North West London
Integrated Care System
Working together for better health and care

Community-based specialist palliative care improvement programme

Hammersmith and Fulham Council

Health and Adult Social Care Policy and Accountability Committee

25 January 2023

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Contents

1 Introduction

We last formally shared an update on progress in this critical piece of work in July 2022. In this paper we cover the entirety of work done and not just the work since July to ensure the full journey is articulated.

Working together with residents, Hammersmith and Fulham and other councils across North West London (NW London) it is going to be critical to ensure we best meet the needs of those who require community-based specialist palliative care.

The North West London Integrated Care System (NW London ICS) acknowledges the strong local interest in the future of the Pembridge Palliative Care Centre inpatient unit and the need to ensure local residents have equal access to the whole range of community-based specialist palliative care and support services depending on their complexity of need.

We are undertaking a NW London exercise so we can learn from good practice across our eight boroughs and meet the ICS objectives around equality of access, experience and outcomes, however within that the specific concerns and needs in each borough are important.

Since attending the Hammersmith and Fulham Health and Adult Social Care Policy and Accountability Committee on 20 July 2022, we have continued to engage with local and wider North West London residents and gather evidence. A final engagement outcome report is due to be published in early 2023 and this will include all feedback received to date, including content from Hammersmith and Fulham engagement events. In the meantime, we continue to regularly update our review website (https://www.nwlondonics.nhs.uk/get-involved/cspc) with details of our latest engagement activity. It is important to confirm that engagement with local residents will continue throughout the life of this important programme.

We welcome the chance for a discussion today on these issues. When we come to mutual decisions we need to know they are backed up by robust engagement and that we have worked through the pros and cons transparently.

Key points for Hammersmith and Fulham

Key points

- A North West London wide steering group has been established that consists of NHS providers, hospices, local authority and resident representatives. We are appreciative that public health representation comes from the Borough team. Our Issues Paper published in November 2021 sets out the key reasons why we are looking at community-based specialist palliative care and helps us have a conversation on what future care could look like.
- There are some things that we have found that needed to be addressed immediately. We found not all boroughs had the same level of in and out of hours' access to end of life care and anticipatory medication. The gap was closed by commissioning an equivalent service which meant that during the pandemic all NW London residents have equal access to these medications 24 hours a day.
- An interim engagement outcome report was published on Thursday 9 June 2022 which contained all the feedback given following discussions with local

residents and those who have first-hand experience of palliative and end of life care received in NW London. A final report is due to be published in early 2023.

- The outcome report was sent to stakeholders across NW London including council and NHS leadership, MPs and Healthwatch. We also used our established channels to communicate with other stakeholders and North West London residents. A short video was produced to accompany the launch and a newsletter that has been distributed widely.
- All the public feedback received is currently being used by the NW London CSPC Model of Care Working Group, which is responsible for designing, planning and recommending the 'must haves' and options for the future model of care for adult community-based specialist palliative care to the steering group.
- Membership of this group consists of local residents, clinicians and other palliative and end of life care stakeholders. The group has been asked to:
    - agree a common specification / common core offer for community-based specialist palliative care.
    - develop a new model of care to deliver the specification / common core offer.
    - map out how this can be implemented in each borough.
- The work is drawing on the national service specification for adult palliative and end of life care, the previous NW London four CCGs palliative care review programme work and qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement. We will also utilise activity trend data obtained through the programme's data working group and undertake further work looking at the structure of our services workforce.
- The expected output is a set of core service standards, requirements and service functions that will need to be delivered across NW London. There will also be a number of additional localised requirements that the local Borough Based Partnerships will have responsibility for implementing in view of their local context and population needs.
- This will include:
    - a core of services that will allow us to deliver care and support in a person's own home.
    - a range of bedded care that allows us to provide care and support to patients with a range of specialist palliative and end of life care needs. This could be in a number of locations including a hospice inpatient unit, a care home or a patient's own home with community support.
    - Our current thinking is that we will propose dedicated beds in care homes, which will benefit from a higher level of specialist input than routinely provided by homes.
    - make sure our providers have access to an extensive range of support services such as IT infrastructure or a workforce with the right knowledge and skills that is able to deliver high quality compassionate care.
- We will work with the Health & Care Partnerships, local residents and stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If substantial service change is needed, we will then need to consider if a public consultation is needed.

- Moving forward, our expectation is that there will be wide ranging resident and stakeholder involvement throughout this process. If significant service change is proposed, we would undertake a formal consultation.
- We also welcome feedback received about the need to progress and develop agreed elements as soon as possible rather than wait until all elements of this important programme as we did where we found some existing gaps in service provision that needed to be addressed immediately.
- The Hammersmith and Fulham Health and Care Partnership conducted a series of meetings and public engagement events to understand what works well and what needs improving in existing End of Life & Palliative Care Services (General and Specialist Palliative care), with feedback being fed back into the overall NWL Community based Specialist Palliative Care review.
- Feedback is also being considered by the End of Life subgroup in the Frailty Health Care Partnership Campaign to agree short term and long priorities in order to deliver service improvements within Hammersmith and Fulham. This group has representation from all partners (NHS, LA, Voluntary sector organisations, HAFSON & Patients representatives) and is currently working to deliver:
    - **A directory of services** – a simple document / central point of information showing current services available within H&F, including information on primary care, district nursing community services, specialist palliative care services via Hospices (inpatient and outpatient support), Care homes/ Nursing home support, Bereavement support and a list of charities and voluntary sector organisations providing support to patients, their friends and family.
    - **"Improving integration between NHS services & Council Services",** specifically considering ways to create and improve integration / connection between social workers and the healthcare staff who are visiting the same patient. The aim is to have a joined up approach between health and social care for residents going through end of life care.
- The inpatient unit at Central London Community Healthcare NHS Trust's (CLCH) Pembridge Palliative Care Centre continues to remain suspended until further notice following its closure due to a lack of specialist palliative care consultant cover and being unable to recruit due to that national shortage of trained personnel. It takes significant consultant resource to run and oversee an inpatient unit and based on current capacity CLCH would not be able to run this safely. All other services (24/7 advice line including palliative care consultant support, community specialist palliative care nursing service, rehabilitation team support service, social work and bereavement support service, and day hospice services at the Pembridge Palliative Care Centre are unaffected and continue to operate.
- Along with a number of unsuccessful attempts to recruit consultants, we have sought to work across the system to 'network' consultants in hospitals and hospices to support reopening Pembridge beds, but have not been able to develop a clinically supported model to do that – this challenge is underpinned by a national workforce shortage.
- In April 2020, the inpatient beds at Pembridge were temporarily re-designated for the for rehabilitation of Covid positive patients. We were able to staff the service – which was not consultant led- because we had national guidance to pause many other services. It is unlikely that Pembridge will be required to fulfil this function again due to the knock on impact on those other services.

- We do recognise that local residents are disappointed with the need to suspend this inpatient service and confirm that a decision on the future of the unit will only take place following the completion of the community-based specialist palliative care review that the North West London Integrated Care System is leading and is currently underway.
- We confirm that qualitative factors such as local accessibility and stakeholder views will be an important consideration alongside quantitative factors such as capacity and referrals when making any decisions regarding future provision of community-based specialist palliative care service in NW London including the future of the Pembridge in-patient beds.

We share with Hammersmith and Fulham and all North West London Councils and residents a focus on palliative care because of the importance of getting care and service provision right.

> ""We have seen what a difference specialist palliative care services can make to a patient and their families and carers as they come to the end of their life but unfortunately we have seen what can happen if the care and support is not there and the damaging legacy for those left behind. That is why it's important that we work together to develop services that are clinically to a high standard but also meet what patients and family's need."
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> **Dr Lyndsey Williams,**
> **NW London GP Clinical Lead for End of Life and Care Homes**

It is widely recognised that when caring for someone in the last year of their life, we have only one chance to get it right.

Anyone at the end of their life should be able to live and be cared for where they want to be and be with the people they want to be with. They (and their family, loved ones and carers) deserve the best quality care and support, regardless of their circumstances. We live in a rapidly ageing society, where people are living longer but are more likely to live with multiple complex long term conditions. As a result, the need for high-quality palliative and end-of-life care is expected to increase dramatically by 2040.

> "We need to remember how scattered families can be and how people in theory would often like to think of dying at home, and so would their families. But the reality and the lack of properly seamless care means that it becomes an impossibility or can lead to a very, very negative death. The repercussions upon individuals of experiencing negative death of somebody they care about go on to have psychological and other repercussions throughout their lives."
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> **Quote from member of the public attending the engagement event on 13 December 2021**

Too many people experience poor care as they approach the end of their life, with many people spending their last months and weeks in hospital, often dying there, which may not be what they want. Not only can this be distressing for the patient and their loved ones, but it also adds more pressure on acute hospitals.

Palliative and end-of-life care is a national priority, as well as a priority for health and social care partners across North West London. In North West London we have some excellent palliative and end-of-life care services for adults (aged 18 and over), provided by very committed partner organisations, but we know that we need to improve the care we provide in hospitals, community settings (such as hospices and day centres), primary-care settings and patients' own homes. We want to make sure all patients have equal access to accessible, consistent, high-quality care across all palliative and end-of-life care services.

More also needs to be done to make sure the care provided by different organisations is more joined up. This includes looking at the IT challenge of not all services having appropriate access to clinical information held electronically by partner providers for patients under their care; and making sure all patients have a personalised care plan that has been agreed with them, and that the plan is available to the different care sectors supporting them and their family.

2 Our focus on community-based specialist palliative care

We are focused on community based specialist care for adults (18+) at this stage because of the fragility of those services.

In North West London we have eight community-based specialist palliative care providers delivering these services. These include seven hospices with inpatient units, as well as separate community specialist palliative care teams and nursing services provided by community NHS trusts.

The providers deliver a wide range of services across them (including inpatient and community-based specialist palliative care nursing, day hospice, hospice@home, outpatient services, well-being services and bereavement services, 24/7 specialist advice, rapid response and overnight nursing services) as well as some additional services (including lymphedema and complementary therapies).

Three providers – Central London Community Healthcare NHS Trust, London North West University Healthcare NHS Trust and Central and North West London NHS Foundation Trust – receive all their funding from the NHS. The other five providers are charitable hospices and receive their funding from a combination of NHS and charitable income.

Provider	**Hospice / Community SPC team/ service**	**The NW London boroughs where they provide services**
Royal Trinity Hospice (based in South London)	Royal Trinity Hospice	West London Central London Hammersmith & Fulham
St. John's and Elizabeth's hospital (based in Westminster)	St. John's hospice	West London Central London Hammersmith & Fulham Brent
Marie Curie London	Rapid response and planned variable nursing services	Ealing and Hounslow
Marie Curie London	Marie Curie Hampstead Hospice	Brent
St. Luke's Hospice (based in Harrow)	St. Luke's Hospice – Kenton	Brent and Harrow * North Brent residents receive support from St Luke's Hospice Community Specialist Palliative Care Team. South Brent residents receive support from the Pembridge Palliative Care service's Community Specialist Palliative Care team*
London North West NHS Trust	Meadow House Hospice at Ealing Hospital site	Ealing Hounslow
Harlington Hospice (based in Hillingdon)	Harlington Hospice and Michael Sobell Inpatient Unit at Mount Vernon Hospital	Hillingdon
Central and North West London NHS Trust	Hillingdon Community Specialist Palliative Care Team	Hillingdon

Central and North West London NHS Trust	Your Life line 24 Service	Hillingdon
Central London Community Healthcare NHS Trust (CLCHT)	Pembridge Palliative Care Centre – St Charles Centre for Health and Wellbeing, Kensington & Chelsea *Inpatient unit is currently suspended but all other services in operation*	West London Central London Hammersmith & Fulham Brent
Central London Community Healthcare NHS Trust (CLCHT)	Harrow Community Specialist Palliative Care team	Harrow

The NHS and its partners are committed to making improvements in community-based specialist palliative care for adults within this review process, but will continue to seek to improve other areas of palliative and end-of-life care where possible in parallel.

Beyond this review there are opportunities for improvement across the wider palliative care landscape

We also want to raise awareness of the importance of palliative and end-of-life care in general, and discuss what we want to see in the future from high-quality, safe, community-based specialist palliative care for adults, which also delivers an excellent patient experience. We want to:

- Make sure everyone receives the care they need, when they need it, regardless personal characteristics such as their gender, ethnicity, social standing or where they live (this is known as equity of access), and improve the quality of care our residents and their families and carers receive.
- Improve the experience for our patients, and their families and carers, by developing services that reflect what is important to them at the end of their lives, from diagnosis through to death.

We are not reviewing children's and young people's palliative and end-of-life care services, community nursing which provides generalist palliative and end-of-life care services, or acute hospital services which provide specialist palliative care services.

However, we will be working hard to make sure that our work links closely and joins up with hospital specialist palliative care and all other generalist palliative and end-of-life care services in North West London. We will also work with a number of NW London ICS's other service-improvement initiatives that are already looking to reduce differences in and improve the quality of non-specialist (generalist) palliative and end-of-life care services. This includes the NW London Community Nursing Review and NW London Enhanced Health in Care Homes programme.

