



**Community Wellbeing Scrutiny
Committee**
9 July 2019

**Report from Brent Clinical
Commissioning Group**

Palliative and End of Life Care in Brent

Wards Affected:	All
Key or Non-Key Decision:	N/A
Open or Part/Fully Exempt: <small>(If exempt, please highlight relevant paragraph of Part 1, Schedule 12A of 1972 Local Government Act)</small>	Open
No. of Appendices:	1
Background Papers:	
Contact Officer(s): <small>(Name, Title, Contact Details)</small>	Rashesh Mehta; Dr. Lyndsey Williams

1.0 Summary

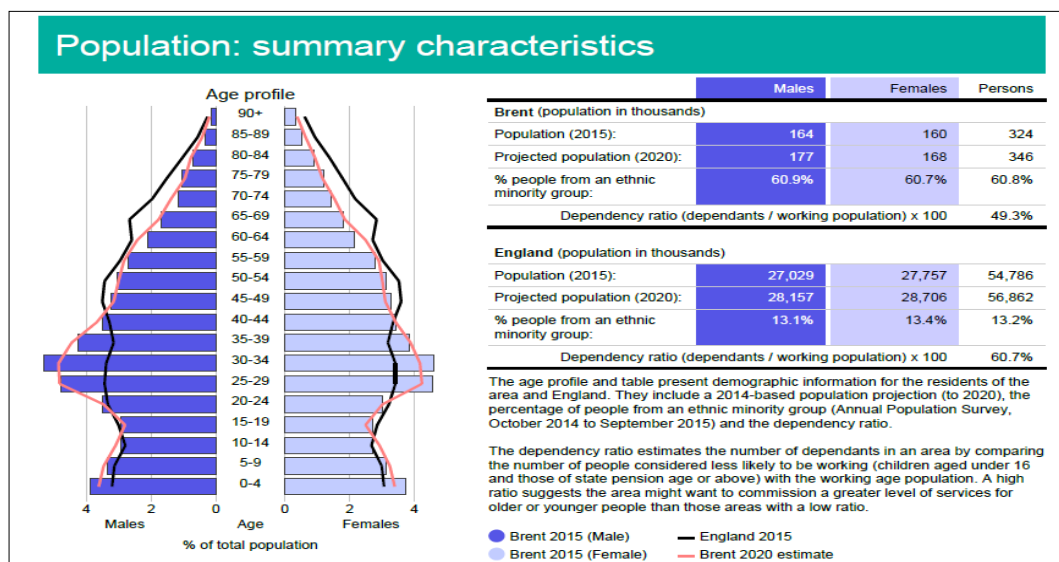
This report provides an update for the Overview and Scrutiny Committee on Community Palliative and End of Life Care (EOLC) services in Brent. The report describes demographic data and activity, the current range of local acute and community specialist palliative care services and the CCG's strategy and commissioning intentions that address some of the challenges in the delivery of EOLC services in Brent.

The suspension of Central London Community Healthcare Trust (CLCHT) Pembridge hospice inpatient unit has provided the CCG with an opportunity to review its End of Life (EOL) strategy and look at the current capacity and demand for community specialist palliative care services and to consider whether the service provided is of sufficient quality, clinically safe and if the service provides good value for money. The CCG has the statutory responsibility to manage its finances effectively and efficiently which meets local population needs. Likewise, any proposed changes to commissioned services must be evidence-based.

The purpose of this report is to identify the current status of service provision, clinical effectiveness and safety. We are initiating a review of palliative care services and depending on that, and further engagement, decisions on the service profile will be taken.

