palliative care beds. These are not currently fully utilised. Bed modelling in appendix L has demonstrated that there is some capacity in the system and that more could be created by extra provision of continuing healthcare beds.
Since the Pembridge Hospice inpatient unit has been closed the majority of patients have been successfully admitted to surrounding hospices. This, combined with the block contracting arrangement that the CCG's have with CLCH who manage the Pembridge Hospice leads me to recommend that the Pembridge inpatient unit is decommissioned and the monies used to purchase provision in other local hospices and in the re tendering of enhanced community services.

Commissioning options
Option One (Recommended option)

Tender a new community service with one lead provider for the specialist palliative care services, to provide an 8am-8pm co-ordination/case management centre as in the above diagram. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs. The Community Model would not preclude subcontracting arrangements.
Renegotiate bed- based care with separate providers.

Strengths: This has the greatest potential of all the options of delivering a standardised newly shaped service to meet the recommendations listed above, particularly fair access and equality. As one lead provider 'palliative care' also has the potential to operate as a key player in the integrated care systems. Palliative care services are by nature 'small' with often isolated professionals such as medical consultants. This model would also ensure less vulnerability in the key professions.	**Opportunities**: To radically change the way the services currently operate, address weaknesses in the current system and move to outcomes-based commissioning. If any bed-based services are re-negotiated it will give an opportunity to use the remaining beds more effectively which is likely to be a cost- effective option whilst still accommodating the current numbers of patients who require a palliative care bed. Create a systems leader to effectively implement change.
Weaknesses: The provider of the in-patient bed services may not be the lead provider of the newly tendered contract for the community meaning the lead provider would have less leverage over the use of the beds.	**Threats:** This is the highest risk in terms of disruption to current providers and therefore potential loss of charitable funds in the health economy and instability of services.

Option Two

Tender a new service and rationalise and reduce the number of specialist providers to two, with the same service specification and contracts. Written within the specification should be the need for the successful bidders to work in partnership to provide a 24/7 co-ordination/case management centre as in the above diagram. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs.

Strengths: Having two organisations operating to the same specification will help to standardize services. This model will ensure central co-ordination of services and address weaknesses in the current system of co-ordination, accessibility and rapid response.	**Opportunities**: To radically change the way the services currently operate, address weaknesses in the current system and move to outcomes-based commissioning. If bed-based services are re-negotiated it will give an opportunity to use the remaining beds more effectively which is likely to be a cost-effective option whilst still accommodating the current numbers of patients who require a palliative care bed.
Weaknesses: Having two providers will be harder to ensure standardization and integration with the new integrated care systems.	**Threats**: if current bed-based providers are not successful in the tender there may be a lack of palliative care beds. There are currently 4 services in the area and with this model two would cease to exist. The boroughs may lose charitable income if the independent providers were not successful.

Option Three

Tender the services based on one community service per borough with the same service specification with one co-ordination centre/case management centre per borough

Strengths: A potential advantage in Hammersmith & Fulham where social care has formally separated from the other two boroughs. Depending on the emerging integrated care systems if the boroughs re model their services based on one single point of access and case management per borough, this model may facilitate integration rather than hinder it.	**Opportunities:** Development of relationships and collaboration with health, social care and voluntary providers at a very local level.
Weaknesses: Unlikely to deliver the new model with co-ordination and case management and rapid response as each provider service would be small with no economy of scale. Therefore, the model would be more expensive as a greater number of staff will be needed to be replicated three times. Less likely to deliver equity of both service provision with 3 providers essentially working separately.	**Threats:** Services would remain fragmented and small unless one provider was successful in all three tenders but the care co-ordination/case management model is unlikely to be realised if there is a need to replicate three times. The potential loss of beds/alignment of bed provision may be problematic.

The preferred option

The reviewer's rationale for recommending option one, a lead provider in the community is due to the significant transformational change needed in the specialist palliative care services to enable them to use their resources in a different way. Acting in a consultative and training capacity to the wider care system whilst managing a small number of highly complex patients themselves, alongside case management for all expected deaths. Achieving the recommended outcomes for the new model of care will be challenging but most likely achieved with a systems leader 'driving' change.

There is also an imperative to become part of the emerging integrated care systems in the boroughs and to provide an equitable service throughout. The reviewer believes this is best achieved by an overall lead provider, accountable for the change needed. The integrated care systems are progressing to different timescales and slightly different models in each CCG and so it has not been possible for the reviewer to make a recommendation on how the palliative care co-ordination centre will integrate, only that it will need to.

The idea of a co-ordination centre, single point of access with extended hours and rapid response was consistent feedback from many of the professionals interviewed and now backed up by the patient, family and friends feedback, 74% of whom rated co-ordination and communication between services fair to very poor and only 26% were satisfied or very satisfied.

Contracting the beds separately to the community contract is a pragmatic approach as the provision of care in this setting requires less change management. The system has been managing with considerably reduced bed days for the last year which has not been problematic as two of the three units have been running at under 70% occupancy. Beds are costly and service only a few people. The reviewer would recommend closing a small number of specialist palliative care beds and investing the money in getting the community model right. The modelling in Appendix L looks at 3 different scenarios with a potential closure of between 4 and 10 beds. This will improve the quality and experience of care for most people and will further reduce the need for as many beds. The actual number of beds that can be closed will be dependent on a further review of delays in the system for patients who need to be transferred out of a specialist palliative care bed into a CHC fast track bed in a nursing care home.

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Appendix C

Palliative Care Public Workshop findings:

Planning services together

Palliative care: how we will use your feedback

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- Thank you to everyone who attended our palliative care services re-design workshops.
- We’re positive about the chance to integrate services better, improve co-ordination and ensure local people get the information & service they need, faster.
- The information we have gathered will be used to inform our future design of palliative care services across Westminster, Hammersmith & Fulham, Chelsea and Kensington and Brent.
- For more information on our next steps, visit the CCG websites.

Talking about your experience of palliative care

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Thank you to everyone who has been involved in this process.

We understand that talking about your experience of palliative care may be emotional and distressing. The organisations listed here are available to provide support and are here if you need them.

Cruse Bereavement Care
0808 808 1677

Grief Encounter
0808 802 0111
https://www.griefencounter.org.uk – online chat available

Winston's Wish
08088 020 021
ask@winstonswish.org.

Child Bereavement UK
0800 0288840
support@childbereavementuk.org

Samaritans
116 123
jo@samaritans.org

Grenfell Health and Wellbeing Centre:
020 8637 6279
grenfell.wellbeingservice@nhs.net

Background to the palliative care review

Brent, Central London, West London and Hammersmith & Fulham Clinical Commissioning Groups (CCGs) are developing plans to improve palliative care services, together with local people.

- Compared to the national average in England, patients in Hammersmith & Fulham, Kensington & Chelsea and Westminster are more likely to die in hospital than their preferred place of death.
- Less than half of local people across these boroughs are accessing palliative care services when they most need them.
- The services offered are inconsistent across the four boroughs, Hospice@Home for example is not available in all boroughs.

Earlier this year we commissioned a review of services, the outcome of this review can be accessed here. As part of this process we invited local patients, carers and their families, staff and other local stakeholders to share their experience and the recommendations were published in June.

These workshops were the next stage of the review where we have involved local residents in feeding in to developing a new model of care.

Patient & Public involvement: workshops

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People across the four boroughs were invited to three workshops which focused on Access to Care, Care and Bereavement.

The purpose of these workshops were to listen to public and patient views about what is currently working and how we can improve.

- Understand patient and families experience of care from palliative care services.
- Use these experiences to co-develop an improved way for patient's palliative care needs to be met from diagnosis to end of life and beyond.
- Feed in to a new model of palliative care across the four boroughs.

Palliative care services
Help to shape our plans

We are recruiting local people to help develop community palliative care services. Join our public working group or attend one of our workshops.

Workshop 1 - Access', 30 September 6-8pm,
Wembley Centre for Health & Care
Workshop 2 - 'Care' 7 October 9-12pm,
St Paul's Church, Hammersmith
Workshop 3 - 'Aftercare & bereavement support'
24 October 3-6pm, Museum of Brands Ladbroke Grove

More information & sign up at:
brentccg.nhs.uk or call 0203 350 4366

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Workshop 1: Access to Care

During the first workshop in Brent on the 30th September attendees discussed the following questions in two breakout sessions.

Breakout Session 1: What is your experience of getting the right help when you need it?

- What is working well and what isn’t?
- Who did you speak to, what help did you get, what was your experience in and out of hours and in an emergency?

Breakout Session 2: How can we improve this experience in the future?