Difference between generalist and specialist palliative care

Palliative and end-of-life care can be generalist or specialist. By community-based specialist palliative care services, we mean care and support services that are not provided in an acute hospital, GP surgery or by district nurses or community matrons. Instead, they are provided in a patient's own home, a care home, a hospice, a community hospital or health centre by specially trained multi-disciplinary teams.

Specialist palliative care professionals, such as palliative care doctors, nurse specialists, therapists and psychologists, are experts in providing palliative and end-of-life care and have specific training and experience. They usually become involved in a patient's care to help manage more complex care problems that go beyond the expertise and knowledge of a patient's generalist and usual care team (for example, their GP and district nurses). They work closely with the patient's GP and district nurse to offer advice on controlling pain and managing symptoms, provide emotional and practical support for patients, their loved ones and carers in preparing for the end of their life and, after the patient dies, offer bereavement support to their loved ones.

Generalist palliative and end-of-life care is provided on a day-to-day basis by many health and social care professionals, such as GPs, district nurses, social workers and care home staff. A patient's family and carers can also provide generalist palliative and end-of-life care in the patient's home.

We are starting by ensuring a shared view of the different issues that we are trying to solve

There are eight broad reasons why we need to improve the way we deliver our community-based specialist services to ensure everyone receives the same level of high-quality care, regardless of their circumstances.

1. To build on the valuable learning and feedback received from previous reviews of palliative and end-of-life care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster, and the further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.
2. To bring services in line with national policy such as the national Six Ambitions for Palliative and End of Life Care and the NHS triple aim of improving access, quality and sustainability, and to make sure providers our aligned to the National institute of Care and Excellence (NICE) guidelines for palliative and end-of-life care services.
3. To meet patients' changing needs arising from changes in the population. By 2040, the number of deaths within England and Wales is expected to rise by 130,000 each year. More than half of the additional deaths will be people aged 85 or older, so there will be an increased need for palliative and end-of-life care services.
4. To reduce health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.
5. To make sure that everyone receives the same level of care, regardless of where they live. At the moment there are differences in the quality and level of community-based specialist care that patients, families and carers across North West London receive. This means that depending on where a patient life, they and their family and carers may not get the support they need, and

may not be able to have their wishes supported at the end of their life. We want to do all we can to make sure this is not the case.

6. To make it easier for people to access services, particularly across our more diverse communities. Some of our services are not joined up and do not work well together, and we need to change this.
7. To cope with the increasing financial challenge, the NHS is facing and the effect this has on community-based specialist palliative care.
8. To reduce the difficulty, we are having finding, recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services.

3 Pembridge Palliative Care Service

A number of our boroughs have a particular interest in the future of Pembridge Palliative Care Service provided by CLCH

When Pembridge inpatient unit was suspended in 2018 we committed to completion of the review prior to any decisions being made on the future of this unit. It is regrettable that the period of time where we have focused on Covid response and recovery has impacted on the timeline for completing this work. Whilst acknowledging the local frustrations on the lack of clarity for the future, we remain committed to do this review properly so there is a clear process and transparency on next steps.

Pembridge Palliative Care services during Covid pandemic waves one and two

As part of a system response to support Covid-19 patients the Pembridge inpatient beds were designated to support the rehabilitation and care of Covid positive patients.

- During the first wave the inpatient unit was opened on 20 April 2020 and closed again on 30 July 2020.
- During the second wave the inpatient unit was opened on 16 November 2020 and closed on 26 March 2021.

Other service elements of the Pembridge Palliative Care Services were operating as follows:

- The community specialist palliative care team continued to offer a 7 day a week service running 8.30am to 5pm Monday to Friday, 9am to 5pm Saturday, Sunday and Bank holidays. The community team were prioritising patients with uncontrolled complex symptoms that have not responded to previous treatments, and actively dying patients with no previous plan of care in place.
- 24/7 advice line including specialist palliative care consultant support.
- Day hospice and patient attendances to the hospice were suspended. Patients known to the service were receiving telephone advice and support from the clinical team.
- The social work and bereavement team suspended visiting and outpatient sessions, but continued to operate, receiving new referrals and providing telephone advice and support.
- The Pembridge teams moved to video conferencing services where possible to further support patient care.

Pembridge Palliative Care service now

The Pembridge Palliative Care Services inpatient unit remains suspended, but the following other services elements continue to be provided:

- Community specialist palliative care nursing team, seven days a week visiting service 8.30am - 5pm Monday to Friday, 9-5 weekends (Saturday and Sunday) and Bank Holidays.
- 24/7 advice line including palliative care consultant support.

- Rehabilitation team support -visiting and virtual from Occupational Therapist (OT), Physiotherapist (PT) and Rehabilitation Assistant five days a week (Monday – Friday).
- Social work and bereavement support, five days' week (Monday –Friday);
- Day Hospice Services Monday – Friday - During Covid there was a period of time that the day centre activity had to be closed for infection control reasons but as many of these services as possible were offered virtually.

NW London ICS End of Life programme team monitors the number of patients who would have been eligible for inpatient care at Pembridge and instead are supported in a different unit. During 21/22 (extrapolated from nine month's data) this was 25 patients. Largely, these patients receive care at St John's Hospice which is part of the St John and St Elizabeth's Hospital and located in St Johns Wood, with a much smaller number at Royal Trinity Hospice. Further work needs to be undertaken to understand if the service closure has resulted in a fall in the number of patients accessing inpatient beds, as well as the impact of Covid-19 across all hospices as a whole.

Over the recent Covid outbreaks our NW London hospices and other community specialist palliative care services have shown considerable flexibility and joint working to provide system support, such as flexing criteria to support discharges. We have consistently had spare bed capacity in NW London hospices (with the exception of a short period during the recent Omicron variant where staff sickness impacted across health and social care services).

In July 2021 prior to relaunching this North West London wide review of community – based specialist palliative care, a number of palliative medicine consultant vacancies arose across three of our palliative care providers, including Pembridge Palliative Care Service, St John's Hospice and Imperial College Healthcare NHS Trust (ICHT). We undertook project work with these providers to review the service requirements for their consultants and how these might be met through new models of consultant service delivery for specialist palliative medicine within community, hospice and hospital domains to ensure a more resilient and sustainable workforce collaboratively. As part of this work we looked to identify if there was, two years on any other potential solutions to the Pembridge consultant workforce challenge to support safe running of the inpatient unit.

Through this work we engaged with a number of NHS Trusts and hospices, both inside and outside of North West London on their consultant models. We learnt that flexibility, rotation between care domains, career progression, being part of clinical network and organizational culture are all important in attracting and retaining consultants. It was also noted that across London and nationally there are palliative care consultant workforce vacancies and shortages, with many organisation struggling to fill and retain these posts.

Despite substantial input from all partners on this work, at that time we could not identify any collaborative solutions that did not destabilise one service to stabilise another. The outcome was that each organisations proceeds to recruit independently to the posts, as the solution would need more dynamic transformation work to address the palliative care workforce challenge, which is not just synonymous to these three organisations. This issue would therefore best be addressed within the North West London wide community-based specialist palliative care review

programme and development of a new model of care, including palliative care workforce.

We reiterate that no decision has been taken on the long-term role of Pembridge and as part of this review the important function that is inpatient palliative care will be addressed. We also recognise the impact this has on individuals and families of those who need to use alternative services elsewhere.

Community palliative and end of life care services activity since suspension of Pembridge palliative care inpatient unit

We previously reported that resources and staff from the Pembridge inpatient unit have been redirected to community services provision to enable more residents to be cared for / supported at home. Councillors asked about the levels of activity of these services as result of this redirection of this resource. Having looked at CLCH's data for community district nursing and Pembridge's community specialist palliative care services we can confirm that there has been an increase in community activity from Pembridge's community palliative care services.

Looking at the average contacts per year prior to the suspension of the inpatient unit (2017/18 & 2018/19) and after the suspension (2019/20, 2020/21 and 2021/22).

- There is a 20% increase in activity for the community specialist palliative care team, this is above the general growth in district nursing activity (6%) for the same period.
- There is a 34.5% increase in activity for Pembridge day hospice services.

We would all acknowledge that during 2020 and 2021 all services were impacted by Covid, particularly face to face services, and that data comparisons should be viewed with this lens.

The modelling that has been undertaken for future CSPC service development utilises data covering this period of increased activity.

This shift to increased provision in residents own homes is mirrored across all providers – and also reflects strongly the messages we have heard from residents – that many would want to be in their own homes as long as the right and responsive care is in place to support them.

4 NW London Hospice and community-based specialist palliative care services workforce information

At the Hammersmith & Fulham Health and Adult Social Care Policy and Accountability Committee, on 20 July 2022, a request was made for the NW London Community-based Specialist Palliative Care review programme team to share the workforce information for these services at the next committee meeting they attended.

Wider National and Local Context:

- There are national and regional challenges in recruiting and retaining both consultant and clinical nurse specialist (Band 7) workforce, which is one of the main issues driving the need for this NW London review, as laid out in the issues paper published in November 2021.
- Although some of the hospices have managed to recruit into some of their vacant posts over the past couple of months, including Consultants, it is important to note that the workforce for our providers is constantly changing.
- Some of the roles work across the various service lines e.g. a consultant or medic working in a hospice inpatient unit may also support the community Specialist Palliative Care (SPC) team for that organisation or an acute hospital as part of their on-call arrangements; a therapist may support inpatient hospice care as well as outpatient services and community SPC team. This level of detail of workforce cross working arrangements has not been included in the information that follows below.
- Some of the hospices provide services across multiple ICSs and not just to NW London i.e. Royal Trinity Hospice, ST John's Hospice and Marie Curie London.

The review underway and development of the new model of care aims to explore collaborative solutions to addressing these workforce challenges to support commissioning and delivery of sustainable, safe, high quality and equitable services for the foreseeable future. The workforce solutions and new model of care work is taking learning from the Covid-Pandemic and recent NHS workforce pressures and includes:

- Rethinking service delivery and future ways of working to meet the rapid growth in demand on services
- The ability to train and upskill staff, increasing a skilled workforce able to deliver high quality and effective clinical care, staff working at the top of their licence.
- More integrated ways of working across services, and ways to increase access to these services for all, particularly our underserved populations.
- Strategy to address immediate and longer term ongoing shortages among critical groups of staff ie. Consultants and Clinical Nurse Specialists

For the providers of these services for NW London (five charitable hospices and three NHS Community Trusts) the workforce information is as follows as of March 2022.

Workforce to deliver hospice inpatient units across NW London.
The roles and responsibilities, banding (NHS agenda for change) and WTE for the staff groups that provide hospice inpatient unit care is as follows:

Staff group	Roles and responsibilities	Banding (AfC)	WTE
Consultants	Named consultant assumes overall clinical responsibility for each patient and completes regular ward rounds. Typically have programmed activities (PAs) split between clinical and non-clinical time – for the purposes of this business case, only clinical PAs have been considered	N/A	4.9
Junior Doctors	Support consultant workforce by completing day-to-day medical jobs, including patient reviews and ward rounds. Junior doctors include doctors from senior house officer level to registrar level and is inclusive of non-training (clinical fellows) and training grade doctors	NA	8.1
Clinical Nurse Specialists	Provide specialist advice and support to patients with high degrees of medical and social complexity. Able to train as nurse prescribers, allowing them to prescribe a range of medications for patients without doctor input. Proportion will have an area of subspeciality	7 and 8+	4.3
Registered Nurses	Provide generalist nursing to patients (i.e. not specialist). May have received additional palliative care training to provide 'specialist-like' services	5 and 6	50.4
Healthcare Assistants	Provide care support to patients. May have received additional palliative care training	2 – 4	33.2
Other Health Professionals	Occupational therapy, physiotherapy, pharmacy services	7	0.08*
Management	Non-clinical function of oversight / managerial work		
Admin	Non-clinical function of administrative work	2 – 4	1.2
Other	Social worker	7	0.03*

*Data only supplied by Marie Curie Hospice

There are specific challenges in the recruiting and retainment of both consultant workforce and clinical nurse specialists. As such options for the future model of care will present opportunities to address these challenges, through models that re-engineer the workforce.