Demographics of EOLC population in Brent

- Brent is a diverse London borough and large proportion of the population are young working age (67.8%) residents with a low proportion of residents aged 65 and over (11.3%) and the fifth lowest number of children of any London borough¹.
- The mean average age is 35, five years below the UK average (40).
- The area has high levels of migration in and out of the borough, and significant ethnic and cultural diversity.
- 66% of the population is from Black, Asian and Minority groups (BAME).
- People between 0–15 y/o comprise 21% of the total population. Those 16-64 y/o,
 - working age population makes up 67.8% of the population and the 65 and over
 - Population makes up 11.3% of the population.
- Brent has the largest proportion of residents born abroad (55%). This ranges from Asia (23%), followed by Europe (18%) and Africa (10%) to Central and South America (3%) and North America (1%). 14.5 per cent of households have no people that speak English as a main language; this is the thirteenth highest proportion in England & Wales.



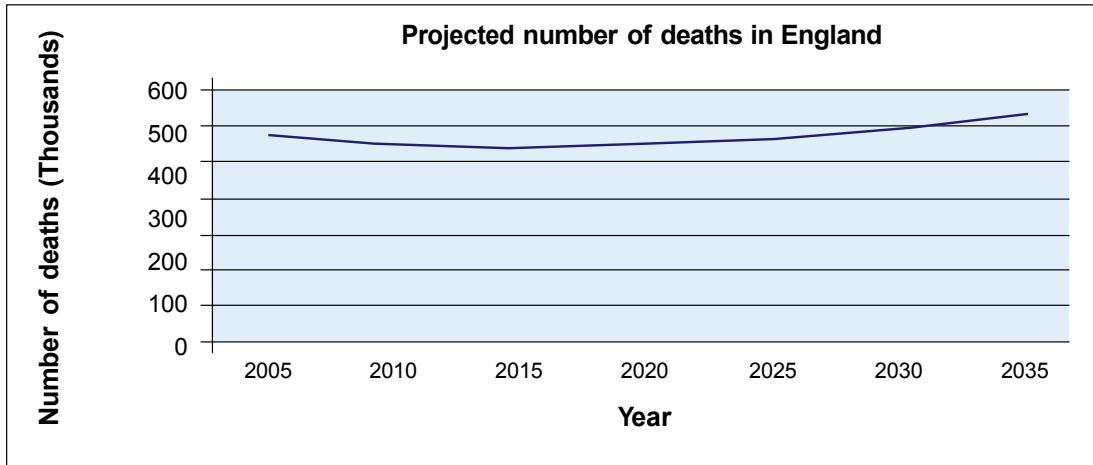
Graph 1: Summary Characteristics of the Population of London Borough of Brent (Feb. 2019)

- Life expectancy for men is 79.9 years and 84.9 years for women. Life expectancy is
 - 5.8 years lower for men and 4.0 years lower for women in the most deprived areas of Brent than in the least deprived areas.

¹ Brent JSNA 2015/16 Refresh - <https://www.brent.gov.uk/media/16412103/jsna-2015-brent-overview-report.pdf>

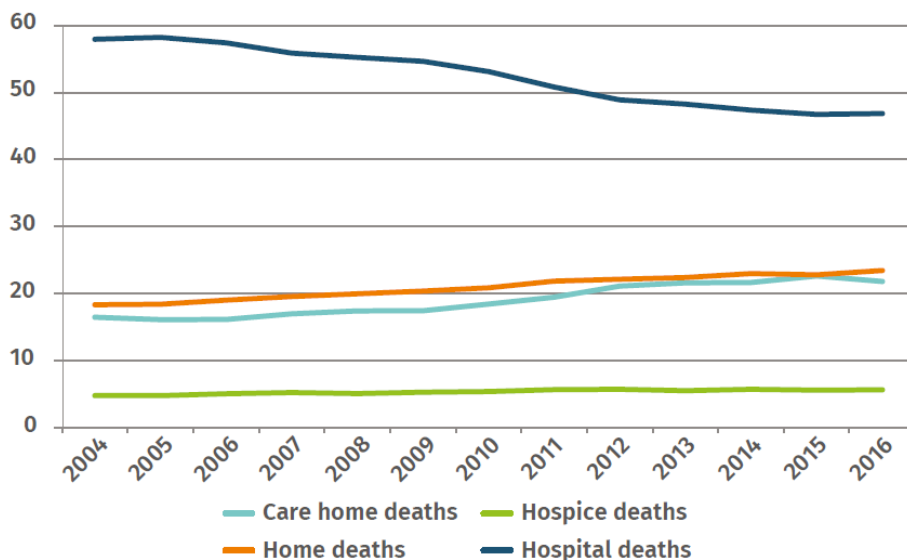
- As a result of the UK's aging population, the number of deaths per year is expected to rise by 17% between 2012 and 2030
- Many more people will be dying at an older age and therefore more likely to have complex needs and multiple co-morbidities as they near the end of their lives.
- To deliver quality care effectively requires a shared vision for end of life care to encourage commissioners and providers to work together.