- How would this process start in the future?
- Who would you want to identify the help, support and care you need?
- What would you want them to do?
- What would the information and co-ordination be like?

Responses to breakout session 1
What is working well?

- What is working well and what isn't?
- Who did you speak to, what help did you get, what was your experience in and out of hours and in an emergency?

"Specialist palliative care was really good and offered more 'hand holding' for the patient and families"

"Acute sector felt like they were better trained"

"Community palliative care we experienced was great"

"If you have past experiences of care it makes it easier to navigate through the system which once you're in is good"

"Hospice inpatient experience – more responsive and available to support needs unlike hospitals"

"In Brent, there is a good relationship between GPs and nurses with regular communication between the two"

"Joint visits with GPs and nurses are liked by patients as they feel like they have a solid team around them and this makes them feel more in control"

Responses to breakout session 2: what needs improvement?

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Themes from the workshop for areas that need improvements centred around **patients access care, communication** and **coordination of care**

Access to care

"There is a lack of information from clinicians about how to access services"

"You often need to ask for palliative care support – but if you don't know it is available how do you ask? This situation could cause inequalities"

"Different languages and cultural complexity may cause issues in accessing palliative care – important consideration in culturally diverse boroughs"

"Lack of awareness of palliative care services"

"Confusion around the system about how to access palliative care leads to unequal access and patient anxiety"

"Traveling for friends and families can sometimes be difficult"

"In certain situations telephone advice is not enough – there needs to be a crisis intervention team"

"Issues with accessing palliative care causes care to be delayed"

"Patients need to feel like they are more in control of the process"

"Travel costs, if family and friends need to travel far, it may deter them from visiting or discourage patients from access care if they don't have their friend and family attending with them"

"If you have been in the system before you know how to navigate it but this is difficult for patients and families who have not been"

"To improve access needs to be greater awareness around what is on offer"

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Responses continued..

Communication

“We need to do more to talk about palliative care – sometimes it feels like people are afraid of talking about death”

“We need to raise awareness of what palliative care means to patients and families”

“It is important to have an honest relationship of trust between patients and clinicians around the reality of dying – sometimes can feel like the clinician isn’t comfortable”

“More could be done to raise awareness of palliative care among minority communities”

Coordination

“There is a lack of early planning around palliative services”

“Staff recruitment – how do we recruit adequate staff and attract them in to the system”

“Lack of care coordination could reduce access to care”

Experience now

Feedback from the workshop was captured in the below illustration by Anna Greyer

Improving experiences

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Workshop 2: Care

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During the second workshop in Hammersmith and Fulham on the 7th October attendees discussed the following questions in two breakout sessions.

Breakout Session 1: What is your experience of palliative care?

- What is working well and what isn't?
- What is your experience of the quality of care you or a loved one have received?
- What was the impact for you?
- Is care available at the times when you need it?

Breakout Session 2: What's important to you and your loved ones about care?

- What makes care excellent?
- What does care mean for you and what makes you feel supported?
- Where do you want your care and how can it be more personalised and inclusive of specific needs?
- What are your priorities?
- What kind of things make a difference to you and your loved ones about the care you receive?

Responses to breakout session 1: What is your experience of palliative care, <u>what is working well ?</u>

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“When patients go in to a hospice it takes the stress away from the carer”

“Hospice environments are much better for families and young children, especially compared to hospitals”

“Hospice@home is brilliant and needs to be available in more areas”

“The quality of hospice care once in a hospice is very good”

“Communication and planning is the key to positive palliative care”

“Care works very well once in the right service or pathway”

“Availability of care in all settings to support patient wishes”

“Palliative care works well when district nurses, carers, GPS are involved in providing care and are part of the patient journey”

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Responses to breakout session 1: what could be improved?

Care

"The system is clearly fragile – providers are often competing for resources (clinicians, nurses and volunteers)"

"We need a better understanding of what complex pain is, this may lead to different referrals and variations of care"

"Patients are often diagnosed as terminal too late and have no palliative care plan"

"Too many hospital deaths – this is not the right place to be dying"

"No standardisation of care between services – hospices are providing very different levels of care"

"More needs to be done to support people to die at home, this needs to include emotional support for families"

"Too many hospital admissions for older people, this can be detrimental to mental health and state-of-mind for the person"

"Sometimes families feel like they need to fight for palliative care support"

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Responses continued…

Communication

“Lots of people are worried about what will happen around end of life care”

“Families are too frequently finding out about palliative care services through word of mouth”

“More conversations about dying are needed to raise awareness of services”

“Communication between providers should improve to reduce competition between services and help them work together More conversations about dying are needed”

Coordination

“Out of hours care coordination needs to improve – for example when you realise a CMC plan is not detailed enough and there is confusion over job roles and responsibilities”

“System needs to be more linked up and work better together – it is not easy to share information at the moment”

“We need a central hub of information”

“More information could be provided on how people can help hospices with volunteering”

Responses to breakout session 2: What is important to you and your loved ones about care?

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Breakout Session 2:

- What makes care excellent? What does care mean for you and what makes you feel supported?
- Where do you want your care and how can it be more personalised and inclusive of specific needs?
- What are your priorities? What kind of things make a difference to you and your loved ones about the care you receive?

Care

"Dying in dignity - offering patients informed choices about dying"

"Hospices need good estates and support facilities"

"Excellent care = human, flexible, 'can-do' attitude and personal"

"If care is in the home you need to think about the whole picture – who keeps the house clean, who does the laundry, who pays?"

"Respecting the patient, family and loved ones and ensuring that the family and carers are involved stops the care feeling too clinical"

"Better supported for people who are dying and information for people who are supporting palliative patients"

"Holistic care – spiritual, emotional, medical friendly – thinking about what to do that makes the patient calm"

"Involving families from beginning to end of palliative care – particularly when administering medication, it is important to keep families involved"

"A future model should provide for people who want to die at home"

"Making hospices feel like a home away from home"

"Going the extra mile to listen to patients and families"

"Giving patients choice – this is particularly important for aging in a multicultural society where religious and spiritual needs are important"

Responses continued…

Communication

"Creating a death/ dying in dignity champion to encourage talking about death – encouraging the voluntary sector to do more around this"

"Improved communication and education around palliative care – potentially working with AgeUK and other organisations"

"Compassion in dying materials need to be available – this need to be socially and culturally aware of diverse communities"

"People's end of life plans should be an ongoing discussion with GPs from the start"

"Early conversations make harder conversations in the future easier"

"Need more information available locally to inform people about dying"

"Provision of help and support earlier in the process"

"Improved communication for carers on how they access resources and support"

Responses continued…

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Coordination

“Promote co-ordinate my care”

“We need a centralised hub that co-ordinates end of life care at hospices – a centralised system that acts as a core support for patients and facilities “

“A hub that includes: information about specialist advice, service information, telephone advice”

“Improved CMC usages and accessibility for patients, staff and families”

“A hub that helps district nurses, GPs, Hospices, Social Care, Mental Health services coordinate care”

“Simplicity and integration – no referrals”

“Future provision needs to take in to account demographic changes”

“Empower social care teams so they can make better decisions that improve co-ordination”

“Timely access to care”

“Improved coordination and accessibility for all e.g. homeless populations, learning disabilities, teenagers”

“Mixed economy of services that can meet the various demographic needs”

“Improved hand overs between teams”

Experience now

Improved experience

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Workshop 3: Moving between care settings, bereavement and aftercare

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During the third workshop in Kensington and Chelsea on the 24th October attendees discussed the following questions in two breakout sessions.

Breakout Session 1: Your experience of moving between care settings

- If you or a family member/ carer have experience of receiving care in more than one place e.g hospice to home, or hospital to hospice
- What worked well and what didn’t
- Was it the right support at the right time?
- What support would you have liked to have received and where?

Breakout Session 2: What is your experience of bereavement and aftercare support?

- What type of support have you received / are receiving?
- What worked well?
- What could be improved? What would make you feel more supported?

Responses to breakout session 1: Your experience of moving between care settings, what is working well ?

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- If you or a family member/ carer have experience of receiving care in more than one place e.g hospice to home, or hospital to hospice
- What worked well and what didn’t
- Was it the right support at the right time? What support would you have liked to have received and where?

