Appendix C

Palliative Care Public Workshop findings:
Planning services together

Palliative care: how we will use your feedback

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

Talking about your experience of palliative care

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

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

Cruse Bereavement Care
0808 808 1677

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

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

Child Bereavement UK
0800 0288840
support@childbereavementuk.org

Samaritans
116 123
jo@samaritans.org

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

Background to the palliative care review

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

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

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

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

Patient & Public involvement: workshops

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

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

- Understand patient and families experience of care from palliative care services.

- Use these experiences to co-develop an improved way for patient's palliative care needs to be met from diagnosis to end of life and beyond.

- Feed in to a new model of palliative care across the four boroughs.

NHS

Palliative care services
Help to shape our plans

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

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

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

Workshop 1: Access to Care

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

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

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

Breakout Session 2: How can we improve this experience in the future?
- How would this process start in the future?
- Who would you want to identify the help, support and care you need?
- What would you want them to do?
- What would the information and co-ordination be like?

Responses to breakout session 1
What is <u>working well</u>?

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

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

"Acute sector felt like they were better trained"

"Community palliative care we experienced was great"

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

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

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

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

Responses to breakout session 2: what needs <u>improvement?</u>

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

Access to care

"There is a lack of information from clinicians about how to access services"	*"You often need to ask for palliative care support – but if you don't know it is available how do you ask? This situation could cause inequalities"*	*"Different languages and cultural complexity may cause issues in accessing palliative care – important consideration in culturally diverse boroughs"*	*"Lack of awareness of palliative care services"*
"Confusion around the system about how to access palliative care leads to unequal access and patient anxiety"	*"Traveling for friends and families can sometimes be difficult"*	*"In certain situations telephone advice is not enough – there needs to be a crisis intervention team"*	*"Issues with accessing palliative care causes care to be delayed"*
"Patients need to feel like they are more in control of the process"	*"Travel costs, if family and friends need to travel far, it may deter them from visiting or discourage patients from access care if they don't have their friend and family attending with them"*	*"If you have been in the system before you know how to navigate it but this is difficult for patients and families who have not been"*	*"To improve access needs to be greater awareness around what is on offer"*

Responses continued..

Communication

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

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

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

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

Coordination

"There is a lack of early planning around palliative services"

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

"Lack of care coordination could reduce access to care"

Experience now

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

Improving experiences

Workshop 2: Care

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

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

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

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

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

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

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

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

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

"The quality of hospice care once in a hospice is very good"

"Communication and planning is the key to positive palliative care"

"Care works very well once in the right service or pathway"

"Availability of care in all settings to support patient wishes"

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

Responses to breakout session 1: what could be improved?

Care

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

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

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

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

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

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

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

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

Responses continued…

Communication

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

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

"More conversations about dying are needed to raise awareness of services"

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

Coordination

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

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

"We need a central hub of information"

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

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

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Breakout Session 2:
- What makes care excellent? What does care mean for you and what makes you feel supported?
- Where do you want your care and how can it be more personalised and inclusive of specific needs?
- What are your priorities? What kind of things make a difference to you and your loved ones about the care you receive?

Care

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

"Hospices need good estates and support facilities"

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

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

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

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

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

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

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

"Making hospices feel like a home away from home"

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

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

Responses continued…

Communication

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

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

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

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

"Early conversations make harder conversations in the future easier"

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

"Provision of help and support earlier in the process"

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

Responses continued…

Coordination

"Promote co-ordinate my care"

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

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

"Improved CMC usages and accessibility for patients, staff and families"

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

"Simplicity and integration – no referrals"

"Future provision needs to take in to account demographic changes"

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

"Timely access to care"

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

"Mixed economy of services that can meet the various demographic needs"

"Improved hand overs between teams"

Experience now

Improved experience

Workshop 3: Moving between care settings, bereavement and aftercare

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

Breakout Session 1: Your experience of moving between care settings

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

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

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

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

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

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

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

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

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

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

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

Responses continued…

Communication

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

"There are poor links and communication between specialists and acute communities"

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

"Services are too fragmented with little communication between them"

Responses continued…

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Coordination

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

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

"We need to improve the discharge experience for patients"

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

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

"Poor use of Coordinate My Care (CMC)"

"Need to improve urgent care at home"

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

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

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

"I felt listened to"

"Safe space to talk and find out information"

"Presence of someone with empathy"

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

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

Responses continued…

Care

"Need to have bereavement support from specialists who are culturally sensitive"

"Taking the time to ask 'what do you want?'"