Office for National Statistics:



- According to the most recent data, just under half of all deaths in England occur in hospital. This number has been steadily decreasing over the past decade, from 58.2 per cent in 2005 to 46.7 per cent in 2015.

The proportion of hospital deaths in England is steadily decreasing
 Location of deaths in England (%), 2017



Source: PHE 2017a

- The picture at a national level obscures considerable variation in the likelihood of dying in hospital by region. In particular, there are a considerably higher proportion of hospital deaths in London (53.2%), and in the West Midlands (49.5%), North West (48.7%) and North East (48.1%).

Region	% hospital deaths	Region	% hospital deaths
South West	42%	North East	48%
South East	43%	North West	49%
East of England	45%	West Midlands	49%
Yorkshire and the Humber	46%	London	53%
East Midlands	48%	England	47%

Source: PHE 2017a

- In addition, there is a correlation between deprivation and likelihood of dying in hospital, with a higher proportion of people living in more deprived areas who die in hospital. This is perhaps to be expected: deprivation is linked to household finance, quality of housing, family situation, as well as health indicators, all of which are likely to affect people's ability and/or desire to spend their final days outside of hospital. This reflects the findings of the Marmot review, which demonstrated more generally that health inequalities flow from social inequalities²
- The latest figures on the number of Brent registered EOL patients with place of death are outlined in the table below³. It shows that in Brent over half of EOL patients were dying in hospital and in line with the national data, around 23% died at home. These figures are opposite to the national data on patients' preferred place of death.

Place of death	All Deaths (2017)	Underlying Cause of Death		
		Cancer	Circulatory disease	Respiratory disease
Hospital	946 (53.9%)	495 (28.2%)	561 (32%)	200 (11.4%)
Home	398 (22.7%)			
Care Home	256 (14.6%)			
Hospice	118 (6.7%)			
Other	36 (2.1%)			
Total	1,754	495	561	200

2.0 Description of current EOLC services in Brent

- 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).

² Marmot M et al (2010) *Fair Society Healthy Lives (The Marmot Review)*. <http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review>

³ Data source: http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles

- 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 in Appendix 1 of this report and in the bullet points below:
 - In-patient Unit – Consultant led 24/7 in-patient beds for terminal care, symptom control and palliative rehabilitation.
 - 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)
 - Day Hospice – Therapy and peer support in a day centre delivered during the week including complimentary therapy (StJ, StL & PH)
 - Outpatient – Consultant or nurse led clinics at the hospices delivered 5 days a week (All)
 - Bereavement/Counselling for carers and families (all)

3.0 Description of CLCHT Pembridge Hospice Provision and Activity

- Pembridge is a 13 bedded hospice service run by Central London Community Healthcare Trust (CLCHT) located at St Charles Centre for Health and Wellbeing. Referrals come from Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster. The service is commissioned on behalf of Brent CCG by Central London CCG (CL CCG) as part of the CLCHT contract.
- The overall service at Pembridge comprises of three main areas of provision:
 - The in-patient unit -13 beds providing 24-hour care for patients with specialist palliative care needs who need continual assessment.
 - The day hospice - treatment, support and complementary therapies for patients visiting Pembridge available Monday to Friday.
 - The community specialist palliative care team - providing advice and support to patients in their own home, Mon-Friday 9am-5pm
- Current activity at the Pembridge Hospice is described in the table below:

Pathway (Activity)	Data Source	APR 18	MAY 18	JUN 18	JUL 18	AUG 18	SEP 18	OCT 18	NOV 18	DEC 18	JAN 19	FEB 19	MAR 19	YTD	Annual Plan
BereavementCounselling - ACTUAL	BIPA	96	100	82	117	66	42	53	202	130	80	122	122	1212	999
BereavementCounselling - PLAN		82	85	82	85	85	82	85	82	83	84	77	85	753	
Variance (%)		17%	18%	0%	38%	-22%	-49%	-38%	145%	57%	-5%	59%	43%	61.0%	
Community - ACTUAL	BIPA	500	554	462	469	549	383	594	789	620	703	591	626	6840	4380
Community - PLAN		361	372	361	372	372	361	372	361	369	370	337	372	3301	
Variance (%)		39%	49%	28%	26%	48%	6%	60%	119%	68%	90%	75%	68%	107.2%	
Day Care - ACTUAL	BIPA	177	138	168	195	129	110	435	512	356	209	202	231	2862	1746
Day Care - PLAN		139	139	148	148	156	139	156	156	130	148	139	148	1311	
Variance (%)		27%	-1%	14%	32%	-17%	-21%	179%	228%	174%	41%	45%	56%	118.3%	
Inpatients (Bed Days) - ACTUAL	BIPA	68	122	62	67	84	93	0	0	0	0	0	0	496	1124
Inpatients (Bed Days) - PLAN		92	95	92	95	95	92	95	92	95	95	86	95	847	
Variance (%)		-26%	28%	-33%	-30%	-12%	1%	-100%	-100%	-100%	-100%	-100%	-100%	-41.4%	
TOTAL - ACTUAL	BIPA	841	914	774	848	828	628	1082	1503	1106	992	915	979	11410	8249
TOTAL - PLAN		675	692	684	701	709	675	709	692	677	697	639	701	6211	
Variance (%)		25%	32%	13%	21%	17%	-7%	53%	117%	63%	42%	43%	40%	83.7%	

- The data for 18/19 requested from CLCH Pembridge is only available in the above format. The CCG has requested more detailed data around the protected characteristics, provision of service for any specialist groups of patients and also total number of patients into different services but have not received this as of to date.
- For Day Hospice the data recorded is based on contacts by face to face or telephone.

4.0 Background to CLCHT Pembridge In-patient Unit Suspension

- On the 19th September 2018, Brent CCG became aware, through another hospice provider that the specialist palliative care consultant had resigned in late July and they were unable to recruit an appropriate medical professional to replace this role. The impact of this member of staff leaving meant that the inpatients unit at the Pembridge Hospice did not have appropriate specialist palliative care clinical supervision and the inpatient unit was suspended as of 1st October.
- Brent CCG was advised by colleagues from the CLCHT Pembridge Hospice that attempts to recruit a lead consultant since then have failed.
- Key stakeholders have raised concerns regarding the viability of the remaining services being provided by the Pembridge Hospice without an available 24/7 in-patient unit on site.
- Interim arrangements have been in place since 1st October 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 would be St John's Hospice, St Luke's Hospice and Marie Curie Hampstead Hospice.
- One of Brent CCG's alternative Hospice providers was able to accommodate the increased inpatient capacity within their current contractual arrangements.

5.0 Independent Review of Palliative Care

- Central London CCG communicated to all CCGs in November 2018 that it would conduct an independent review of the CLCHT Pembridge and other local service, Brent CCG agreed to this recommendation whilst reviewing their current end of life and community specialist palliative care provision with remaining community specialist palliative care providers.
- The 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 an independent reviewer and overseen by a Specialist Palliative Care Review Steering Group.
- The terms of reference for the review were to review national strategy, policy and best practice alongside local context and report recommendations to CL CCG on options for a new commissioning model which ensured that local care is delivered in a way which provides the highest quality care for patients, their families and carers at the best value.
- 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. Brent CCG was not part of the strategic review as CL CCG considered that Brent CCG had already conducted its End of Life Care review in 2017.
- The review was published in March 2019 and can be found at this link: <https://www.centrallondonccg.nhs.uk/news-publications/news/2019/06/strategic-review-of-palliative-care-services.aspx>
- 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”
- The review report suggests various options but recommends the option, “to have one lead provider in the community, due to the significant transformational change needed in the specialist palliative care services...” This suggests the recommendation to go out to procurement for one lead provider for palliative care which will then subcontract with the other providers. It also has an additional recommendation regarding Pembridge Hospice in-patient bed provision, which the report states could probably be reduced as other available providers have managed the activity within their existing capacity.