Workforce to deliver community-based service lines

The workforce to deliver community-based service lines vary based on the service scope and specification. The workforce, banding and WTE (not scaled to NWL commissioning) for each service line across NWL is as follows:

Banding (AfC)	WTE

		Community SPC Team	Day Hospice	Outpatients	Psychological Support & Bereavement	Hospice @ home	24/7 SPC	Rapid Response	Total
Consultant	N/A	2.4	0.1	0.1	-	-	0.5	-	3.1
CNS	7 and 8+	64.1	2.0	3.0	-	0.8	1.0	8.5	79.4
RNs	5 and 6	8.8	2.8	1.6	-	6.1	4.6	2.9	26.7
HCA	2 - 4	-	1.0	5.8	-	9.9	0.0	4.8	21.5
AHP	3 - 8	1.1	-	17.1	4.7	-	-	-	22.8
Administrators	3 - 5	4.2	-	1.4	0.4	1.0	-	2.0	9.0
Managers	5 - 8	0.8	1.0	0.4	0.2	1.0	-	-	3.4
Other	3 - 7	-	-	4.5	11.0	-	-	-	15.5

The workforce model in community-based service lines utilise additional staff groups than IPU;

- Allied Health Professionals (AHP) to provide services including Clinical Psychologists, Psychotherapists, Occupational Therapists, Physiotherapists and Complimentary Therapist
- Rehab assistants to support the physiotherapists
- Psychosocial teams including bereavement coordinators and spiritual care advisors
- Social workers and social support staff

5 Demographics of Community-based Specialist Palliative Care services users for NW London

Overview of the data

From the outset it is important to articulate transparently that palliative and end of life data availability and reliability are a challenge. The data we have comes from multiple sources and there is no national data set. There is also a wide variation in what data our providers collect and how they do this, so we do not have an overarching view of the provider data. This is particularly true for patient/service user demographic data. We do however have some elements of data, alongside the feedback from our residents and our different communities, that can help inform our new model of care. One of the priorities of the Community-based specialist palliative care (CSPC) review programme work is to ensure a common data set, that includes demographics, across all our providers. A longer term goal of the last phase of life programme is also to have all the data joined up and in one place.

The CSPC review programme is currently developing our future model of care, looking at current service activity data across all care domains, the data available on numbers of deaths in NW London and any demographic information related to these deaths, as well as the workforce we currently have in our community specialist teams. This will involve review of any other demographic data available about the NW London population. In conjunction with a review of the literature around capacity and ultimately the agreed new model of care and single common offer/ service specification, this work will allow us to articulate what our future services capacity needs to be and see where our resource needs are greatest across NW London.

NHS North West London and this programme is committed to promoting equality and diversity amongst all our staff, stakeholders and patients - fulfilling our obligations under the Equality Act 2010 and the associated guidance from the Equalities and Human Rights Commission. We aim to commission healthcare services that are equitable to everyone regardless of:

- Age
- Disability
- Gender-reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race, ethnicity or national origin
- Religion or belief
- Gender
- Sexual orientation
- Domestic circumstances
- Trade union membership (or non-membership)
- Socio-economic or employment status

We will be fully transparent with this work and share our outputs and recommendations with relevant stakeholders to support decision making.

Mortality data and demographics

We have utilised the mortality data from 2021 to give an indication of where residents who have died by setting of care and the current demographic data that is also available around this.

Figure 1 shows a breakdown of all deaths in North West London by setting. Clearly the majority of people died at hospital, whilst a secondarily large number died at home.

Figure 1: Number of deaths and place of death for 2021 for NW London - split by borough

	Deaths					
Commissioner	Care Home	Home	Hospice	Hospital	Other	Total
Brent	209	622	117	1,141	66	**2,155**
Ealing	300	702	132	1,251	72	**2,457**
Hammersmith and Fulham	119	357	41	496	52	**1,065**
Harrow	197	569	89	921	40	**1,816**
Hillingdon	423	591	110	1,028	58	**2,210**
Hounslow	153	503	69	941	103	**1,769**
West London	107	398	44	606	55	**1,210**
Central London	94	217	64	426	101	**902**
NWL	**1,602**	**3,959**	**666**	**6,810**	**547**	**13,584**

Figure 2: Percentage of deaths in NW London by place of death

	Percentage of Total Deaths				
	Care Home	Home	Hospice	Hospital	Other Places
Brent	10%	29%	5%	53%	3%
Ealing	12%	29%	5%	51%	3%
Hammersmith and Fulham	11%	34%	4%	47%	5%
Harrow	11%	31%	5%	51%	2%
Hillingdon	19%	27%	5%	47%	3%
Hounslow	9%	28%	4%	53%	6%
West London	9%	33%	4%	50%	5%
Central London	10%	24%	7%	47%	11%
NWL	**12%**	**29%**	**5%**	**50%**	**4%**

Figure 3: Health Borough Comparison - Deaths in NW London boroughs by age, gender, deprivation decile, cancer vs non cancer, top 10 causes of death and top 10 countries of birth

Note: A decile is a dimension which places the deprivation scores of individual areas into one of ten groups of equal frequency. The deprivation decile 1 represents the most deprived and deprivation decile 10 represents the least deprived.

Health Borough Comparison

dod_Year: 2021 — <-- Select the filters to change the table below

Place of Death: (All) — Cells highlighted red are greater than the NWL percentages

	Brent	Central London	Ealing	Hammersmith and Fulham	Harrow	Hillingdon	Hounslow	West London	NWL
Age									
<65	23.4%	19.1%	22.1%	24.5%	15.9%	16.8%	21.9%	18.0%	20.2%
65-74	16.6%	16.7%	16.7%	17.4%	15.1%	17.6%	19.2%	16.2%	17.0%
75-84	25.5%	26.4%	28.6%	27.3%	28.0%	27.1%	27.1%	30.4%	27.5%
85+	34.6%	37.8%	32.6%	30.8%	41.0%	38.5%	31.8%	35.4%	35.3%
Gender									
Female	44.6%	47.8%	45.3%	46.7%	49.9%	49.3%	47.3%	44.9%	46.9%
Male	55.4%	52.2%	54.7%	53.3%	50.1%	50.7%	52.7%	55.1%	53.1%
Deprivation									
1	8.6%	19.3%	4.4%	7.5%	0.1%	0.1%	1.0%	15.5%	5.6%
2	14.5%	13.4%	14.8%	13.3%	2.0%	2.7%	10.2%	21.4%	10.9%
3	16.4%	17.5%	19.6%	25.3%	5.5%	21.5%	18.9%	13.5%	17.2%
4	22.5%	11.1%	13.7%	13.8%	6.6%	12.4%	19.0%	10.6%	14.2%
5	15.9%	11.1%	14.9%	13.5%	15.6%	9.2%	19.9%	7.7%	13.9%
6	13.5%	14.6%	14.7%	11.3%	16.4%	12.0%	17.6%	13.2%	14.3%
7	5.3%	9.6%	7.8%	7.8%	19.6%	10.2%	9.7%	11.2%	10.0%
8	2.2%	3.1%	3.6%	4.3%	13.3%	10.2%	3.2%	6.4%	6.0%
9	0.7%	0.2%	6.4%	3.2%	10.2%	13.9%	0.6%	0.6%	5.3%
10	0.2%	0.0%	0.0%	0.0%	10.7%	7.7%	0.0%	0.0%	2.7%
Cancer vs Non-Cancer									
Cancer	23.4%	28.0%	23.0%	23.1%	22.7%	24.7%	21.9%	25.6%	23.7%
Non-Cancer	76.6%	72.0%	77.0%	76.9%	77.3%	75.3%	78.1%	74.4%	76.3%
Top 10 ICD 10 Codes									
Emergency use of U07.1	41.0%	41.2%	36.5%	35.3%	36.2%	37.2%	40.8%	38.1%	38.2%
Chronic ischaemic heart disease,	15.2%	9.7%	10.7%	9.6%	15.2%	8.7%	7.9%	8.7%	11.0%
Unspecified dementia	9.1%	12.4%	11.6%	11.3%	11.2%	11.7%	11.1%	9.0%	10.9%
Malignant neoplasm: Bronchus or	7.1%	11.6%	8.3%	12.0%	8.2%	10.8%	9.7%	12.5%	9.5%
Acute myocardial infarction, unsp	8.7%	6.6%	8.3%	6.6%	9.5%	7.8%	8.5%	8.8%	8.3%
Stroke, not specified as haemorrh	5.2%	4.7%	4.1%	6.4%	5.7%	5.7%	7.1%	5.9%	5.5%
Malignant neoplasm: Breast, unsp	3.5%	5.0%	5.1%	5.4%	4.0%	5.1%	3.2%	5.7%	4.5%
Atherosclerotic heart disease	2.3%	1.9%	5.6%	7.6%	2.5%	5.3%	6.1%	4.1%	4.5%
Pneumonia, unspecified	4.4%	2.8%	5.3%	2.9%	4.6%	2.8%	2.7%	3.1%	3.8%
Alzheimer disease, unspecified	3.5%	4.1%	4.5%	2.9%	2.8%	5.1%	2.8%	4.1%	3.8%
Top 10 Countries of Birth									
England	37.4%	76.6%	51.3%	66.9%	57.3%	76.8%	64.0%	73.7%	61.0%
India	20.3%	3.6%	18.6%	5.4%	16.3%	7.9%	16.8%	3.2%	13.3%
Ireland	13.7%	8.0%	9.2%	13.9%	6.8%	5.6%	4.8%	8.8%	8.4%
Kenya	6.3%	1.4%	3.5%	0.6%	7.9%	1.7%	3.5%	0.6%	3.7%
Jamacia	12.3%	1.0%	2.7%	3.7%	2.2%	0.6%	0.7%	3.2%	3.3%
Pakistan	3.2%	1.0%	3.8%	1.0%	1.6%	1.4%	3.8%	1.3%	2.4%
Scotland	1.1%	4.4%	2.4%	4.0%	1.5%	1.9%	2.0%	4.7%	2.3%
Poland	2.0%	1.3%	4.8%	2.4%	1.1%	0.9%	1.9%	1.6%	2.1%
Sri Lanka	2.7%	0.4%	2.2%	0.6%	4.0%	1.0%	1.1%	0.7%	1.8%
Wales	1.1%	2.2%	1.5%	1.7%	1.3%	2.2%	1.4%	2.1%	1.6%

Figure 2 (above) shows deaths by borough and NW London average split by age, gender, deprivation decile, cancer vs non-cancer, top ten causes of death and top ten countries of origin. We do not have within our data set the ability to split the death data by ethnicity. Where highlighted red this indicates that the proportion is above the NWL average.

For NW London death rates amongst the deciles 3 and 4 are generally higher, but there are boroughs for example Brent and Central London where there is higher level of deaths amongst the most deprived residents compared to other boroughs like Hillingdon where the highest level of deaths is at decile 9. In terms of age, for NW London the highest rate of death is amongst the over 85s whereas for some boroughs,

Brent, Ealing, Hammersmith & Fulham and Hounslow there are a higher proportion of deaths in the under 65s. NW London's average shows a higher proportion of men dying than women. Interestingly for NW London roughly two-thirds (76.3) of deaths are non-cancer related, with Central London borough having a higher rate of cancer deaths than the rest of the boroughs and NW London average.

The bottom of Figure 2 and Figure 3 (below) shows the top 20 countries of birth for those that died in NW London in 2021. This has limitations as there is significant ethnic diversity amongst those born in the UK, however, it does give a level of insight, for example a significant proportion of deaths were amongst the Indian community and also fairly high amongst the Irish and Jamaican community.

Figure 4: top 20 countries of birth

NW London population demographics and health inequalities at a glance[1]

Health inequality is a major problem for North West London. People in less well-off areas are more likely to have a disability and/or be living with a long term condition. People from a Black, Asian or other ethnic minority background are more likely to live in less affluent areas, as are people who are less well educated or working in lower paid jobs. People from these populations can find it harder to access healthcare, receive a high quality service and get a good health outcome. They have fewer opportunities for better paid jobs. The Covid-19 pandemic has both increased health inequality in North West London and shone a spotlight on it.

[1] NW_London_ICS_-_Addressing_Inequalities_across_NW_London_July_2022.pdf (nwlondonics.nhs.uk)

North West London has a diverse population of over 2.4 million people across eight London boroughs, comprised of over 173 wards and served by over 470 councillors. We have over 360 GP practices arranged into 46 Primary Care Networks, and 12 hospitals, including two major mental health providers. North West London benefits from a diverse population. More than 50% of the population in some of our boroughs come from a black, Asian and other minority ethnic (BAME) background.