“When transitioning between care settings it is vital the patient and the family are kept informed and felt listened to”

“Changing between care settings works well when there is clear communication between healthcare providers and professionals”

“When 24 hours a day care is offered by hospices it helps carers”

“Hospice@home works well as the staff are well trained and know how to deal with complex pain and pain relief”

“The night nurse services works well – having an inhouse services makes it easier to be responsive but important that they are part of a 24 hr core service”

“Coordinate My Care (CMC) gives staff in various settings information about a person's wishes and treatment options, but only if the quality of the information is good”

Responses continued…

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Communication

“Need to have more conversations about transitioning between care settings before the change takes place”

“There are poor links and communication between specialists and acute communities”

“We need to have a means of getting answers for quick advice and support needs”

“Services are too fragmented with little communication between them”

Responses continued…

Coordination

“Moving between care settings needs improved coordination. Experiences included long waits, horrible journeys between care settings and confusion between staff”

“Lack of coordination leads to confusion and trauma for the patient and families”

“We need to improve the discharge experience for patients”

“Need to make sure that when patients are moved to a new care setting that the location works for the patient and their families”

“Coordination needs to be improved when patients move between care settings as it is during this time when patients may fall in-between cracks”

“Poor use of Coordinate My Care (CMC)”

“Need to improve urgent care at home”

“When moving between care settings need to make sure that the distance carers have to travel to visit patients is considered”

Responses to breakout session 2: What is your experience of bereavement and aftercare support, what worked well?

"Hospices are the ultimate hub for bereavement services where you can talk to people who have experienced similar issues"

"I felt listened to"

"Safe space to talk and find out information"

"Presence of someone with empathy"

"Having informal support through being part of a network which is really important if family live abroad"

"Being able to talk to people who have been through similar experiences"

Responses continued…

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Care

“Need to have bereavement support from specialists who are culturally sensitive”

“Taking the time to ask ‘what do you want?’”

“Can we provide training to bereavement staff on responding to grief”

“Personalised care – we need to listen to what people say they want and take in to account different opinions and cultural needs”

“Additional support around anniversaries and death - People going through bereavement and grief need specialist support or it can impact people long term”

“We need to de-medicalise support so it can be more holistic”

“Additional support around anniversaries and death”

“Care needs to take in to account family situations – for example considering the impact of death on family members”

Responses continued…

Communication

“Patients and families feel like they don’t have a voice”

“Spending time to understand the diagnosis and timeframe for patients”

“Need to support more people talking about death”

“We need more services that offer people opportunities to talk about their bereavement”

“Recognise that bereavement and aftercare services need to be promoted more – this could involve more signposting to bereavement services where people can receive support”

“Hospice services need to ask for feedback”

“We need a public campaign to normalise death and normalise conversations about care planning”

“Awareness campaign for hospital staff about what services are on offer in the community”

Responses continued…

Coordination

“We need to make sure that support is accessible to different communities and that we don’t have gaps”

“Services need to be accountable, so patients aren’t passed around different services”

“Bereavement starts before death, services need to be prepared to offer families support pre-death”

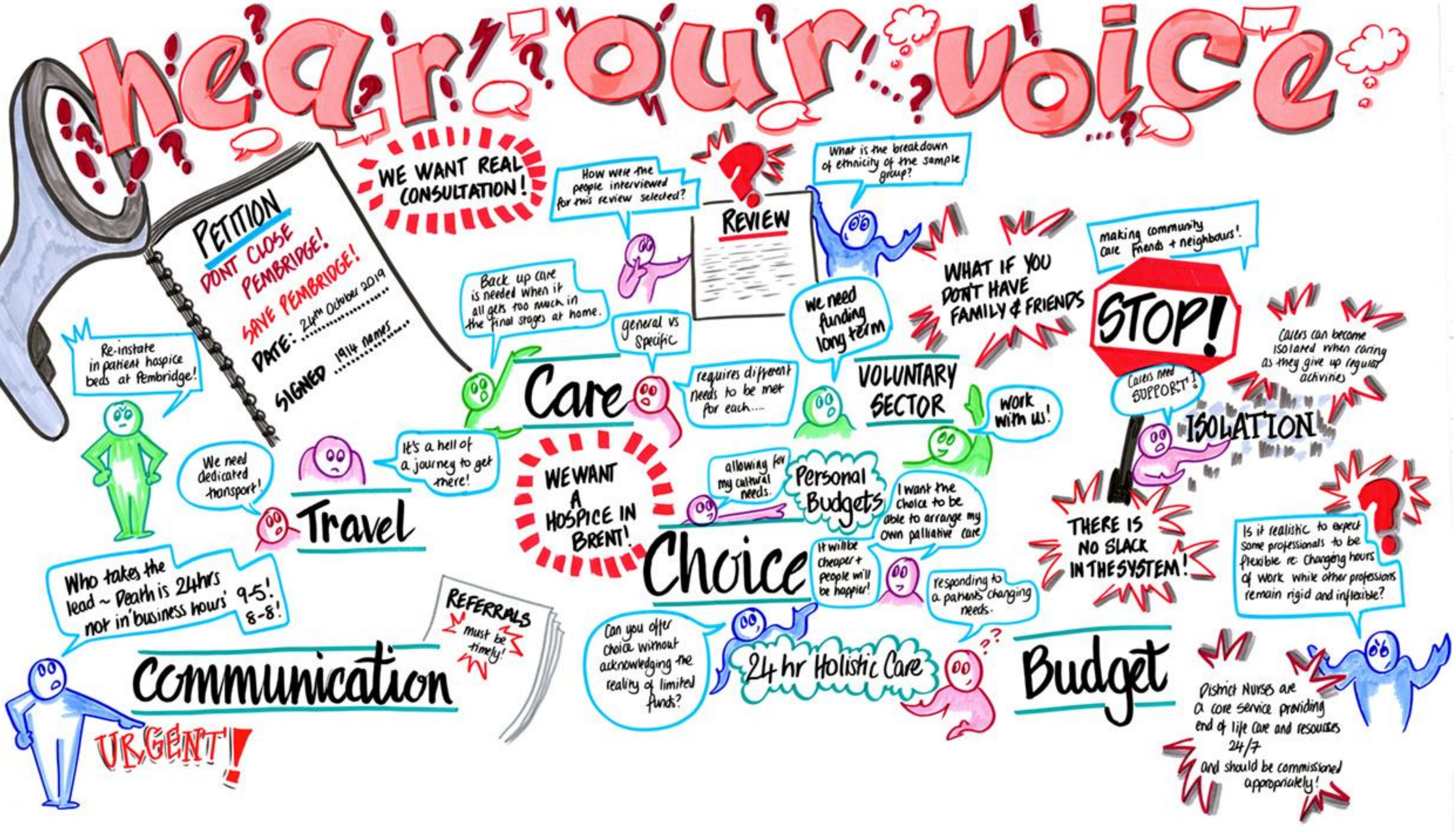
“Flexible timeframe for counselling”

“We need to think about bereavement services in the context of integrated care”

“To get good outcomes bereavement support needs to begin pre-death”

Improved experience

Hear our voice



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Summary of key themes

Access to care

- **Currently there is inequitable access** to information and support to access and navigate available services

- **Travel** times and the importance of services within a reasonable proximity of home as well as families, friends & carers

- Consider **barriers to accessing services** from certain population groups.

Care

- **Care planning** should be transparent with family, friends and carers and start at an earlier stage

- **Care** works very well once a service or pathway has been accessed

- **Place of death -** the acute sector isn't the most appropriate setting for end of life care

- Care is **not standardised** across these areas.

Coordination

- **Out of hours** care isn't consistent
- Services including **health and social care need to be better linked** particularly regarding transfer of care
- **Minimise distress** when transferring a patient between settings.
- **A single point of access** would improve service integration and improve patient experience
- Improvements needed for **integration & promotion of bereavement services**

Communication

- Equip clinicians in all settings to have type **appropriate vocabulary** around palliative and end of life care.
- **Greater transparency of services** available with all clinicians informed as to what these are.
- **Conversations** around dying need to happen earlier
- **Stronger links & working** between specialist and general clinicians and teams.
- **Access to information in an emergency**

Personalised care – it is important that services are personalised to reflect the different needs of people and the diversity of our communities.

Thank you to everyone who attended our palliative care workshops and shared their views and experiences.

What happens next?

Visit your CCG website for more information.

Appendix D

Palliative care services

Re-designing services for people with an incurable illness or in their last phase of life in Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster

Your feedback on potential scenarios

Thank you if you have been involved in the process so far and for your patience. We are confident that by continuing to work together with local patients, carers and partners we have an opportunity to improve palliative care services across the four boroughs.

What this document is for

The local NHS is reviewing specialist palliative care services across Brent, Kensington & Chelsea, Hammersmith & Fulham and Westminster.

This document sets out our current thinking about how we may organise specialist palliative care services in future. It is intended to provide a background to our current situation and form a basis for further discussion.

