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
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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).

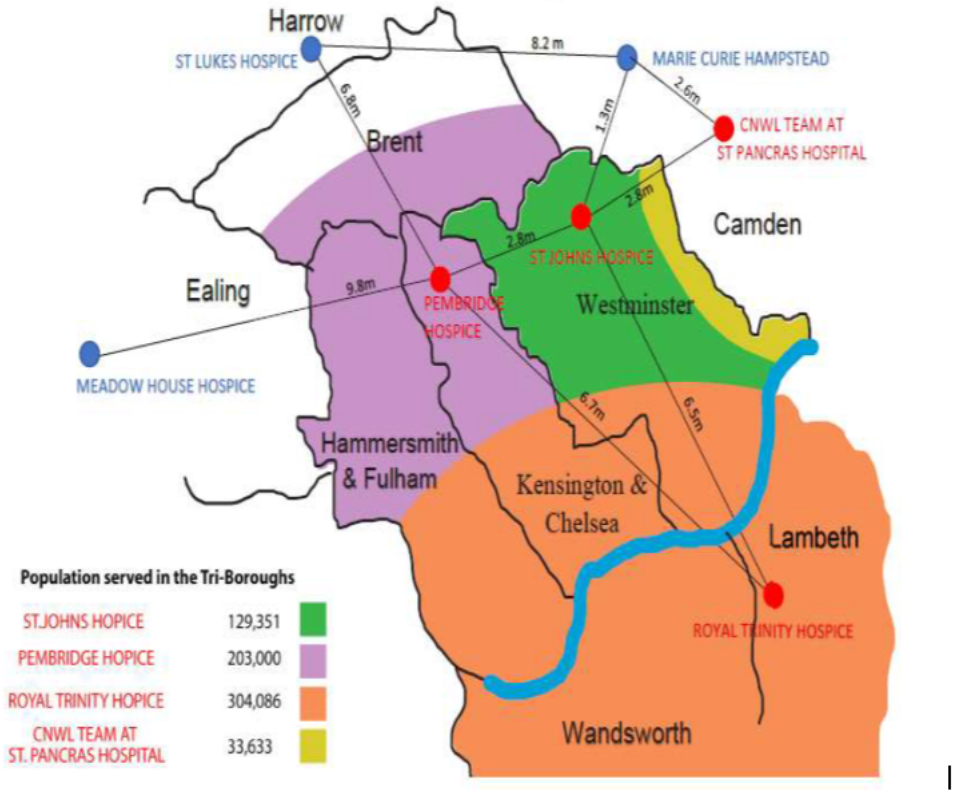
Specialist palliative care is mostly provided for Brent patients in the following hospitals: Northwick Park and Central Middlesex Hospital (London North West Healthcare NHS Trust), Charing Cross and St Mary's Hospitals (Imperial College Healthcare NHS Trust) and the Royal Free Hospital (Royal Free NHS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

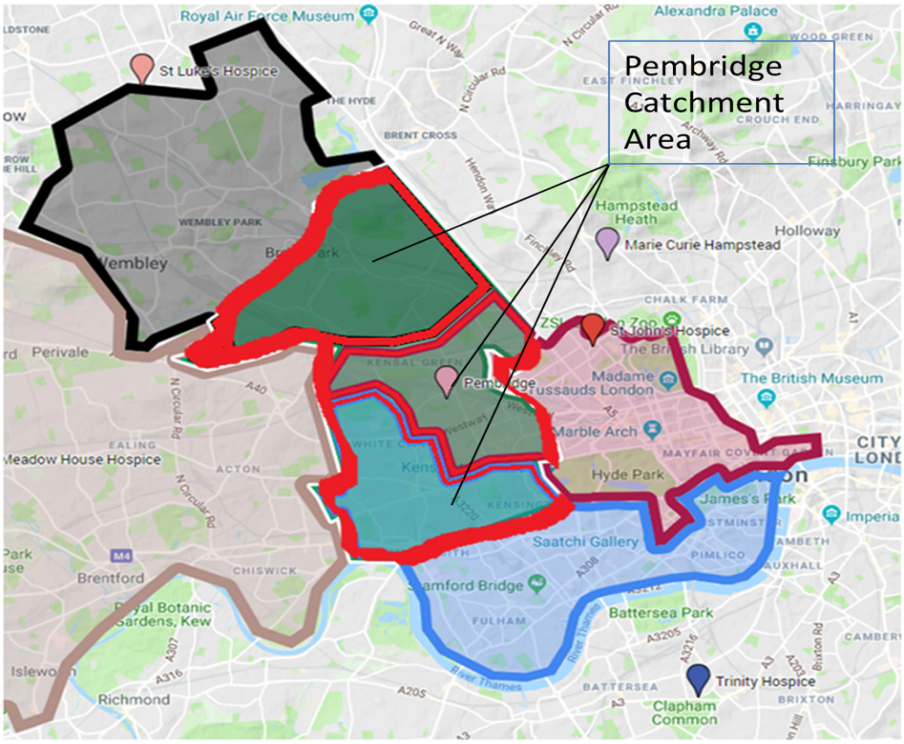
Community specialist palliative care is provided by services are provided by St Luke's Hospice (StL), CLCHT Pembridge Hospice (PH), St John's and Elizabeth Hospice (StJ) and Marie-curie Hospice Hampstead (MC). The 6 main elements of community hospice provision are described below:

- 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.