Below is an Illustration of some of the key challenges NW London faces

Long term conditions

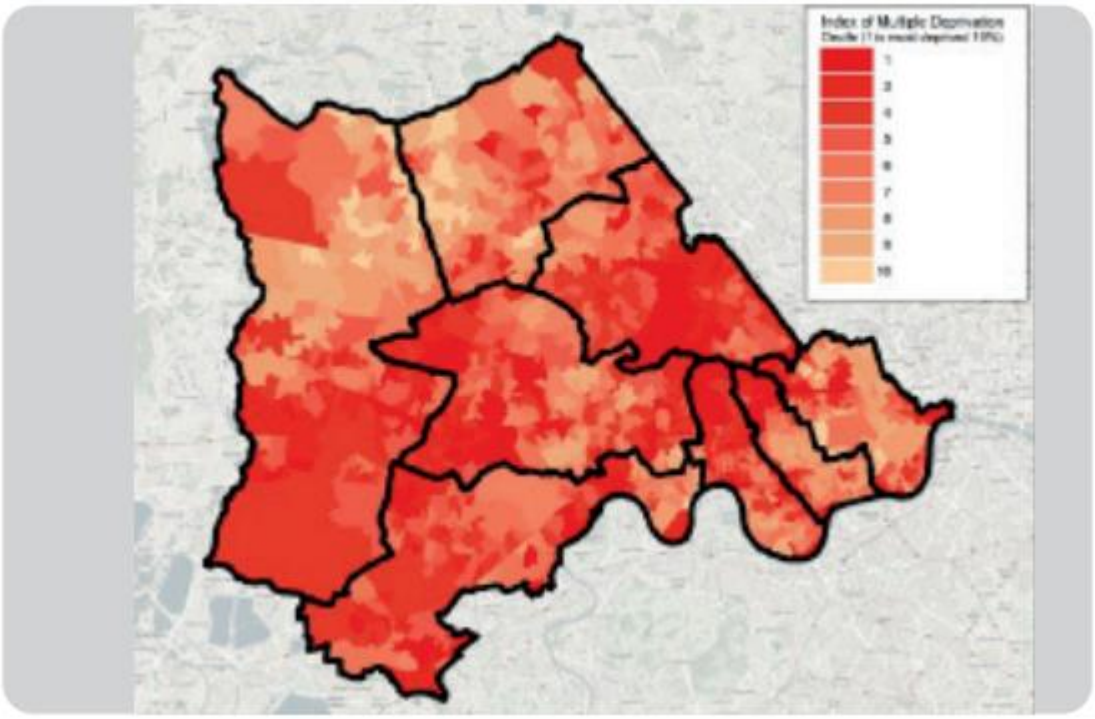
21% One in five (21%) of our population is classed as having complex health needs.

16% of the population has one or more long term condition.

Our data and information tells us some of our most prevalent long term conditions across North West London include:

Hypertension | Diabetes | Obesity | Anxiety and Depression | Sickle Cell

This graphic to shows the levels of deprivation across the 8 North West London ICS boroughs. The darker the red, the more deprived that areas is.



An Index of Multiple Deprivation (IMD) is used to identify how deprived an area is. It uses a range of economic, social and housing data to create a single deprivation score for each small area of the country.

Figure 5. Unique patient activity for Community-based specialist palliative care services by provider for 2021

	St Luke's Hospice	Marie Curie London	Harlington Hospice including MSH	Royal Trinity Hospice	St John's Hospice	Meadow House Hospice (LNWH)	Pembridge (CLCH)	Harrow CSPC Team (CLCH)	Hillingdon CSPC Team and Your life Line service (CNWL)
Hospice inpatient unit	206	15	181	91	162	307	N/A	N/A	N/A for either service
Community SPC Team	584	N/A	N/A	754	455	1805	1062	499	1,486
Day hospice services (social activities)	0	N/A	N/A	N/A	60	N/A	19	N/A	N/A
Outpatients (Specialist appointments)	29	19	319	N/A (Covid)	397	190	N/A	N/A	N/A
Bereavement	49	14	N/A	73	165	156	49	N/A	N/A – separate service
Psychological Support	0	N/A	273	144	279	N/A	N/A	N/A	117
Hopsice@home	230	514	154	N/A	126	N/A	N/A	N/A	N/A
24/7 SPC advice line	1229	N/A	147	169	TBC	Data not available	TBC	N/A	N/A for Hillingdon Community SPC team. Your life line (YLL) 24/7 service has 24/7 advice line offer visits overnight (not daytime) to known patients only – data TBC
Rapid response	108	796	N/A	N/A	N/A	N/A - Marie Curie London provide Rapid Response	N/A	N/A	801

Please note for above activity data the way in which the data has been captured is slightly different provider to provider, and the providers have different service configurations and offers so a direct comparison is not advised

The below information is a snapshot example of the patient/service user demographics data that we receive from one of our providers, Royal Trinity Hospice, for services commissioned across three of our boroughs – Central London, Hammersmith & Fulham and West London. As mentioned above we currently do not have this data from all our providers and are work aims to ensure we receive this data consistently and in more detail going forward.

EXAMPLE - ROYAL TRINITY HOSPICE Quarter 4 Report for 2021-2022: Patient information for Central London, Hammersmith & Fulham and West London

Hammersmith & Fulham Borough Patient information: January – March 2022

Ethnicity

	Q4 All Services		YTD All Services	
	No	%	No	%
Asian/Asian British - Indian	0	0%	0	0%
Asian/Asian British - Pakistani	1	1%	1	0%
Asian/Asian British - Bangladeshi	0	0%	0	0%
Asian/Asian British - Chinese	1	1%	1	0%
Asian/Asian British - Other background	0	0%	8	3%
Black/African/Caribbean/Black - Other background	7	7%	17	7%
Mixed/Multiple - White and Black African	1	1%	1	0%
Mixed/Multiple - White and Asian	0	0%	0	0%
Mixed/Multiple - Other background	2	2%	3	1%
Other ethnic group - Arab	0	0%	2	1%
Other ethnic group - Other background	1	1%	4	2%
White - English/Welsh/Scottish	54	51%	129	52%
White - Irish	8	8%	19	8%
White - Other background	18	17%	33	13%
Not given	13	12%	31	12%

Age

	Q4 All Services		YTD All Services	
	No	%	No	%
19-24	0	0%	0	0%
25-64	27	25%	42	17%
65-74	14	13%	41	16%
75-84	28	26%	78	31%
85+	37	35%	89	36%

Gender

	Q4 All Services		YTD All Services	
	No	%	No	%
Male	45	42%	101	40%
Female	61	58%	149	60%

Diagnosis

	Q4 All Services		YTD All Services	
	No	%	No	%
Cancer	66	62%	163	65%
Non-cancer	40	38%	87	35%

6 Building on feedback previously given

We must build on feedback previously given – valuing people's time and views, by showing progress wherever possible

When we talked to people about community-based specialist palliative care services previously, we heard what a crucial role the services play. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We have also heard that services need to be made available to more people 24 hours a day, particularly that out-of-hours services (those provided between 5pm and 9am) need improving to make them more inclusive and adaptable, and to offer more choice and be more co-ordinated. People told us it is important to improve access to these services so more people receive care and are supported to die in their preferred setting, whether this is at home, in a hospice or in hospital. It is also important that people don't have to travel too far to access service.

> Mum wanted to die at home and was told that there were drugs that would be needed and they'd arrange for these to be prescribed. I then got a call from the palliative care team the next day to tell me they'd sent the prescription to mums nominated chemist. When I got there, I was told one item wasn't in stock and they'd order it. When I got outside I realised it was the pain relief which is what I needed the most and I had to run around trying to get it."
>
> **Example from a bereaved resident on the challenges of integrated care**

The feedback showed that people have different views on how we should make these improvements. We want to build on the feedback and what we have learnt from it. We also want to fully understand the role culture and religion can play in influencing the way people relate to their health, the support they want to receive and the way they experience loss and grief. We will then use this insight to develop services that can take this into account.

7 Engagement in Hammersmith and Fulham and NW London

We have arranged a number of events and webinars in Hammersmith and Fulham and NW London as a whole, attended external meetings and arranged numerous one on one interviews with local residents with lived experiences and representatives of the voluntary, community and faith sectors. This engagement will continue throughout the length of the review.

Engagement in Hammersmith and Fulham

Event	Boroughs	Date
BME Health Forum Director interview	Hammersmith & Fulham, Kensington & Chelsea and Westminster	08 February 2022
SOBUS Community Lead interview	Hammersmith & Fulham	10 February 2022
Public involvement event with a focus on ethnic minorities	Westminster, Kensington & Chelsea, Hammersmith & Fulham	15 March 2022
Hammersmith and Fulham Integrated Care Partnership end of life meetings	Hammersmith & Fulham	8 March & 3 May 2022
Hammersmith and Fulham Integrated Care Partnership Event	Hammersmith & Fulham	11 May 2022
Hammersmith & Fulham Health and Adult Social Care Policy and Accountability Committee	Hammersmith & Fulham	20 July 2022

A number of stakeholders submitted written responses via email to the engagement. All the stakeholder responses have been considered and responded to.

Hammersmith and Fulham Save our NHS (HAFSON) provided a number of submission and emails throughout the engagement period including a detailed response.

We thank them for these and the positive comment on the approach being taken.

"HAFSON would want to acknowledge that the NW London CCG has, in preparing their engagement documents, dated November 2021, taken into account the earlier engagements including the serious concerns at the proposed permanent closure of the inpatient beds at Pembridge. We also note that there were a number of other widely shared concerns about the kind and quality of palliative care available to residents in this part of NW London. We are pleased that these concerns have not been side-lined in these papers."

However, HAFSON did express concern about the limited focus on 'community-based specialist palliative care' across NW London.

"From a resident, patient and carer perspective – and possibly from the perspective of many providers – palliative care needs to be considered as a totality."

HAFSON commented in detail on a number of areas.

Patient choice

- Many people wish to die at home in the company of family, friends and/or people they trust and services need to be organised to allow that to happen.
- Many people who say they wish to die in a home setting, may change their minds about their desired place of death as their health condition deteriorates and services need to flexible enough and have enough capacity to be able to manage this.
- More people are living on their own and are isolated and services need to be capable of supporting this situation.

Demographics and health Inequalities

- Palliative care should be able to provide many different kinds of help to isolated people but must also be able to facilitate speedily a transfer to another care setting such as a care home, hospice or hospital when home care becomes inadequate.
- LGBTQ+ people are often overlooked because they do not belong to 'traditional' families.
- Services need to take into account of the fact we have an aging population and that much palliative care is carried out by an elderly person looking after another elderly person who themselves may not be very well.
- The need to take into account the needs of carers including physical and mental health needs.
- The question of gender inequality with women living longer than men, being main carers and more likely to live in poverty.
- More needs to be done to recruit staff from diverse backgrounds and training needs to take into account diversity.
- Palliative care planning needs to make sure it takes into account diverse communities and the fact they are more likely to live in poverty and poor housing conditions.

Respite/rehabilitation

- There is passing reference to respite care and none to rehabilitation. Both are needed with respite in particular being important for the carer and often the difference between them being able to manage.

Travel and access

- In looking at service provision it is important to look at public transport/access taking into account cost and time, with poorer communities most effected. It is essential that care is provided in communities.

NHS provision

- In developing the new model of care, HAFSON would like to see a greater development of direct NHS provision.

Data and realism

- Accurate data on bed numbers, staffing, adequacy of current services etc. is needed to inform the development of the model of care.

The full HAFSON submission and our response is available in the interim engagement report here:

https://www.nwlondonics.nhs.uk/application/files/4616/5469/7513/20220608_CSPC_interim_engagement_outcome_report.pdf

Engagement in rest of NW London

Event	Boroughs	Date
Hounslow Integrated Care Patient & Public Engagement (ICPPE) Committee	Hounslow	07 December 2021
Public involvement event	NW London wide	13 December 2021
NW London Joint Health and Overview Scrutiny Committee	NW London wide	14 December 2021
Older people's Engagement at the Pavilions Shopping Centre in Uxbridge	Hillingdon	28 January 2022
BME Stakeholder Event	Kensington & Chelsea and Westminster	22 February 2022
North Kensington Health Partners	Kensington & Chelsea	03 March 2022
RBKC Adult Social Care and Health Select Committee	Kensington & Chelsea	03 March 2022
Trustee, Kosher Dementia UK	NW London wide	04 March 2022
Public involvement event with a focus on ethnic minorities	Hounslow and Ealing	10 March 2022
Hounslow and Ealing Integrated Care Partnership Engagement Event	Hounslow and Ealing	17 March 2022
Public involvement event with a focus on ethnic minorities	Brent, Harrow and Hillingdon	17 March 2022
Public involvement event feeding back what we have heard so far and actions we have taken as a result	NW London wide	18 March 2022
Westminster Workshop on homelessness	Westminster	May 2022
Harrow Palliative Care and End of Life Webinar	Harrow	11 May 2022
Come and help us shape the end-of-life care in Brent	Brent	15 June 2022
Spectra CEO interview	NW London wide	21 June 2022
Brent Community and Wellbeing Scrutiny Committee	Brent	05 July 2022
Come and help us shape end-of-life care in Kensington and Chelsea and Westminster	Kensington & Chelsea and Westminster	12 July 2022

A conversation with a carer and spokesperson for people with dementia	NW London	19 July 2022
A conversation with a carer of someone living with dementia	NW London	22 July 2022
A conversation with the team lead for St Luke's Hospice about caring for someone living with a mental illness	NW London	22 July 2022
Dementia Group for Hounslow	Hounslow	25 July 2022
North West London Joint Health and Overview Scrutiny Committee	NW London	12 October 2022
Biborough PEOLC delivery group	Kensington & Chelsea and Westminster	29 November 2022
Royal Borough of Kensington and Chelsea Adult Social Care and Health Select Committee	Kensington & Chelsea	29 November 2022
Hounslow BBP patient and public engagement committee	Hounslow	20 December 2022

We have committed to transparent and meaningful engagement at every stage of the work

We also linked in with experts both locally and nationally in certain areas including learning disabilities and homelessness. Their advice led us to carry out two literature reviews for people living with homelessness and people living with a disability which have been published and used as evidence in the review.