"Can we provide training to bereavement staff on responding to grief"

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

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

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

"Additional support around anniversaries and death"

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

Responses continued…

Communication

"Patients and families feel like they don't have a voice"

"Spending time to understand the diagnosis and timeframe for patients"

"Need to support more people talking about death"

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

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

"Hospice services need to ask for feedback"

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

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

Responses continued…

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Coordination

"We need to make sure that support is accessible to different communities and that we don't have gaps"

"Services need to be accountable, so patients aren't passed around different services"

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

"Flexible timeframe for counselling"

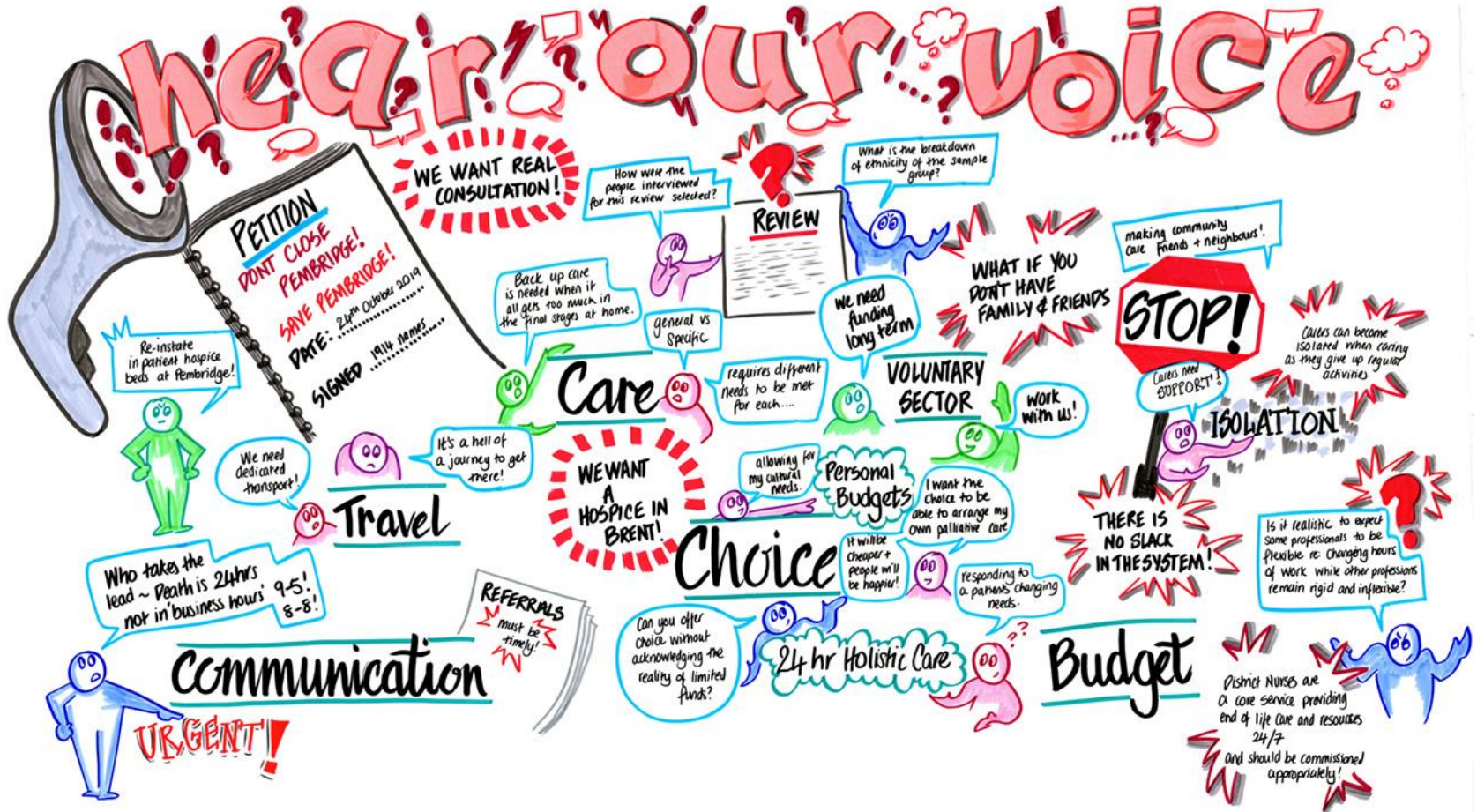*"We need to think about bereavement services in the context of integrated care"*

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

Improved experience

Hear our voice

Summary of key themes

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Access to care

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

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

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

Care

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

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

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

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

Coordination

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

Communication

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

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

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

What happens next?

Visit your CCG website for more information.