We want to involve our patients and local people in agreeing the way forward, so we have produced this document as a way of discussing potential scenarios for improving specialist palliative care.

This is not a consultation document. At this stage we want to open up a discussion which we hope you will want to take part in.

Contents

Accessibility

We want as many people as possible to tell us their views, if you need this information in a different format like a printed or large print copy, easy read, audio recording or a translated version, please let us know what you require and we'd be happy to help.

- Email the project inbox at nwlccgs.triborough.palliativecare@nhs.net
- Call our office to speak to us to discuss on 0203 350 4366.

What do we mean by palliative care services?

- **Palliative care** is support for people living with an illness which isn't curable and aims to improve a patient's quality of life. Examples of these illnesses include advanced cancer, motor neurone disease (MND) and dementia. You can receive palliative care at any stage in your illness. Having palliative care doesn't necessarily mean that you're likely to die soon – some people receive palliative care for years.
- Palliative care also includes care of people who are in the last months or years of their life, known as **'end of life'.** End of life care aims to help people to live as comfortably as possible in their time left. It involves managing physical symptoms and getting emotional support for the patient, their family and friends.
- Palliative care takes into consideration a patient's physical, emotional, psychological, social and spiritual needs. This is called a holistic approach, because it deals with people as a "whole" person, not just your illness or symptoms.

What is the difference between general and specialist services?

- **Palliative care** is often delivered at a person's home (including care or nursing home) by local **'general' services** such as your GP, community and district nursing teams.
- Depending on a person's condition, needs and preference **'specialist care'** may also be required. This is often provided by hospice services and staff. Hospice care is a style of care, rather than something that takes place in a specific building. It can be delivered at home by community nursing teams or through in-patient or day care services.
- Specialist palliative care teams are made up of many different healthcare professionals who co-ordinate care for an individual. This may include consultants, specialist nurses, occupational therapists or physiotherapists trained in palliative medicine.
- As specialists, they also advise other professionals on palliative care such as GPs and community nurses.
- For more information on these terms specialist palliative care and other terms we may reference in this document please see the accompanying information pack or visit nhs.org.uk.

Doesn't everyone need specialist services?

- Not everyone will need specialist palliative care and will be managed by their 'local general' team. Some people dependant on their situation and the complexity of their needs and circumstance will do and this would be classed as 'specialist palliative care'.
- People also have the right to express their wishes about where they would like to receive care and where they would like to die.

This review focusses on specialist palliative care services (often provided by hospices) in these areas, the aim however is that any proposed changes to specialist care supports improvements in 'general' care, as described above, so that everyone has access to the right care when they need it.

Why do we need change?

Inpatient care within our local hospices resoundingly provides high quality and expert care to those patients with the most complex medical needs. Patients, families and carers who have used inpatient care rate this care as excellent and it is clear that all of our local providers of specialist palliative care are well-loved and respected by the communities they serve.

We are now bringing together the findings from the independent review (available on our website) undertaken earlier this year with the views of patients, the public and professionals working in providing palliative care. The most consistent feedback from professionals and the public however is about the inconsistency in services provided to people in different areas, and the difficulty for some people in accessing these services. Poor co-ordination and communication between services is also a key theme, as well as timeliness and the lack of emergency response when most needed.

The independent review also highlighted that our current inpatient services may not be appropriately sized for the needs of our population and that it's important that we invest in a mix of services to ensure improved consistency and better meet people's preferences, in their last phase of life.

What challenges are we trying to address?

Access to services - only 48% of people with a palliative care need are accessing services when they need them. Reaching only 48% of patients is not good enough. It is paramount that we increase the reach of palliative care services to all patients who need it, regardless of their condition.

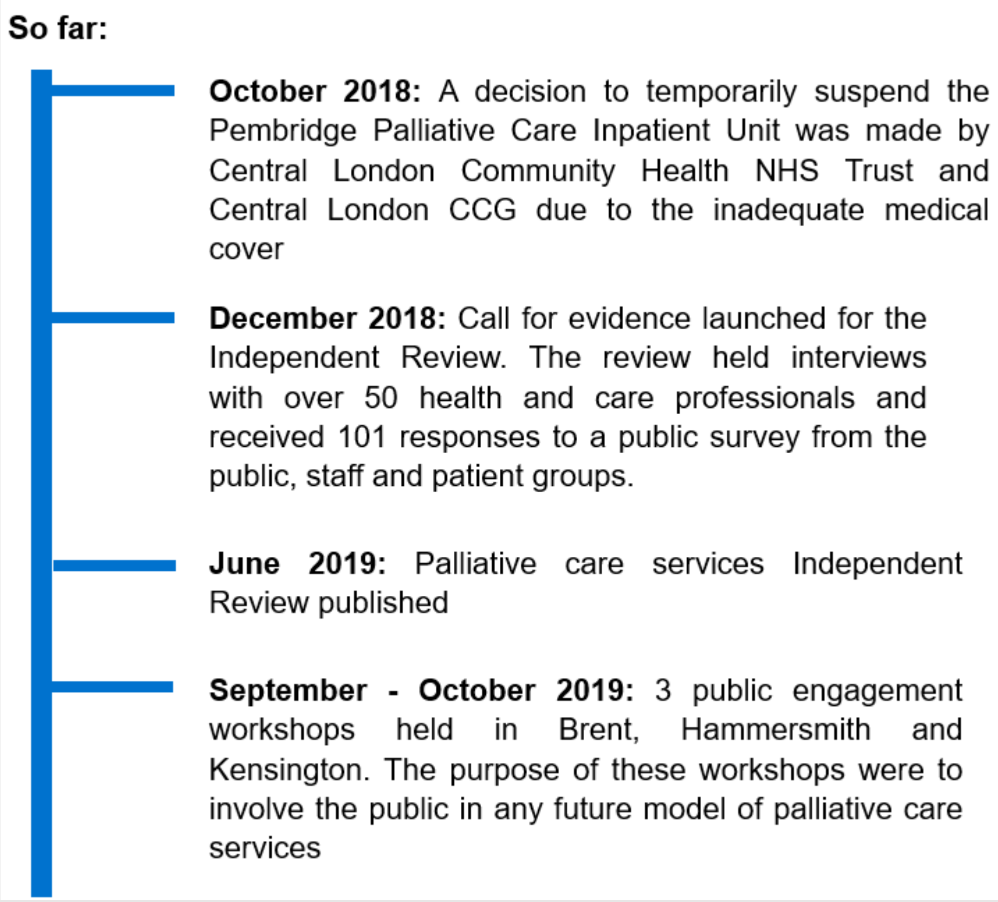
Inconsistency between services – depending on where you live you will have more or less access to specialist palliative care services and this is not acceptable. For example, while some hospices can support people to die at home if they wish, others do not. There is also variation in what services can be accessed out of hours and how quickly, for example in the middle of the night or at the weekends.

Underinvestment in community services contributes to differences in what services are available for people to access. Our vision is that everyone gets the palliative care that they need. We aim to increase this number up to a **minimum** of **75% initially**. Investing in community services will enable us to reach more people in their last phase of life.

A lack of co-ordination between services can result in care being delayed or interrupted which causes anxiety and stress for patients, carers and families and unnecessary discomfort to the patient.

National staff shortages in palliative care specialists - this has been a challenge locally and due to a specialist palliative consultant not being available led to the suspension of the in-patient unit at the Pembridge palliative care centre, highlighting the fragility of our local system.

Timeline of the process so far



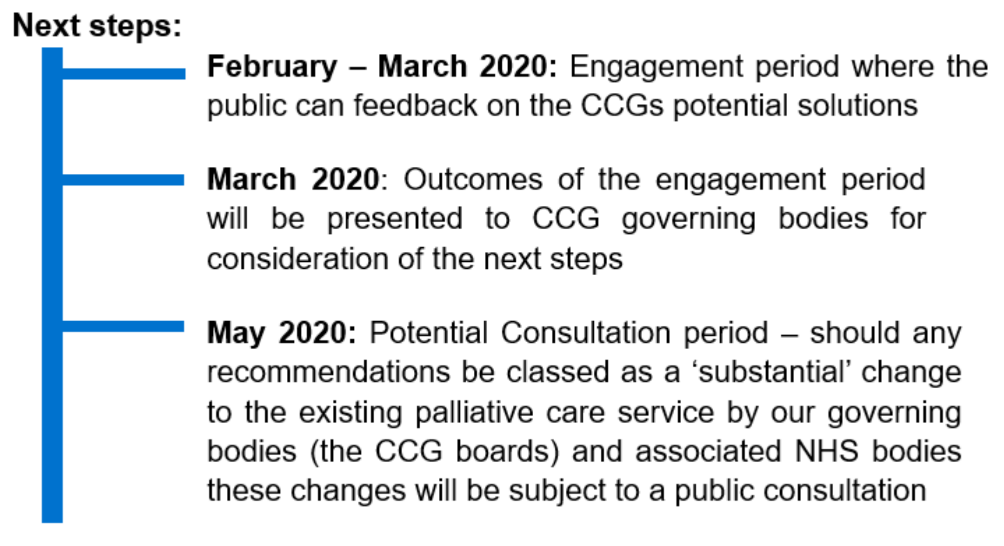
So far:

October 2018: A decision to temporarily suspend the Pembridge Palliative Care Inpatient Unit was made by Central London Community Health NHS Trust and Central London CCG due to the inadequate medical cover

December 2018: Call for evidence launched for the Independent Review. The review held interviews with over 50 health and care professionals and received 101 responses to a public survey from the public, staff and patient groups.