During the first stage of public engagement on the NW London adult community-based specialist palliative care (CSPC) review, it was suggested that younger adults (approximately 18-45) may have specific needs that were not being fully considered.

NW London hospices and stakeholders were asked through the Model of Care Steering Group to provide any specific insights and advice for this age group and desk research was also undertaken, reviewing the information published by health providers, charities and journals leading to the publication of a further literature review.

We received a large amount of feedback which we are responding to and some actions have already been addressed as a result. There are also areas we are currently developing and implementing, or propose to do so, in order to address the issues raised. Some local residents have been kind enough to share their stories so we could use them as case studies to illustrate the good experiences and the challenges that people face when using community-based specialist palliative care services, so that we can learn from their experiences.

In addition to these meetings, we developed a number of online surveys through which local residents and health and social care professionals could give their views. Open-

ended questions were also included to give respondents the opportunity to express their opinions in their own words. We also received a number of written submissions which were responded to.

It is our expectation that engagement with local residents will continue as we move forward. All boroughs have had the opportunity to be involved in a webinar or complete a survey.

All the public feedback received is being used by our model of care working group, which is responsible for co-designing the future model of care for adult community-based specialist palliative care.

Membership of this group consists of local residents who bring lived carer and patient experience, clinicians and other palliative and end of life care stakeholders. The group is being asked to:

- agree a common specification / common core offer for community-based specialist palliative care
- develop a new model of care to deliver the specification / common core offer which also facilitates tailoring in response to local need
- support the development of a long list of options for delivery of the new model of care

The work draws on the national service specification for adult palliative and end of life care, the previous NW London 4 CCGs palliative care review programme work and qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement. We also are utilising activity trend data obtained from service providers and will undertake further work looking at the structure of our services workforce.

The expected output is a set of core service standards, requirements, service line definitions demonstrating what we believe good community-based specialist palliative care looks like and co-designed principles required to successfully design and deliver the model of care across NW London. There will also be a number of additional localised requirements that the local Borough Based Partnerships will have responsibility for implementing these in view of their local context and population needs.

We will work with the Integrated Care Partnerships, local residents and stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If substantial service change is needed, we will then need to consider if a public consultation is needed.

We understand and share local residents' feedback that having good community-based specialist palliative care services is really important. In some cases, the feedback that has been provided has led us to make changes to services where possible and have plans to do some more of this via this review programme. This is detailed in an insight report where we also detail areas where we are not able to make changes.

We would like to reiterate our commitment to work collaboratively with our public, patients, clinicians and other system partners as we move forward to develop the

future model of community-based specialist palliative care for adults, which includes consideration of current services and where the locations we need our services in

1.1 Key findings from the feedback received

As laid out in the Issues Paper, there are eight broad reasons why we need to improve the way we deliver our community-based specialist services to make sure everyone receives the same level of high-quality care, regardless of their circumstances.

We have carried out an analysis of all the feedback received through the webinars, surveys, one to one conversations, meetings attended and literature reviews and grouped the feedback received against the eight broad reasons.

1. **To review the valuable learning and feedback received from previous reviews of palliative and end-of-life care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster, and the further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.**

In the previous review of community-based palliative care provision in in 2019 and 2020 we talked to people about community-based specialist palliative care services and heard what a crucial role the services play. The feedback confirmed that people value their local specialist services and would like to receive them as close to home as possible, and people with experience of these services are very positive about the care they have received. Local residents and stakeholders said they would like the NHS to reopen the Pembridge Palliative Care Unit in-patient beds following their temporary closure in October 2018 due to a lack of specialist care consultant cover and being unable to recruit due to the national shortage of trained personnel (see Section 1.2 Insight report and actions taken for further details).

We also heard that services need to be made available to more people 24 hours a day, availability of care needs to be improved during the out-of-hours periods (between 5pm and 9am) particularly, services need to be more inclusive and adaptable, offer more choice and more be more joined up. People told us it is important to improve access to these services so more people receive care and are supported to die in their preferred setting, whether this is at home, in a hospice, or in hospital. It is also important that people don't have to travel too far to access services.

The feedback showed that people have different views on how we should make these improvements. We want to build on the feedback and what we have learnt from it.

See the Palliative care services Independent review - full report Review of provision in Kensington & Chelsea, Hammersmith & Fulham and Westminster.

See the Palliative Care Services Public Engagement Report July 2020 In the boroughs of Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster.

In January 2020, Hillingdon Commissioning Group (HCCG) performed a review of End of Life Services looking at the views of general practitioners (GPs) and the lesbian, gay, bisexual, and transgender community (LGBT).

See the Review carried out on End of Life Services in Hillingdon in January 2020.

2. **To bring services in line with national policy. Such as**
    a. **the national Six Ambitions for Palliative and End of Life Care**
    b. **the NHS triple aim of improving access, quality and sustainability**
    c. **Ensure providers follow the National institute of Care and Excellence (NICE) guidelines for palliative and end-of-life care services.**

- We will utilise the learning and gaps in improvements taken from the borough and ICS level self-assessments against the six national ambitions for palliative and end of life care.
- Future community-based specialist palliative care services will need to align with national standards and guidelines.
- This includes adhering to the national service specification for community-based specialist palliative care.

3. **To meet patients' changing needs arising from changes in the population. By 2040, the number of deaths within England and Wales is expected to rise by 130,000 each year. More than half of the additional deaths will be people aged 85 or older, so there will be an increased need for palliative and end-of-life care services.**

- We will need to take into account aging population with likely increased demand on community-based specialist palliative care.
- The number of people living with dementia is increasing which brings increased complexity of care needs.
- The number of elderly people living on their own is increasing with no one to care for them. Often they can live away from their family leading to social isolation.
- This includes support for the family and carer supporting them.

4. **To reduce health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.**

- Review should look at ways of tackling the widening Health Inequalities for people who require palliative and end of life care and support service.
- Attention should be given to isolated people, those with family outside the country or in different regions, elderly couples that are physically or mentally unable to care for each other, the large number of disabled people that require specialist care and those who experience homelessness.

5. **To make sure that everyone receives the same level of care, regardless of where they live. At the moment there are differences in the quality and level of community-based specialist care services that patients, families and carers across North West London receive. This means that depending on where a patient lives, they and their family and carers may always be able to get the support they need, and may not be able**

to have their wishes supported at the end of their life. We want to do all we can to make sure this is not the case.

- Implement a 24/7 telemedicine co-ordination, advice and support service for care home staff to better support their residents at end of life.
- To improve co-ordination and navigation of care and support available, implement a single point of access (preferably a single telephone line) for patients, family, carers and clinicians to contact to obtain information about what palliative and end of life care services are available, how to access them, support with getting medication and equipment etc.
- To build flexibility into the service model that supports a person and their family to change their mind about place of care and place of death even if it is at the last minute. This could be where a person has always said they wanted to die at home but change their mind as they and the family are scared or believe it is too hard on the family who initially thought they could cope. Instead they want to go to a hospice or a hospital.
- Align GPs more closely with individual care homes and develop enhanced care services.
- Pembridge in-patient service should be reopened.
- A review of the number of hospice inpatient beds should take place.
- The number of and quality of care plans need to be improved. Patients and families need to be given access. More needs to be done to ensure health professional access the care plan routinely when seeing patients.
- There needs to be improved record keeping around preferences, treatment etc. and more needs to be done to make sure they are automatically accessed by the people providing care.
- The need to identify that someone is dying and recognise this earlier was identified as an important point that feeds directly into the patient and families choices about appropriate treatment etc.
- We need to make sure that there are wrap around care to provide support to the patient if they are to stay at home.
- Care needs to be holistic, and include clinical and non-clinical support e.g. Home adaptations, advice and support on what to do when a patient passes away.
- There is a lack of bereavement support across NW London for families and carer. A review of current provision is needed to understand what type of support is needed and how it could be delivered.
- We need to ensure we consider the impact of caring for someone who is dying on family and carers. Concerns were raised about impact on:
    - unpaid carers and those who are older
    - Those who have their own health issues and are struggling
    - Are trying to hold down employment or have kids and are busy and what that means for them trying to undertake a caring role.
- The way someone dies can have a big impact on the person caring for them and we need to ensure that support for relatives and carers continues after the person has died.
- Palliative and end of life care needs to be patient centred and the importance of family/carers/those of importance to the person being involved in decision making and kept informed.
- We need to think about how we design more integrated services, between the patient and family, the community, social care and clinical services.

- Care and support needs to be available 24/7 365 days a year (including pain relief). out-of-hours service (OOH), consider including an OOH service to impatient services to enable carers and patient seek help when needed.
- Lack of clarity for carers/family around medication. Medication for EoLC patients should be thoroughly explained to carers/family members so they are able to identify which medications are missing and act quickly.
- Family members and carers should be kept informed at every point during a patient's care pathway.
- Professionalism, Confidentiality and Compassion - Clinicians visiting family homes to see EoLC patients should be briefed fully on the patient's condition/situation and maintain the highest level of confidentiality when they are communicating with other clinicians in the presence of the patient and other family members.

6. To make it easier for people to access services, particularly across our more diverse communities. Some of our services are not joined up and do not work well together, and we need to change this.

- More needs to be done to create culturally competent services that take into account cultural and faith beliefs.
- We need services that are able to care for people from ethnic minorities who may not speak or have difficulty speaking and understanding English.
- Participants identified a need for existing care and support services to do more in reach into different communities in a culturally sensitive way.
- More needs to be done to promote community-based specialist palliative care, encouraging people to think, talk and plan about end of life care.
- The importance of having local services was stressed with reference to the cost, time and difficulty of using public transport.
- Need to design services that take into account people cultural and faith needs.
- Creating seamless service provision with services properly integrated with other ancillary services like 111 would make them easier to access and improve patient experience of care.

7. To cope with the increasing financial challenge, the NHS is facing and the effect this has on community-based specialist palliative care.

- Consider a proper financial settlement for hospices as their financial situation has been exacerbated by Covid.
- Local residents wanted to know more factual information on finance, demography and the help available locally.
- Look at ways of clawing back some funding from the NHS service providers when patients with intensive clinical needs decide to die at home.

8. To reduce the difficulty, we are having finding, recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services.

- A comprehensive workforce plan is needed to address the workforce challenges mentioned in the report.
- More needs to be done to educate and train all workforce to identify need. This should be NHS, Local Authority (social care) and voluntary groups so they can capture and signpost potential need.

- Need to build extra capacity and extra staff to meet growing demand.

The full interim engagement outcome report is available here.

8 Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

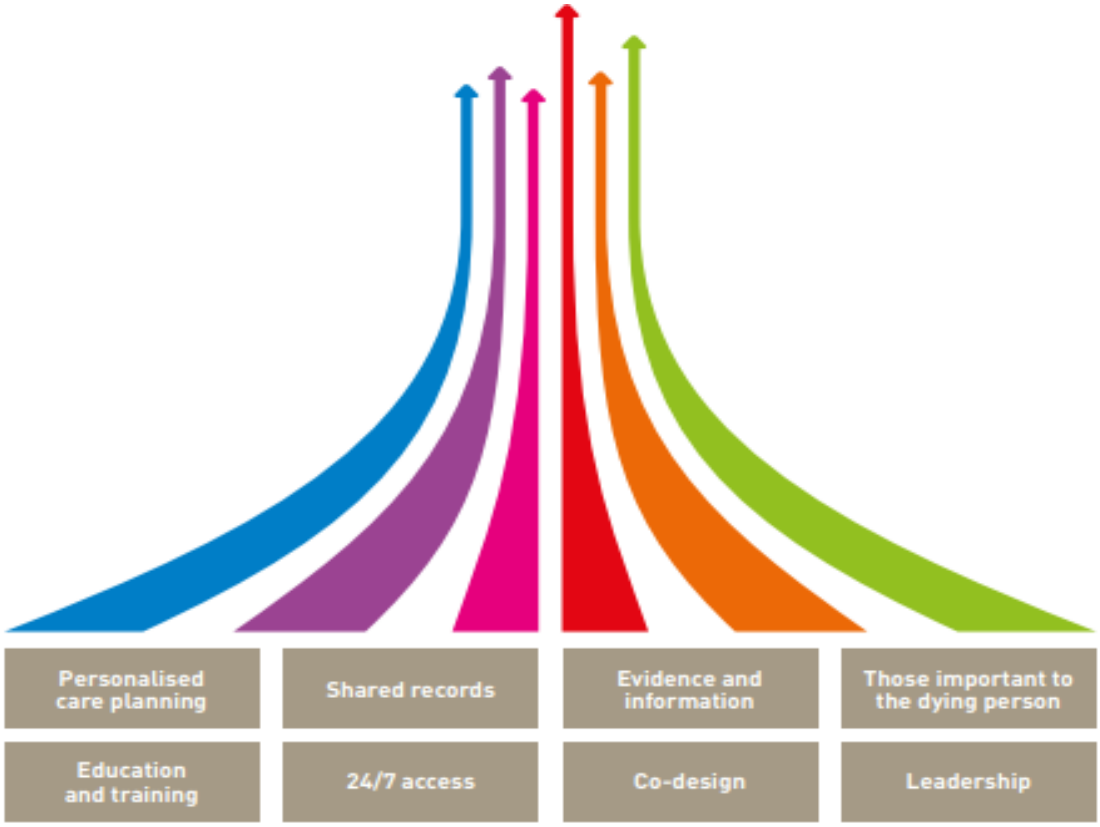
In 2015 The National Palliative and End of Life Care Partnership published the **Ambitions for Palliative and End of Life Care: A national framework for local action (2015-2020)** to improve palliative and end of life care (PEoLC), building on the 2008 Strategy for End of Life Care and other strategies and reports.