6.0 Brent CCG Patient and Carer Engagement

- Brent CCG has been engaging with patients on End of Life and community Specialist Palliative Care services since a strategic review was conducted by the CCG in 2017 and with a particular focus on the Pembridge in-patient since

October 2018 when it was notified to the CCG that the consultant had resigned from his post.

- The suspension of the in-patient unit at Pembridge has provided the CCG with an opportunity to review all EOLC services in Brent and engage with local patients and other interested parties on what kind of services should be delivered to Brent patients.

- An on-line questionnaire had been distributed through a list of local stakeholders for wider distribution to EOLC patients and carers. The online questionnaire has been disseminated through the current community specialist palliative care services and was available on the CCG End of Life webpage. Hard copies of the questionnaire were also shared with patients at EOL stakeholders meetings.

- With regards to public engagement, Brent CCG has undertaken four public engagement events. The four engagement events were held at various locations as mention in the table below, to gain the views about the future of community specialist palliative care in Brent.

Date	Time	Venue
Monday 4th March	12 - 2pm	Boardroom, Brent CCG, 116 Chaplin Road, Wembley
Monday 25 th March	1pm – 2pm	St John's Hospice Day Centre
Monday 1 st April	1 - 2pm	St Luke's Hospice Kenton Grange, Kenton Rd, Harrow HA3 0YG
Monday 15 th April	1.30pm – 2.30pm	Pembridge Hospice St Charles Centre for Health and Wellbeing, Exmoor Street, London W10 6DZ

- The CCG has been transparent with patients about commissioning a complete community specialist palliative care service across the whole of Brent that permits equity of access and the need for a better co-ordinated service with the opportunity to develop a 'first point of contact' and rapid response service for patients, carers and healthcare professionals.

7.0 Access to other In-patient Hospice Care during Suspension Period

- Since the closure of the Pembridge Hospice Inpatient Unit on 28th September 2018, St Luke's Hospice, Marie Curie Hampstead Hospice and St John's Hospice have provided additional Specialist Inpatient Palliative Care services

for Brent patients in order to ensure that there has been continuity in terms of available service.

- The Hospices have indicated a willingness to work with commissioners in Brent in order to provide Specialist Palliative Care services to meet the needs of patients who would otherwise have been accessed all services offered by Central London Community Healthcare NHS Trust at the Pembridge Hospice.
- Current Hospices commissioned by Brent CCG have the capacity to ensure continuity of service by seeking to assimilate existing services into our existing Community and Day Specialist Palliative Care services, and would work together with commissioners to determine an optimal service configuration that meets the needs of Brent patients.
- The current hospices have confirmed to continue to work together to ensure efficiency and effectiveness as we design more collaborative and integrated services.

▪ **8.0 Next Steps**

We are initiating a review of palliative care services that will be closely aligned with the tri-borough CCGs. Since we are moving towards a single CCG structure, and a new collaborative way of working between providers and commissioners, Brent CCG needs to have due consideration to the impact that any proposed service change will have on North West London providers and the other 7 CCGs.

Depending on the outcome of that review, and further engagement, decisions on the service profile will be taken.

Meetings will now be taking place between the commissioners to align the engagement processes for the next stage across the CCGs.

Appendix 1 The diagram below describes the proposed EOLC pathway for EOLC, with the advent of First Point of Contact to manage EOLC patient referrals.

Proposed Brent CCG End of Life (EoL) strategy 2019 and beyond