June 2019: Palliative care services Independent Review published

September - October 2019: 3 public engagement workshops held in Brent, Hammersmith and Kensington. The purpose of these workshops were to involve the public in any future model of palliative care services



Next steps:

February – March 2020: Engagement period where the public can feedback on the CCGs potential solutions

March 2020: Outcomes of the engagement period will be presented to CCG governing bodies for consideration of the next steps

May 2020: Potential Consultation period – should any recommendations be classed as a ‘substantial’ change to the existing palliative care service by our governing bodies (the CCG boards) and associated NHS bodies these changes will be subject to a public consultation

What we have heard so far

Since December 2018 we have engaged; local patients, families, carers, residents, the voluntary and community sector, and patient representative groups across the four boroughs. Initially we launched a 'Call for evidence' to hear from local people and professionals about their views on services and how they are working. This information formed the basis of an Independent review. Between September and October 2019 three well attended public workshops were held to look at people's experience of palliative care services from end to end; focussing on access, care and the transfer of care and bereavement.

Key themes

There is also a findings report of key themes – this can be accessed **here**.

Summary of themes from the workshops:	
	Care works well once a service or pathway has been accessed with inpatient hospice services offering peace of mind for family, friends and carers. However many people aren't in contact with any services at all
	Care is not standardised across different areas in the four boroughs
	Access to information and support to help navigate available services is inconsistent
	Care planning should be transparent with family, friends and carers and start at an earlier stage
	More could be done to ensure that minority groups are aware of palliative care services and ensuring that these services are personalised for a diverse range of communities
	Travel times to hospice services have a significant impact on carers and families. This should be a focus for any future model of care
	More could be done to improve integration and coordination between services
	Bereavement services need to be in place at the right time and be promoted better to friends, family and carers

Feedback from our engagement: below is a summary which details how we are listening to your feedback and improving patient & public involvement in the process.

You said	***You would like more information about the consultation process***
We did	We have provided the above timeline of the review process so far and the next steps for the process. We are not in consultation now but if significant change is proposed to these services then we consult the public which would happen later this year.

You said	***You would like an opportunity to discuss the future of the Pembridge Palliative Care Centre***
We did	In the survey below also available online we would like to hear your thoughts and feedback on the 4 proposed scenarios. Please use this opportunity to voice any concerns you have around the suspension of the Pembridge Palliative Care centre.

You said	***You would like to be more involved in developing future scenarios for palliative care services***
We did	We advertised for patients and the public to join a Patient and Public Palliative Care Working Group to ensure local people have a voice. We are working together with this group to discuss possible scenarios which we are now sharing with you in this document.

You said	***You would like more information about palliative care to help you make an informed decision about the future of these services***
We did	We have produced an **information pack** to support this document that has a glossary of the different aspects of the palliative care review. If you require more information around a certain topic please let us know through the contact details at the bottom of this document.

You said	***You would like to be more involved in the process***
We did	We are committed to involving residents and patients throughout this process as much as possible. We gathered people's feedback as part of the independent review and in Autumn 2019, we ran a series of workshops on how we can improve palliative care services. From this feedback and through working with our Patient and Public Palliative Care Working Group, we have now developed some potential scenarios, outlined in this document that we would like to hear your feedback on. You can also sign up for the latest updates and we will add you to our mailing list.

Current services

Here is a description of the different elements of specialist palliative care services:

- **Community services**
  You may not need to move away from home to receive care, community nurses can come to your home at any stage in your condition and provide nursing care for you there.
- **Inpatient services**
  This is care of patients whose condition requires an admission to a hospice or hospital bed.
- **Day services**
  Services and activities that can be accessed during the day including clinical, financial, emotional and spiritual support when an admission is not needed.
- **Hospice@Home**
  You may need more specialist care from community palliative care nurses who visit you at home, this tends to be in the last phase of life and therefore may be more intensive.
- **Out of hours**
  This is the period from when the day and community services close until the following morning.

An overview of what is currently being commissioned across these four boroughs by each of the main specialist palliative care services:

	Inpatient unit (IPU)	Community visiting service	Day service opening hours	Hospice@home	Out of hours (after 5pm)
Marie Curie: **11 Lyndhurst Gardens, Hampstead, London NW3 5NHS**	*26 beds 24/7 admissions available*	*Not provided to 4 boroughs*	*5 days a week service 9-5pm Mon – Fri No weekend services*	*Not provided to 4 boroughs, except Marie Curie Night Nursing Service available.*	*24/7 clinical advice line available Mon – Sun.* *No visiting service.*
Pembridge Palliative Care Centre Services: **St Charles Centre for Health & Wellbeing, Exmoor St Ladbroke**	*13 beds 24/7 admissions available* ****currently Suspended due to no consultant cover – all other services***	*7 days a week 8:30 -5pm Mon- Fri 9 – 5pm Weekends & Bank holidays*	*4 days a week service, 8.30am – 4pm No weekend services*	*Not provided to 4 boroughs.* *(accessed via other providers)*	*24/7 clinical advice line available Mon – Sun.* *No visiting service.*

Grove, London W10 6DZ	***operating as usual from this location****				
Royal Trinity Hospice: **30 Clapham Common North Side, Clapham Town, SW4 0RN**	*28 beds 24/7 admissions available*	*7 days a week 9-5pm Mon – Sun (including bank holidays)*	*5 days a week service, 9-5pm No weekend services*	*Not provided to 4 boroughs.* *(accessed via other providers)*	*24/7 clinical advice line available Mon – Sun.* *No visiting service.*
St John's Hospice: **60 Grove End Rd, St John's Wood, London, NW8 9NH**	*18 beds 24/7 admissions available*	*7 days a week 9-5pm Mon - Sun*	*4 days a week service. 8.30 – 5pm No weekend service*	*Service is provided to Westminster, Kensington and Chelsea and south Brent residents.*	*24/7 clinical advice line available Mon – Sun.* *No visiting service.*
St Luke's Hospice: **Kenton Grange, Kenton Rd, Harrow HA30YG**	*12 beds 24/7 admissions not <u>available.</u>* *Admissions are available Mon – Fri, 9am – 4pm. and only if planned for weekends.*	*5 days a week 9-5pm Mon– Fri (7 day a week service April 2020)*	*5 days a week service, 9 – 4:00pm No weekend service*	*Service is provided to north Brent resides.*	*24/7 clinical advice line NOT available.* *Advice available Mon – Fri 9am – 5pm.* *No out of hours or weekend cover.* *No visiting service*

Potential scenarios

Working with our local hospice providers in the area and from the information we have gathered from our working group and the local community around specialist palliative care services, we have proposed some potential scenarios that we would like to hear your views on. These potential scenarios aim to address the challenges we face which are:

- Current services are only reaching half of people with palliative care needs
- Services offered across the four boroughs are inconsistent
- There is an underinvestment in our community services which means we may not be able to meet people's preferences in their last phase of life
- A lack of co-ordination between services and support out of hours
- A national shortage of specialist staff to cover these services safely

Please complete the feedback survey at the end of this document or our online survey here.