It describes what is needed to realise that ambitions, and calls for local health and social care leaders to use these foundations and building blocks to collaboratively build the accessible, responsive, effective, and personal care needed, via a process that is open, transparent and effective.

A refresh of the Ambitions Framework (2021-2026) was published in May 2021, with a reminder that more must be done, building on the learning from COVID-19 pandemic to focus more efforts on personalised palliative and end of life care, to improve support for people of all ages including those bereaved, and to drive down health inequalities.

Each ambition includes a statement to describe the ambition in practice, primarily from the point of view of a person nearing the end of life. Each statement should also be read as our ambition for carers, families, those important to the dying person, and where appropriate for people who have been bereaved.

The eight foundations that underpin the ambitions and are required to bring about this improvement. Different individuals and organisations can lay these foundations, either on their own or collectively.



Foundations for the ambitions

To support delivery of the six ambitions, the NHS England & NHS Improvement Palliative and End of Life Care Team worked alongside stakeholders to further develop the Ambitions for Palliative and End of Life Care self-assessment tool as a national resource.

This tool provides a self-assessment framework and process to support localities/ boroughs to

- Support a more coordinated response for localities to determine their current level of delivery of services against the Ambitions for Palliative and End of Life Care - A National Framework for local action (2021-2026).
- To understand where there are strengths and opportunities for improvement and growth that need prioritising within future strategy for palliative and end of life care.

In order for this self-assessment process to become a meaningful and useful exercise, localities are encouraged to be as honest as possible, with cross-organisational collaboration to complete the tool and achieve the improvements being vital. Localities are strongly encouraged to ensure health and social care are equal partners in this assessment process.

All eight Borough Based Partnerships (BBP) completed the self-assessment tool and came together in two workshops facilitated by the NW London last phase of life programme to facilitate its completion. Participants included representatives of local councils and residents.

All BBPs have now completed the self-assessment tool. The rich discussions that took place in each BBP breakouts, and feedback from multiple workshop stakeholders, that completing the self-assessment tools with multiple stakeholders locally for each BBP was really beneficial:

- To ensure the information on the tool is as accurate as possible for each BBP and ultimately for completion of the NW London self-assessment.
- To raise the profile of PEoLC locally and regionally.
- To identify the relevant PEoLC stakeholders and building place-based links.
- To start the basis for driving PEoLC improvement work forward at place and within other programme areas.

An analysis has now taken place and a NW London level and this will be used to inform the new CSPC model of care (MOC) in development by the CSPC MOC working group. In addition:

- Key gaps/ areas of improvement identified for other parts of the end of life pathway will be shared with other NW London programme areas.
- BBP self-assessments will be shared with BBP and borough directors with an ask to support any local PEoLC improvements using the findings to inform this work.
- NW London Last phase of life programme will host a 3rd workshop later in the year for all PEoLC stakeholders across the system to share the outcome of the NW London self-assessment, learning and areas of good practice identified.

We would like to thank partners and local residents for taking part in the workshops and contributing to their success.

9 How do future predictions for service demand shape the inpatient unit service we design?

We have carried out future service capacity and demand modelling that will allow us to project the likely level of service provision that is needed over the next five years. We need an inpatient bed base that allows us to care and support patients with a range of needs. This includes

- Complex patients with a range needs who require intensive support
- Patients nearing the end of their lives who are not able or do not wish to stay in their own home

As palliative need and deaths are directly correlated, we know that palliative need across NW London is projected to grow by 12.7% over the next 5 years. Approximately 3% of those with palliative needs may end up using an inpatient bed.

This leads to a projected increase in the number of admissions to inpatient units (IPU) where people have to stay in a bed for at least one night from 962 per year to approximately 1,084 admissions by the year 2027. Similarly, it is predicted that the number of days in which NW London patients occupy beds will grow from 15,775 to 17,781 by the year 2027.

It is, however, important to relate this to the number of bed days contracted by NW London across the seven hospice providers with inpatient units.

Presently, NW London contracts 20,719 bed days (inclusive of Pembridge Palliative Care Service commissioned beds). Taking into account that many, if not all patients who would have used Pembridge used alternative hospice beds average occupancy of hospice beds across NW London in 2021 was 76%.

Based on future demand projections, with current hospice inpatient unit's arrangements remaining in place (consultant-led hospice inpatient unit commissioned bed days), the average occupancy of contracted beds would increase to 86%.

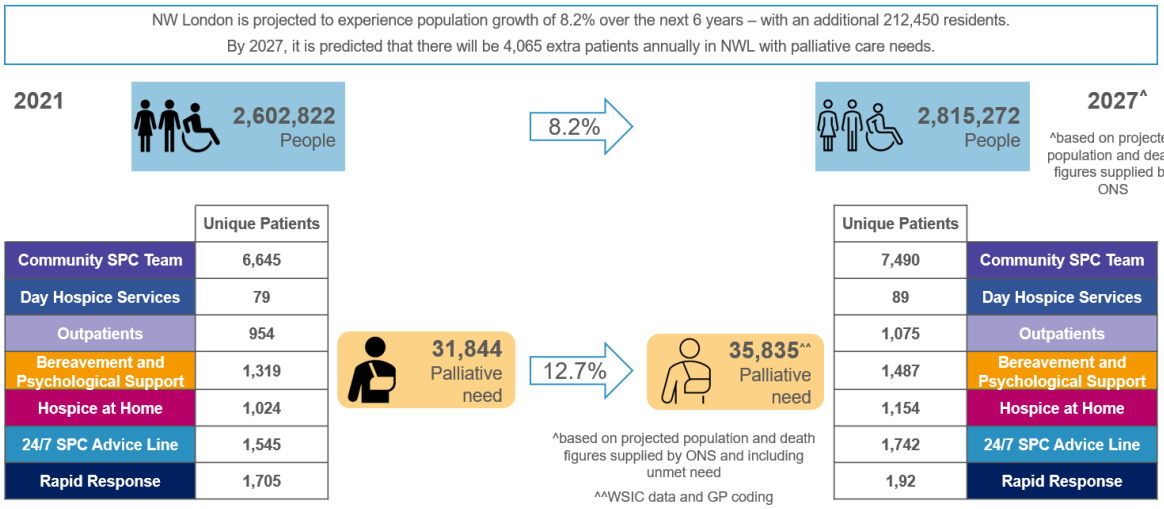
Although 'unused' capacity must remain in place to account for fluctuations in demand and operational constraints, it is projected that there is both sufficient and unutilised capacity in the inpatient unit bed-stock to address the predicted increase in demand for hospice beds.

Projecting our future inpatient bed (IPU) requirements over the next five years

We have calculated a 12.7% increase in the number of unique patients accessing all service lines by the year 2027 against current usage. We are able to do this as palliative care need is directly linked to the number of deaths.

We have used NW London and ONS death data and projections for future rates of death and this shows there is a predicted year on year increase of deaths and thus palliative need of 1.99% across NW London, translating to a 12.7% increase by 2027. See figure below.

NW London is projected to experience a 12.7% increase in CSPC demand by 2027



Variation in service access, demand and provision may be hidden by looking at service lines in totality and using averages, which unless effectively addressed, may widen over time.

There is fragmentation of services and variation in across boroughs, resulting in differential access to varied service types for populations across NW London.

10 What is the NW London CSPC Model of Care Working Group?

The NW London CSPC Model of Care Working Group has been asked to develop and co-design a new model of care for CSPC. This will be based on best practice and evidence and help us develop high quality community-based specialist palliative care that is delivered equitably and sustainably across NW London.

The new model of care will aim to make sure people have a choice, get the right care, at the right time, by the right team and in the right place, alongside their wishes and preference. All residents no matter their circumstances will be able to access the services they need.

Co-design is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of design. Whenever we are designing new services and patient pathways, it is important that anyone who would like to contribute has the opportunity to input into the process.

Membership of the NW London CSPC Model of Care Working Group, which meets on a weekly basis, consists of local residents, practitioners and other palliative and end of life care stakeholders. Patient/carer members with lived experience contribute and provide feedback on the group's work, reflecting the voice of patients, carers and their families.

Who are the members of the NW London CSPC Model of Care Working Group?

Key palliative and end of life care stakeholders (generalist and specialist) including 12 patient and carer representatives:

- NW London NHS community specialist palliative care (SPC) and NW London Hospice providers (Also see Appendix 1)
- Twelve patients and carer representatives
- Primary care
- Acute hospital specialist palliative care
- Acute hospital discharge
- NW London care homes lead
- Local authority and social care
- London Ambulance Service
- Community nursing
- Continuing Health Care (CHC)

We also invite additional topic or other programme related stakeholders when needed. This makes sure the new model of care that is being developed supports integrated care as it is developed with all appropriate interdependent programmes and considers the patient journey through the whole pathway e.g. district nursing.

What is the NW London CSPC Model of Care Working Group's remit?

The NW London CSPC Model of Care Working Group is being asked to:

- Develop a new model of care that will help us decide what type of services we need and what the common core offer that every patient in NW London should have access to.

- Develop a set of good practice and evidence-based core service standards, requirements and service definitions. These will demonstrate what we believe good community-based specialist palliative care looks like for all our residents.
- Develop a set of co-designed principles that will help us to successfully design and deliver the new patient-centred model of care across NW London.
- Support the development of a long list of options for delivery of the new model of care.

The NW London CPSC Model of Care Working Group have also looked at the future need of the NW London population over the next five years. In particular:

- The need to develop bedded care that allows us to care and support patients with a range of specialist palliative and end of life care needs. This could be in a number of locations including a hospice inpatient unit, or dedicated beds in in care homes which benefit from higher level of specialist input than routinely provided by homes' or a patient's own home with community support.
- The principles by which we will decide the size and shape of our future palliative inpatient and other bedded services
- The future requirements for other community-based services (Hospice@Home, Community Specialist Palliative Care Teams, Psychological and Bereavement Support, 24/7 SPC Advice Line, Outpatients, Day Hospice Services).
- The principles by which we will decide the size and shape of the community-based services required for the future.
- They have also put forward recommendations as to what supporting services activity (for example, improving uptake of the Urgent Care Plan (UCP), training for staff and having a workforce recruitment and retention plan) are needed to deliver good and sustainable community-based specialist care services and the mechanisms for developing these programme enablers.

The model of care is being designed to support local flexibility and equity of access. This means that the local Borough Based Partnerships will have the ability to develop additional services beyond the NW London core service offer if they wish to, based on their local priorities and local population needs.

What happens in the NW London CSPC Model of Care Working Group?

The NW London CSPC Model of Care Working Group has met weekly for the past six months and we thank them for their hard work and determination in helping us deliver excellent community-based specialist palliative care services for NW London residents. During the meetings they have been provided with detailed background evidence and information and have discussed what good community-based specialist care services should look like and what future capacity and demand for these services will be.

The background evidence and information they have been provided with includes:

- The eight broad reasons why we are doing this, national and regional good practice and evidence.
- The wonderful, rich feedback we have received from our residents, healthcare professionals and various other stakeholders through our engagement.
- The current and projected future demand for our services and the capacity and the structure of our workforce that will be needed to deliver it, as provided by the NW London CSPC Data Group.

Many local residents have been kind enough to share their stories to illustrate both the good experiences and the challenges that people face when using community-based specialist palliative care services. We need to learn from their experiences and the feedback has been used in the NW London CSPC Model of Care Working Group meetings so it can directly influence the discussions that are being had on a topic-by-topic basis.

The minutes for the Model of Care Working Group are available on our website.

11 Our developing model of care

A core and common offering will be created across all other community-services to make sure all populations have access to a consistent level of high quality care, reducing inequality and unwanted variation.

In addition to the core service offering, individual boroughs will be able to develop additional services in order to meet local needs, and better safeguard against service inequity.

We are committed to making changes to community services that will meet the needs of NW London residents. Co-design (and integration) the different types of bedded care that are available will ensure maximal utility is achieved from repurposed resource.

We will retain the current hospice inpatient service capacity and the resource needed to deliver it. This will make sure we are able to respond to fluctuations in demand and meet the projected increase in need.

We need to make sure we use the budget allocated to community-based specialist palliative care as efficiently as possible so that we are providing the maximum amount of high quality care services that we can. This could include investing in the other community-based specialist palliative care core services including:

- Different types of bedded care such as enhanced care home beds
- Community-based specialist palliative care team
- 24/7 specialist palliative care advice
- Hospice@home
- Hospice outpatient clinics and wellbeing services
- Psychological support
- Bereavement support

The NW London CSPC Model of Care Working Group is continuing to finalise these service models (including the types of beds being suggested). These will be made available when this work is completed.

We will make sure community-based specialist palliative care services have the flexibility to increase service provision against the projected growth in need for the next five years and beyond.

We will develop sustainable services that recognise current and projected service demand and take into account our current workforce and the limited availability of specialist palliative care professionals including consultants. Whilst recommendations have been set out by national bodies such as the Association for Palliative Medicine APM), there are limitations in how these can be applied to NW London services.

We will continue to focus on developing existing services and reaching out to communities and groups who are not currently using community-based specialist palliative care services.

Supporting services and activity

In order to deliver the new model of care, we will need to make sure our providers have access to an extensive range of support services such as IT infrastructure or a workforce with the right knowledge and skills that is able to deliver high quality compassionate care.

It also builds on much of the feedback we obtained through our engagement about what the need to make sure we reach and take into account the different cultural and faith needs of our NW London population. This includes

- Digital & data (e.g. Urgent Care Plan (UCP), remote working, information sharing tools)
- Governance (e.g. how to ensure accountability for service improvement and safeguard high standards of care)
- Workforce support (e.g. exploring ways to improve our workforce skills, tools and abilities to deliver high quality care, e.g. training offer/programmes)
- Organisational development (e.g. exploring ways to drive workforce recruitment, retention, deployment and development)
- Developing culturally competent services (e.g. making sure that our services have the skills and knowledge to take into account the diverse needs of our population)
- Community outreach (e.g. developing a community outreach programme to explain the importance of CSPC and how to access it)
- These are crucial support functions which will allow us to achieve improvements in the quality of care we are able to deliver.

These do not directly affect the delivery of patient care but are important in their own right as they provide the support mechanisms by which the workforce and their organisations deliver care.

These supporting services and activity are needed to make sure we can deliver our future model of care. They are not options which require long listing, short listing or consultation, but rather consistently underpin all elements of future working arrangements.

Our future bedded care needs

Our definition of the new Model of Care for community-based specialist palliative care services will continue to iterate as we continue to engage - the description below is our current position to inform the committee of current thinking. We need to develop bedded care that allows us to care and support patients with a range of specialist palliative and end of life care needs. This could be in a number of locations including a hospice inpatient unit, a care home or a patient's own home with community support.

Patients with complex needs who require intensive support and are unable to or do not wish to stay at home

We need to be able to care for people with unresolved very complex needs that cannot be met by the capability of the community teams e.g. district nursing, specialist palliative care nursing and primary care and need more intensive specialist palliative care intervention. These needs may be physical with management of

complex symptom or rehabilitation required; psychological, social and/or spiritual where we need to take into account family situations and ethical dilemmas regarding treatment and other decisions.

Mr X has a brain tumour and has only a few weeks to live. He has recurrent seizures and nausea which is difficult to manage and needs constant medical support to control his symptoms. The best place for Mr X to receive his care could be a hospice inpatient unit where he will have support of a specialist consultant palliative care consultant and specialist palliative care nurses.

Mrs D has metastatic cancer that has spread to different parts of the body. She has severe pain which is distressing for her and her family and they are struggling to cope with managing her care at home. The best place for Mrs D to receive her care could be the hospice inpatient unit where she will have support of a specialist consultant palliative care consultant and specialist palliative care nurses. If her pain becomes stable she may be able to return home and continue to be supported by community services in the home.

Patients with less complex needs and are unable to or do not wish to stay in their own home but are also not appropriate for hospice inpatient unit admission

We need to be able to care for people with a progressive life-limiting illness, with or without comorbidities, where the focus of care is on quality of life, including complex symptom control.

Example: Ms B lives on her own, without nearby family, and has a life-limiting illness. Her condition has gradually progressed and although she is not in crisis the community-based specialist palliative care services, general health and social care services are now unable to meet her care needs. Ms B and her family are worried that she is not coping well in her last months of life. The best place for Ms B to receive her care could be in a care home where they can provide enhanced support and care for her symptoms 24-hours a day.

Mr S has deteriorating dementia. Whilst he has a life limiting illness he is physically still quite strong but his family is struggling to cope. The best place for Mr S to receive support is a care home where they can provide enhanced support and care for his symptoms 24-hours a day.

Patients with less complex needs who wish to stay in their own home and with the right level of support are able to do so

We need to be able to care for patients with less complex needs who, in their final weeks of life, wish to and, are able to stay at home using general community services (e.g. District Nursing, GP, Continuing Health Care Fast Track) alongside a range of specialist community palliative care services (e.g. the Community Specialist Palliative Care Team who are able to provide specialist advice and input and Hospice@home who are able to provide time limited support for increased in care). However, should these patients' needs exceed the capability of the community

services available, a change in place of care (i.e. hospice inpatient unit/ hospital/ care home) may be necessary.

Mr J has COPD and is in the last few weeks of life. He wants to die at home and his family wish to support him to do so. A range of services have been put in place to allow him to do so including oxygen, pain management and bereavement support for the family available from community services, both general and specialist. Mr J deteriorates rapidly and passes away at home.

Mrs G has rapidly deteriorating lung cancer. She and her family wish her to stay and die at home, she has increased care needs with less complex symptoms. Hospice@home, which provides time-limited but intensive support, has been able put in the support to allow that to happen in her final weeks.

Mrs K has metastatic breast cancer. The family wished Mrs K to stay at home and with support from a variety of community services, including hospice at home and community based specialist palliative care team this had been achieved for some time. Sadly, as Mrs K continues a gradually deteriorates her family and community services are no longer able to cope with her care needs. Mrs K's needs could be best met at a care home where she is able to get 24-hour enhanced support for her on-going care.

Patients only needing generalised palliative care and no specialist input who wish to, and with the right care and support, to stay in their own home in the last few weeks of their life

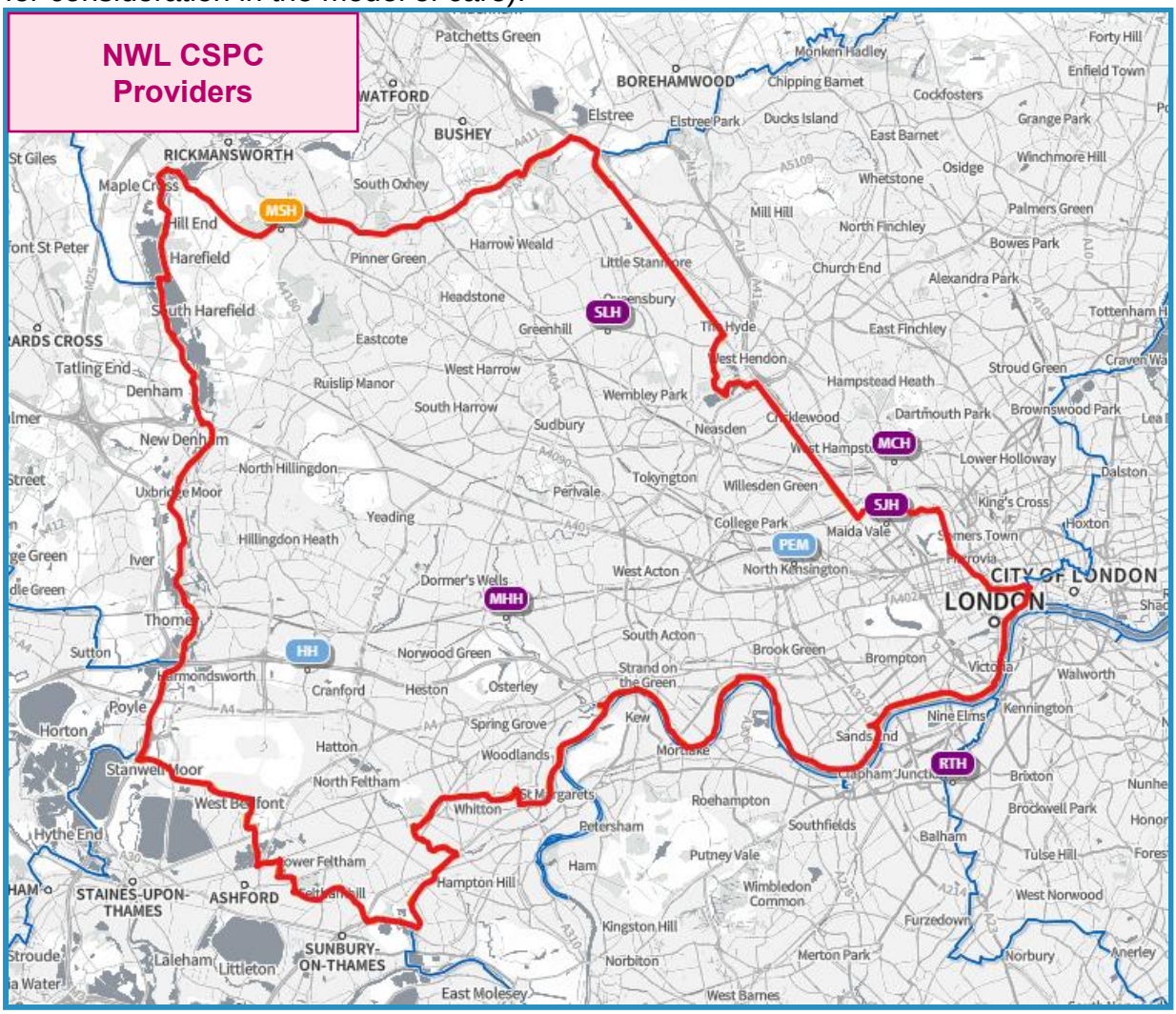
Mrs X has stable but non-curable Myeloma. She has end of life care needs that does not require input from the community-SPC team. She and her family wish for her to stay at home for her care and death. With the support of their GP they have developed an Urgent Care Plan that sets out what they want to happen if Mrs G symptoms deteriorate and they are no longer able to cope. Community Nursing, Continuing Health Care and the patient's GP could enable this to happen.

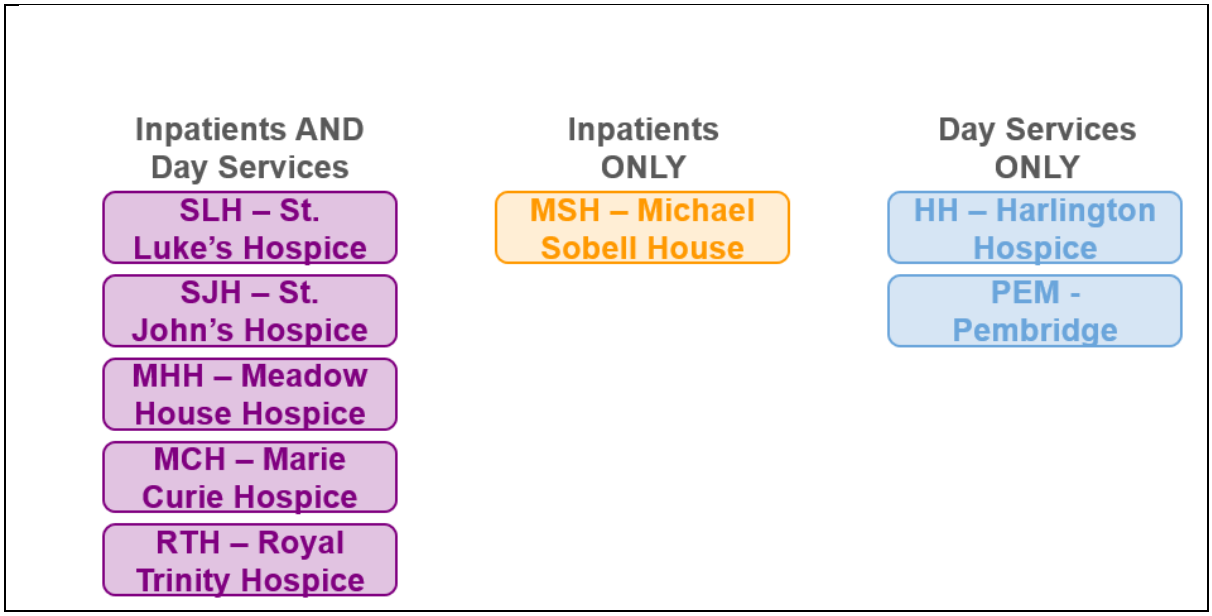
12 Access - travel is key to providing care that supports individual needs

We will be carrying out a travel mapping exercise on access to CSPC services for the NW London population so we can understand:

- The current state of access to service and areas of specific challenge
- Where there are existing inequalities
- If and how changes will impact future access (specifically whether inequalities are created).