<table>
<tr><th colspan="2">Potential scenario 1 – services remain the same</th></tr>
<tr><td colspan="2">This scenario would keep all specialist palliative care services as they are including the re-opening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.</td></tr>
<tr><th>Benefits</th><th>Disadvantages</th></tr>
<tr><td>• No change to the location of any services.</td><td>• Services won't increase the number of patients that they see, currently services only have the capacity to support around half of patients with a palliative care need.</td></tr>
<tr><td>• This would mean re-opening the in-patient unit at the Pembridge Palliative Care Centre.</td><td>• Improvements needed raised by patients and staff regarding communication and coordination of services will be addressed but limited.</td></tr>
<tr><td>• No increase in travel for specialist in-patient services.</td><td>• Services will not be in line with national guidance.</td></tr>
<tr><td></td><td>• Access to day services will remain inconsistent.</td></tr>
<tr><td></td><td>• Access to community services will remain inconsistent.</td></tr>
<tr><td></td><td>• 'Out of Hours' service will remain inconsistent.</td></tr>
<tr><td></td><td>• Hospice@Home not available to all.</td></tr>
<tr><td></td><td>• No guarantee of when it will be possible to recruit a specialist palliative care consultant into this post.</td></tr>
</table>

Potential scenario 2 – Some improvements to day and community services with in-patient services remaining the same	
This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge palliative care centre subject to the appointment of a palliative care consultant. Community and day services would be standardised across the boroughs. *This scenario would lead to some but limited improvements in the co-ordination of out of hours advice.*	
Benefits	***Disadvantages***
• *Community services would be open consistently 7 days a week.*	• *Services won't increase the number of patients that they see significantly, currently services only have the capacity to support around half of patients with a palliative care need.*
• *Day care services would increase from 4 to 5 days a week with consistent opening hours.*	• *Access to community services will remain inconsistent.*
• *Some, limited improvements to out of hours services.*	• *Improvements needed raised by patients and staff regarding communication and coordination of services will be addressed but limited.*
• *This would mean re-opening the in-patient unit at the Pembridge Palliative Care Centre.*	• *Services will not be in line with national guidance.*
• *No increased travel for specialist in-patient services.*	• *'Out of Hours' service will remain inconsistent.*
• *No change to the location of inpatient or day care services.*	• *Hospice@Home not available to all.*
• *Improved co-ordination of services with providers working together.*	• *No guarantee of when it will be possible to recruit a specialist palliative care consultant into this post.*

Potential scenario 3 – A re-design of all elements of specialist palliative care services

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Benefits	***Disadvantages***
• *A greater level of access and consistency of services available to all.*	• *The hospice locations where patients can access inpatient care would reduce from 5 to 4.*
• *A greater level of funds for community and day-care services would be available so that more people can benefit from these services and services would work better together.*	• *As a result of reducing the hospice locations where patients can access inpatient care, some patient's carers and family will have to travel further or longer to visit patients who are receiving inpatient care.*
• *Community services would be available 7 days a week and the hours would increase to 8am-8pm.*	• *The hospice location likely to close is the Pembridge in-patient unit. However this requires further consideration and has not been confirmed.*
• *There will be no reduction in NHS funded hospice beds.*	
• *Hospice@Home available to all.*	
• *Day care services would increase from 4 days to 5 days and extended to be consistent.*	
• *Increased investment will improve co-ordination of care for patients and families with 24/7 palliative care needs.*	
• *Increased investment will deliver responsive out of hours urgent and emergency palliative care, joined up with London Ambulance Service and NHS 111.*	
• *Specialist services will deliver increased training and education in palliative care for GPs, District Nurses and Care Homes and enable easier access to advice from the specialists when required.*	
• *Increased investment will deliver improved palliative care for homeless patients and other hard to reach groups, with support from outreach teams.*	

Potential scenario 4 – A re-design of all elements of specialist palliative care services including access to a new nurse-led in-patient service

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. This would enable CCGs to fund community services 7 days a week, with 24/7 admissions for patients, consistent day care and out-of-hours services, and Hospice@Home available to all.

Patients who do not require specialist inpatient care but cannot be supported at home or have a preference to die in a hospice environment, can access respite and end of life care in their local area via a nurse led in-patient service.

Benefits	***Disadvantages***
• *A greater level of funds for community and day-care services would be available so that more people can benefit from these services and services would work better together.*	• *Patients who require specialist consultant-led inpatient care will be affected and have to travel to an alternative hospice service.*
• *A greater level of access and consistency of services available to all.*	• *The hospice location likely to close is the Pembridge in-patient unit. However this requires further consideration and has not been confirmed.*
• *Community services would be available 7 days a week and the hours would increase to 8am-8pm.*	
• *There will be no reduction in NHS funded hospice beds.*	
• *Hospice@Home available to all.*	
• *Day care services would increase from 4 days to 5 days and extended to be consistent.*	
• *Increased investment will improve co-ordination of care for patients and families with 24/7 palliative care needs.*	
• *Patients who do not require specialist consultant-led inpatient care can access respite and end of life care in their local area via a nurse led service.*	
• *This would overcome the current issue with specialist staff shortages.*	
• *Increased investment will deliver responsive out of hours urgent and emergency palliative care, joined up with London Ambulance Service and NHS 111.*	
• *Specialist services will deliver increased training and education in palliative care for GPs, District Nurses and Care Homes and enable easier access to advice from the specialists*	

when required.	
- *Increased investment will deliver improved palliative care for homeless patients and other hard to reach groups, with support from outreach teams.*	

Thank you for reading this document

Please now complete the feedback survey at the end of this document or complete the online survey **here** and let us know what you think about these scenarios.

We are happy to consider additional potential scenarios that might help to address the challenges outlined above – please include any suggestions in your response.

What happens next?

Once we have heard your views a proposal will be put forward to CCG governing bodies for consideration of the next steps. Should they take the view that a significant change from the current service provided is required, then we would move to a public consultation which would ensure further engagement opportunities for local people to be involved in, to develop the future model of care.

Thank you for your on-going participation

Brent CCG

Central London CCG

Hammersmith & Fulham CCG

West London CCG

Survey

Complete online, return FREEPOST - NW LONDON
or email nwlccgs.triborough.palliativecare@nhs.net

Now you've read our aims and possible scenarios for the future, we want to know what you think. **This is not a consultation,** but an engagement period to get your thoughts to help shape the future design of these services. These scenarios are based on the challenges outlined above and what will reach the most amount of people across these boroughs.

Section 1 – Should we change our services

Have you or a family member or friend used the following services in Westminster, Hammersmith & Fulham, Kensington & Chelsea or Brent? *(Please circle as appropriate)*

Yes / No

Which of the following services did you use?

- General local palliative care services - *Yes / No*
- Specialist palliative care (often provided by a hospice) - *Yes / No*
- End of life care (often provided by a hospice) - *Yes / No*
- Unsure - *Yes / No*

If yes to any of the above, please tell us the name of this service.

Do you agree that we need to help more people to access palliative care services and to make what is available more consistent for everyone? *(Please circle as appropriate)*

Yes / No

Please rank the importance of the following aspects of palliative care for you? *(Definitions available on page*

(1 = most important, 6=least important)

Community Care	
Out of hours care and support	
Access to specialist advice	
Services delivered at home	
Day centre services	
In-patient services	

What is the most important thing that palliative care services offer to those that need them?

Section 2 – your views on each scenario

Potential scenario 1

Services remain the same

This scenario would keep all palliative care services as they are including the re-opening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.

Comments:

Concerns:

Suggestions to improve the scenario:

Potential scenario 2

Some improvements to day and community services with in-patient services remaining the same.

This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge subject to the appointment of a palliative care consultant. Community services would also be standardised to 5 days week.

This scenario would also lead to some improvements in the co-ordination of out of hours advice.

Comments:

Concerns:

Suggestions to improve the scenario:

Potential scenario 3

A re-design of all elements of palliative care services

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund enhanced community services 7 days a week, with 24/7 admissions for patients. It would also provide an out-of-hours nurse visiting service and Hospice@Home available to all.

Comments:

Concerns:

Suggestions to improve the scenario:

Potential scenario 4

A re-design of all elements of palliative care services including access to a new nurse-led in-patient service

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. CCGs would then fund enhanced community services.

Patients who do not have complex medical needs, but whose preference is to die in a hospice environment could receive care by a nurse-led service at a bed in North Kensington provided by the Pembridge Palliative Care Centre.

Comments:

Concerns:

Suggestions to improve the scenario:

Section 3 – your preferred scenario

What is your preferred potential scenario? (Please circle as appropriate)

1	2	3	4

Please rank each scenario? (1 = most preferred scenario, 2 = preferred scenario 3 = least preferred)

Potential scenario 1	
Potential scenario 2	
Potential scenario 3	
Potential scenario 4	

Is there another scenario you would like to be considered?

Any other comments?

Section 4 – About you

Which borough do you live in?

Where is your closest hospice?

How did you hear about this survey?

How would you like us to involve you and the wider community in the future?

If you would like to join our mailing list please include your email below:

Contact - any questions call 0203 350 4366 or nwlccgs.triborough.palliativecare@nhs.net

About you

To ensure we are representing our diverse community, we would be grateful if you could complete the below questions - the details you provide are strictly confidential. It’s a legal requirement for us to ask these questions, but you are not obliged to answer any you do not wish to.

Gender (please circle):

Man / Woman / Non-binary / Prefer not to say
If you prefer to use your own term, please specify here:

Is your gender identity the same as the gender you were originally assigned at birth (please circle as appropriate):

Yes / No / Prefer not to say

Age group (please put an x in the correct box):

Under 18	18 - 24	25 – 34	35 – 44	45 – 54	55 – 64	65 – 74	75 or over	Prefer not to say

Which of the following best describes your sexual orientation (please put an x in the correct box):

Heterosexual/straight	Lesbian/Gay Women	Gay Man	Bisexual	Prefer not to say

If you prefer to use your own term, please specify here:

…………………………………………………………………………………………

Which of the following best describes your religion or belief (please put an x in the correct box):

No religion	Buddhist	Christian	Hindu	Jewish	Muslim	Sikh	Prefer not to say

Other (please state)

……………………………………………………………………………………………

How would you describe yourself?

Using the following classifications, how would you describe your ethnic origin (please tick appropriate box).

White		**Black or Black British**	
White British		Caribbean	
Irish		African	
Gypsy/Irish traveller		Other Black background	
Polish		All Black groups	
Other white background			
All white groups			
Mixed		**Other**	
White and Black Caribbean		Somali	
White and Black African		Irish traveller	
White and Asian		Romany	
Other mixed background		Arab	
		Other ethnic group (please describe below)	
Asian or Asian British		Prefer not to say	
Indian			
Pakistani			
Bangladeshi			
Other Asian background			
All Asian groups			

Do you consider yourself to have a disability/impairment?

Yes ☐ No ☐

Contact us

- Email this back to our inbox at nwlccgs.triborough.palliativecare@nhs.net
- Post your survey back to us at FREE POST: HEALTHIER NW LONDON.
- Any problems call us on 0203 350 4366.

NHS
Central London
Clinical Commissioning Group

Appendix E

Sent By Email

87 - 91 Newman Street
London
W1T 3EY
Tel: 020 3350 4000
Email:
http://www.centrallondonccg.nhs.uk/

Friday, 03 January 2020:

Dear Stakeholder,

As you may be aware, Central London in collaboration with West London, Hammersmith & Fulham and Brent are undergoing a review of palliative care services across the four boroughs with the aim of improving access and quality of care. An independent review led by Penny Hansford was initiated by the temporary suspension of the inpatient unit at Pembridge palliative care centre due to insufficient medical cover; this review highlighted a number of challenges currently facing the local services. If you would like to find out more information on the work undertaken so far you can find out more at https://www.centrallondonccg.nhs.uk

We would now like to inform you of the outcome of a series of public workshops that were held in Autumn 2019 to hear the views of patients, the public, health and care professionals and local politicians. These workshops were well attended with an average of 30 attendees per workshop and we are very grateful to all those who gave up their time to help us to improve palliative care services in these boroughs.

The workshops focussed on three themes; ‘Access to services’, ‘Care’ & ‘Aftercare & transfer of care’. It was really useful to talk to workshop attendees and hear their experience and feedback of palliative care services across the boroughs. We have produced a workshop summary report which can be accessed here.

In summary, across the three workshops we found:

1. Care works well once a service or pathway has been accessed with inpatient hospice services offering peace of mind for family, friends and carers.
2. Care is not standardised across different areas in the four boroughs
3. There is inequitable access to information and support to access and navigate available services
4. Care planning should be transparent with family, friends and carers and start at an earlier stage.

5. More could be done to ensure that minority groups are aware of palliative care services and ensuring that these services are personalised for a diverse range of communities
6. Travel times to hospice services has a significant impact on carers and families and should be a focus for any future model of care.
7. More could be done to improve integration and coordination between services.
8. Bereavement services need to be planned earlier in the patient journey and be promoted better for friends, family and carers.

The information we have gathered will be used to inform our future design of palliative care services across Westminster, Hammersmith and Fulham, Chelsea and Kensington and Brent. We will be sharing our initial solutions for how we could improve palliative care services with the public so we can hear your feedback on these plans so far.

If the new model includes a significant change there will then be a public consultation so we can hear your feedback on the service. We will of course keep you posted on any updates arising from the programme.

If you have any further questions or comments, please contact us at nwlccgs.triborough.palliativecare@nhs.net

Yours Sincerely,

Jules Martin

Managing Director, NHS Central London CCG.

NHS
North West London
Collaboration of
Clinical Commissioning Groups

North West London Clinical Commissioning Groups
15 Marylebone Road
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17 January 2020

Appendix F

Dear colleague,

Following our communication earlier in January, we are writing to update you on the progress and next steps of the review of palliative care services taking place across Brent, Kensington and Chelsea, Hammersmith and Fulham and Westminster.

Public engagement - what we have done so far
Since December 2018 we have engaged; local patients, families, carers, residents, the voluntary and community sector, and patient representative groups across the four boroughs.

Initially we launched a ‘Call for evidence’ to hear from local people and professionals their views on services and how they are working. This information formed the basis of an Independent review which was led by Penny Hansford, who previously worked as Director of Nursing at St Christopher’s Hospice in South London.

The review findings were published and a series of recommendations were outlined. Three very well attended public workshops were then held to look at people’s experience of palliative care services from end to end; focussing on access, care and the transfer of care and bereavement.

In summary, across the three workshops we found:

- Care works well once a service or pathway has been accessed, with inpatient hospice services offering peace of mind for family, friends and carers. However, many people aren’t in contact with any services at all.
- Care is not standardised across different areas in the four boroughs.
- There is inequitable access to information and support to access and navigate available services.
- Care planning should be transparent with family, friends and carers and start at an earlier stage.
- More could be done to ensure that minority groups are aware of palliative care services and ensuring that these services are personalised for a diverse range of communities.
- Travel times to hospice services have a significant impact on carers and families and should be a focus for any future model of care.
- More could be done to improve integration and coordination between services.
- Bereavement services need to be planned earlier in the patient journey and be promoted better for friends, family and carers.

Plans for a future model of care for palliative care services
Listening to patients so far and working with our providers, we are now thinking about how we meet the challenges identified in the independent review and the feedback we have gathered from the public, palliative care clinicians and staff to date, which identified:

- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services; and
- inequity of funding arrangements for the services from the CCGs
- inequity of specialist palliative care services in the three boroughs.

We know that contact with specialist palliative care services results in an improved patient and family experience for people with an incurable condition or in their last phase of life.

We are in agreement that reaching only 48% of patients who may have a palliative care need is not good enough. It is paramount that we increase the reach of specialist palliative care services to all patients who need it, regardless of their disease type.

The four CCGs involved in this review along with our providers, are committed to increasing the ‘reach’ of these services, with the aim of 75% of patients with an expected death, their families and their carers, supported either by services, case management and/or advice, when they most need it.

What next?

At the beginning of February 2020 we will be publishing some potential solutions which seek to address the current challenges services face in terms of access, service provision and workforce shortages in this specialism, for further discussion and engagement.

We will engage with the public and key stakeholders on these proposed scenarios to gather people’s views, as we continue to develop the future model of care. The results will be presented to CCG governing bodies for consideration of the next steps and also to overview and scrutiny committees in due course.

Should we take the view that a significant change from the current service provided is required, then we would move to a public consultation which would ensure further engagement opportunities for local people to be involved in developing the future model of care.

The Pembridge palliative care centre

We know people will want to know what this means for the in-patient unit at the Pembridge palliative care centre. Commissioners and providers share the view that it is not advisable to recruit to the vacant palliative care consultant position during this period of review and transformation.

The in-patient unit will therefore remain suspended at this time, with the community and day care services continuing to operate as normal. Alternative provision will remain in place during this period. We are keen to progress this to a successful resolution as soon as possible and look forward to engaging with you in support of this.

Yours sincerely,

Sheik Auladin
Managing Director
Brent CCG

Jules Martin
Managing Director
Central London CCG

Louise Proctor
Managing Director
West London CCG

Janet Cree

Janet Cree
Managing Director
West London CCG

Steve Barnes
Hospice Director
St John's Hospice

DPounds

Dallas Pounds
Chief Executive Officer
Royal Trinity Hospice

Alpana. A Malde

Alpana Malde
Chief Executive Officer
St Luke's Hospice

Dr Joanne Medhurst
Medical Director
Central London Community Healthcare NHS Trust

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Appendix G: Mortality rates and preferred place of death

In Brent, life expectancy for the population born between 2011 and 2013 is estimated to be 80 years for men and 84.9 years for women. However, life expectancy is 4.7 years lower for men and 4.4 years for women in the most deprived part of the borough than the least deprived part.