In doing so, we can transparently understand and address any implications for different populations (public transport v those who have their own transport) and identify appropriate locations for any new services, should this be within the option for consideration in the model of care).





Approach and limitations

It is of paramount importance that this process adopts a standardized and recognised approach, that results in a fair and equal outcome for all populations. In addition to outlining the methodology below, it is crucial to note there are several caveats and limitations in what is possible.

The proposed methodology:

- Mirrors the approach taken for other NW London work (e.g. Elective Orthopaedic Centres).
- Map from all Lower Super Output Areas (LSOA) – the centroid (i.e. not the centre, but the most populated part). Some postcodes can become almost patient identifiable which is not appropriate.
- Map from LSOA to a hospice / service postcode – select most accessible postcode
- Postcode = 40 people, LSOA = 1000 therefore better to go with LSOA.
- Travel times – we suggest doing peak (e.g. 8 am) and non-peak (e.g. 12 pm)
- Map best case (e.g. no traffic and green lights), worst case and average journey (e.g. some traffic, some green lights)
- Explores different modes of transport to support decision making
- Maps existing bus routes and not future proposed bus routes.

The standard issues with this approach are:

- It is not possible to map carer / relative travel within NW London or outside of, as there is not a way to identify where carers live if not with patient within NW London [this is mitigated as we seek to understand the NW London population's access to services, not just current service users only].
- It cannot not take into account temporary roadworks
- It is not possible to take into account the frequency of buses / trains for public transport routes.
- It is not possible to take into account accessibility e.g. transfer between stations or transit within stations.
- As this is a 5-10 year plan we cannot take into account future and unconfirmed changes - e.g. to bus routes [**although it is important for all to**

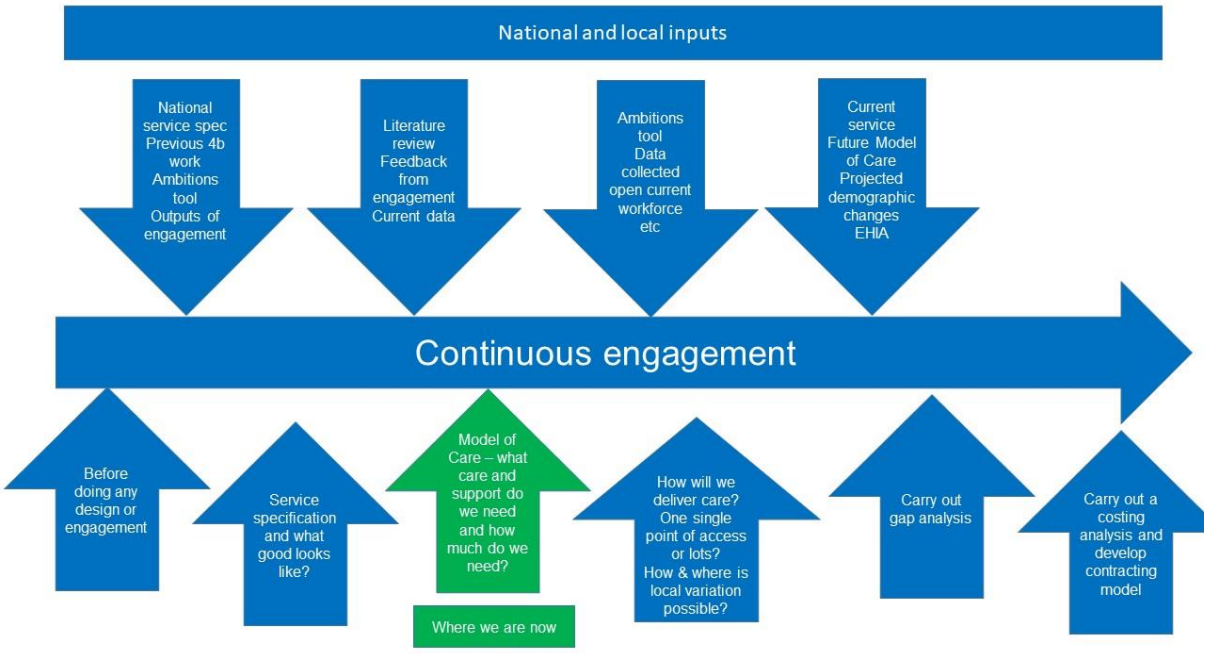
highlight any pending changes to be implemented]. In practical terms, we do not have access to any proposed new routes/changes to routes as they are not loaded onto the planning system used.

- We are aware that there are route changes happening London wide and this will impact on any analysis.
- Presently, we can only map those services commissioned within our footprint (i.e. from our current providers only) and not look at travel to other services outside of NW London.

13 Timeline

We are taking a flexible approach to the timeline to make sure that we can carry out good conversations with local residents and our partners within the Integrated Care System.

The diagram below shows the national and local inputs into the development of the model of care and immediate next steps.



Due to the complexity of discussions the work of the NW London CSPC Model of Care Working Group has been taking longer than anticipated. As soon as this work is completed we will move into the next stage of the process which will include a long-listing and appraisal exercise. Further details will be published in due course but we can confirm that Hammersmith and Fulham residents will have the opportunity to get involved.

14 Next steps

The NW London CSPC Model of Care Working Group has been meeting weekly since May 2022, receiving background evidence and information, including all the wonderful and insightful feedback we received through our engagement and which is detailed in the Engagement Outcome Report and we have heard what they have said is important to them.

We would like to thank all the members of the NW London CSPC Model of Care Working Group and the wider patients, families, carers and other stakeholders for their feedback and suggestions that are so integral for the success of this programme.

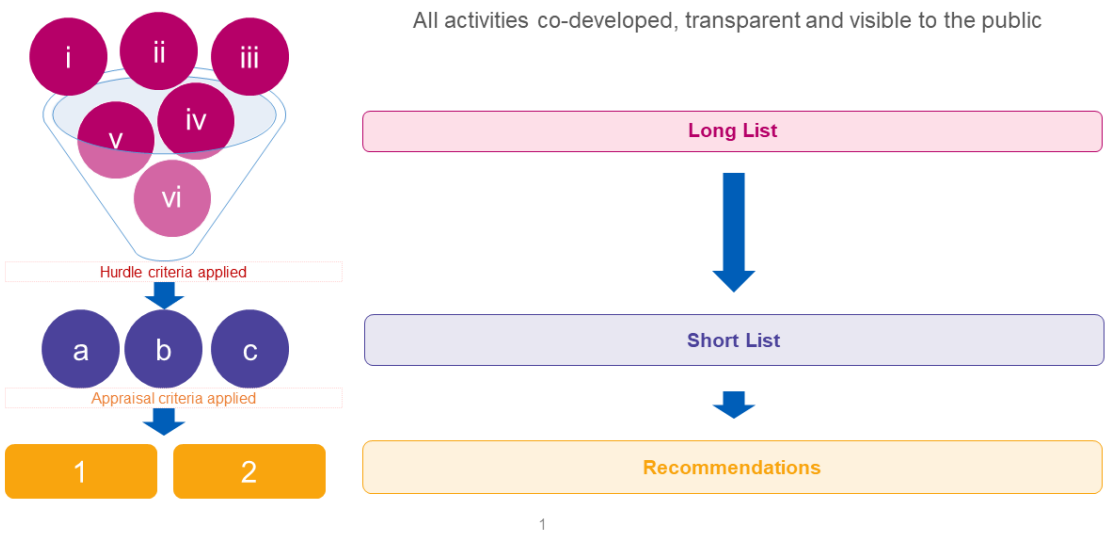
Once their work is complete we will move into a transparent and robust appraisal process that will allow us decide between different options and to develop a preferred way forward that addresses all the issues as laid in the Issues Paper that was published in November 2021.

This strong appraisal process will help us:

- Give due consideration of all options
- Reduce the options to a manageable number as quickly as possible
- Support the weighing up of different options
- Can be completed as simply as possible

Diagram one shows how the appraisal process will work.

Diagram 1 - Developing the future model of care – options appraisal process



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Long-list	• The NW London CSPC Model of Care Working Group will generate an initial list of options for delivery of the future model of care.

	• We will be asking members of the public and other stakeholders to help us generate a long list of options. • It's important to note that all suggestions can be included in the long-list whether feasible or not.
Short-list	• Long-list of options is analysed by NW London CSPC Steering Group using ratified hurdle criteria which determines which options are feasible. • Short-list of fewer options is then generated and these are taken forward for further analysis
Recommendations	• Short list of options undergoes in-depth assessment by the NW London CSPC Appraisal Task and Finish Group that is set up specifically to do this. • Membership will consist of NW London stakeholders as well as independent external stakeholders, including patient/carer representatives. • Using appraisal criteria, they will reduce the short-listed options to a list of recommendations that will go to public consultation if that is deemed to be needed. • The recommended options will be agreed, including a preferred option, by the NW London CSPC Steering Group.

Following the appraisal process, we will then work with our Borough Based Partnerships, local residents and palliative and end of life care stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed.

If it is deemed that substantial service change is needed, we will then need to consider if a public consultation is necessary. If consultation is needed the options will then go into the development of a pre-consultation business case which will be presented to The NHS North West London Board for approval.

However, where it is possible to progress and develop agreed elements as soon as possible, rather than waiting until all elements of this programme are completed, we will do so. As we did, when we found some existing gaps in service provision that needed to be addressed immediately.

We cannot resolve the current situation and issues unless we work in partnership with residents and other stakeholders –we welcome Hammersmith and Fulham's support to do this

This is not a plan to replace work that is already going on. It is a plan to build on the on-going commitments in NW London for community-based specialist palliative care and identify where there are gaps and opportunities.

Appendix 1 – Detail on the Palliative care services improvement programme in the London Boroughs of Brent, Hammersmith & Fulham, Kensington and Chelsea and Westminster. Note this review has been superseded by the current NW London wide process and as such the outcomes will feed in to that process but the options are not recommendations that we are actively progressing

In November 2018 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; to independently review provision of community-based specialist palliative care services in the three boroughs following suspension of the in-patient unit at The Pembridge Hospice following that failure to recruit a consultant registered on the specialist register for palliative care which is required to cover inpatient care.

This event, combined with commissioner's 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. The independent review of palliative care services published with the aim of developing recommendations for an improved commissioning model that would deliver high quality services for patients, families and carers across the three boroughs.

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, with the final review published in June 2019.

The report 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.

Findings and future options

The review of services offered to patients identified the following three overarching challenges to be addressed:

- 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; and
- inequity of funding arrangements for the services from the CCGs.

The review put forwards three options in order to address these challenges whilst providing a sustainable local system, which ensures all patients receive care in their preferred place at the right time:

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. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs

Option two

Tender a new service and rationalise and reduce the number of specialist providers to two, with the same service specification and contracts and

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.

Read the review in full here.

In Autumn 2019, the three CCGs were joined by Brent CCG as a commissioner of services at the Pembridge Hospice in holding a number of workshops to understand the experience of the end to end pathway.

Workshops were on held on ‘Access’, ‘Care’ and ‘Bereavement / aftercare’ with the purpose of having some in-depth conversations on the whole end to end pathway and use the information to feed into future potential scenarios for service delivery.

After listening to feedback from the public and stakeholders following the public workshops, we launched our ‘potential scenarios’ to the public for discussion and feedback and work in partnership with the public to design future potential options for service delivery.

This led to the development of four scenarios that set out how we might organise palliative care services in the future and in February 2020 we asked the public for their feedback on them.

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.

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.

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 sites 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.

Scenario 4—A re-design of all elements of palliative care services including access to a new nurse-led inpatient 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 nurse-led care at a bed in North Kensington provided by the Pembridge Palliative Care.

There followed a period of further engagement on the options with the public and a wide range of stakeholders which brought forward a number of themes and feedback on the scenarios.

- Dying in dignity and agreement on the importance of palliative care and local services
- Communication and awareness of death and dying, palliative care and the need to plan for it
- Capacity of service provision now and in the future
- Review process – residents wanted more information on the evidence being used to inform the process
- A strong desire to keep inpatient services at Pembridge and opposition to closure
- Agreement on the need to improve access to services
- Better and more clear engagement
- More information on the staffing issues
- More information on the finance issues
- To consider the impact of travel and transport when making decisions
- Recognition that there was a need for change

In summary we heard throughout the engagement period, that specialist palliative and end of life care services play a crucial role for people. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We also heard that we could improve and that these services could be available to more people, be more inclusive, adaptable and offer more choice. The feed-back indicates however that there are differing views about how we make these improvements, and create a more equitable service for all.

View the full public engagement report

The decision was then taken to pause the programme of work due to the current coronavirus outbreak and the subsequent decision by the NW London ICS to look at community-based specialist palliative care services across the eight boroughs in NW London.