When asked, nationally nearly 80% of people express a preference to die in their usual place of residence and, while this may not always be possible (and preferences change for some people when the time comes) this is nearly the exact opposite in percentage of patients who actually achieve this.

There were 1,739 deaths in Brent in 2018/2019. According to the most recent data, just under half of all deaths in England occur in hospital. This number had been steadily decreasing over the past decade, from 58.2 per cent in 2005 to 46.7 per cent in 2015. The comparative figures for Brent show just over half of patients die in hospital and only 15% die in Care Homes, significantly less than the national figure.

2018/19 data on preferred place of death

Place of death	All Deaths In Brent	England %	London %	NWL STP %
Hospital	920 (53%)	46	53	53
Home	397 (23%)	24	24	24
Care Home	262 (15%)	23	15	14
Hospice	110 (6%)	6	6	6
Other	50 (3%)	2	3	3
Total	1,739			
Usual Place Residence	628 (37%)	46	38	26

Source 4/2019 Public Health Education England End of Life Data

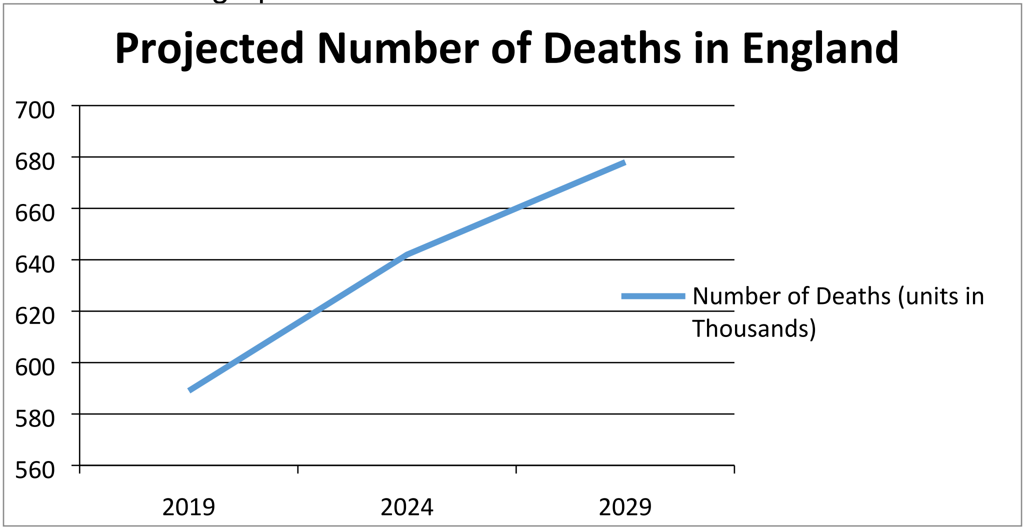
The mortality rate for Brent is slightly above the average compared to other North West London boroughs:

Mortality rate by borough

Local authority: county / unitary (as of April 2019)	**Deaths**	**Age-standardised mortality rate**	**Percentage of population**	**Population**
Brent	1,753	786.25	0.530	330,754
Ealing	2,057	852.63	0.601	342,262
Hammersmith and Fulham	995	908.63	0.537	185,288
Harrow	1,509	700.65	0.603	250,248
Hillingdon	2,185	965.22	0.717	304,742
Hounslow	1,593	932.24	0.588	270,918
Kensington and Chelsea	791	618.52	0.506	156,324
Westminster	1,075	630.67	0.421	255,344
Total	**11,958**		**0.571**	**2,095,884**

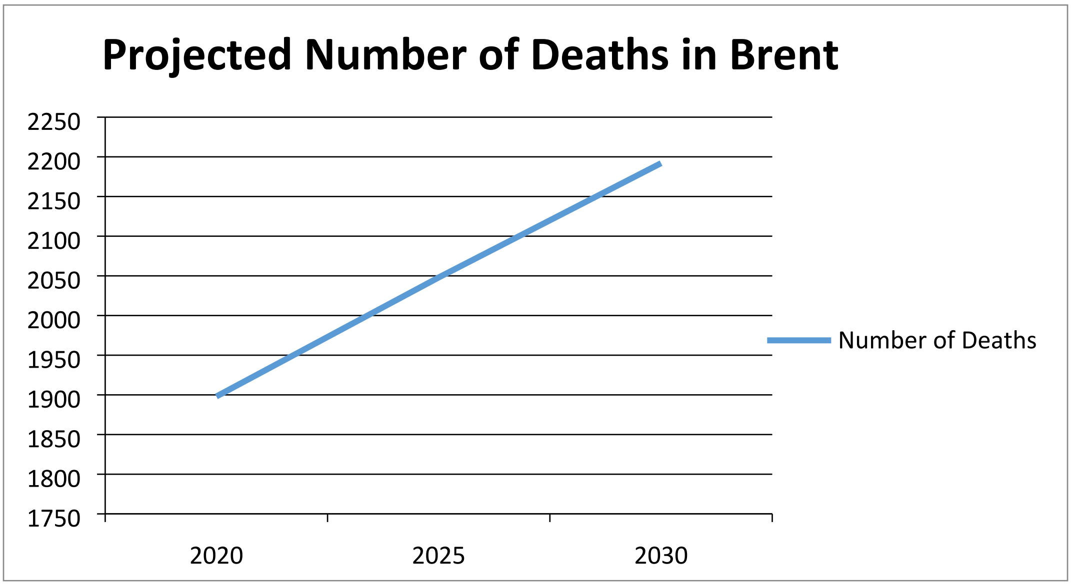
Source: ONS data January 2020

As a result of the UK's aging population, the number of deaths per year is expected to rise by 15% in England between 2019 and 2029. More people will be dying in older age who will be more likely to have complex needs and multiple co-morbidities as they near the end of their lives. The projected number of deaths in England is outlined in the graph below.



Source: ONS data 2020

For Brent, the number of deaths is also projected to increase from 1,898 in 2020 to 2,192 in 2030, an increase of 15%.



Source of data – GLA 2020

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Appendix H

The current spend by Brent CCG on palliative care services is outlined in the table below:

Current Spend	% of total funding	**Brent**
Inpatients (Bed Day)	52%	£1,178,008
Day Care/Outpatients (Attendances)	11%	£323,824
Community (contact)	37%	£782,416
Total	100%	**£2,284,248**

Appendix I - National Guidelines on End of Life Care

The Health and Social Care Act 2012 created CCGs, clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. There is not a specific statutory requirement for CCGs to commission palliative care. There are, however, a number of guidelines and standards for commissioning high quality palliative care services, some of which are described below.

The National Palliative and End of Life Care Partnership published 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020' in September 2015. It builds on the Department of Health's 2008 National Strategy for End of Life Care and the NHS Five Year Forward View. It encompasses all elements of palliative and end of life care for all age groups within its scope. The Ambitions framework underpins the contribution of specialist level palliative care services as an integral part of the overall care in meeting the person's changing needs as their illness progresses, and those of families, carers and those important to the person, and other professionals who have primary responsibility for a person's direct care.

In 2017, the National Council for Palliative Care Services published the report 'Best Practice in Care Co-ordination for Palliative and End of Life Services: Information for Commissioners'. The report reviewed 66 palliative and end of life care co-ordination systems with the aim of identifying best practice, improving people's experience and choice at the end of life. The components of service models from the report combined with other components from research include the following:

- Clinical triage 24/7 with a single phone number and the availability for face to face home assessment with a short response times for clinical situations that are urgent
- Rapid response mobilisation of health and social care that is able to stay with patients for prolonged periods including overnight
- Availability of medication and equipment
- Integration with all other service providers in the area, evidence of joined up services with acute care and discharge

The report can be found at the following link: http://endoflifecareambitions.org.uk/wp-content/uploads/2017/06/Care-Coordination-Quick-Guide-for-Commissioners.pdf

The NICE Quality Standard QS13 End of Life Care for Adults (Nov 2011) covers the full spectrum of palliative and end of life care. The standard provides health and social care workers, managers, service users and commissioners with a description of what high-quality end of life care looks like, regardless of the underlying condition or setting. Delivered collectively, these quality statements should contribute to improving the effectiveness, safety and experience of people approaching the end of life and, their families. The quality standard requires that services are commissioned from and coordinated across all relevant agencies, including specialist palliative care, and encompass the whole end of life care pathway. The standard is available at: http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13