EALING SAVE OUR NHS

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Proposed new model for Community-based Specialist Palliative Care for Adults in NW London

Ealing Save Our NHS Response

In drawing up these comments and questions we have consulted our members with experience of using palliative and end of life services both as patients and carers, and who work in palliative care services.

Clearly a great deal of work has gone in to developing this model and ensuring the voices of diverse communities have been heard.

We welcome many of the proposals, which we hope will end the disparity and unequal provision across the eight Boroughs in NW London ICS.

However we do have a number of questions and concerns and in particular the lack of concrete information on how the model will be funded and a workforce plan.

Issue 1: Responding to future need and meeting the palliative care needs of NW London's changing population

- Clarity is needed over the modelling used. The report mentions both predicted population needs and an audit looking at current use of beds, but then seems to base most of the recommendations on the audit rather than population level data.
- Population data suggests a 5% increase in population but a 30% increase in ageing population. But with fewer inpatient hospice beds; 13 hospice beds being closed at the Pembridge Hospice, and 54 beds taken from existing community provision, it looks like NW London is losing beds while the population is growing. We are concerned that the loss of beds will place additional pressure on patients to remain at home, even when care in a hospice would be more suitable.

Issue 2: Addressing service variation, improving access to care for all, and making sure that everyone receives the same level of care, regardless of where they live

- Regarding 8pm to 8am cover, following the report's recommendations there does still seem to be service variation.
- Following implementation, will everyone in NW London who rings the 24/7 advice line and then needs a visit between 8pm and 8am get one and is that visit provided by an equally trained person across the area?
- Standardising access to existing services may be a better use of funds than rolling out Hospice at Home across the region. It would have helped to have seen other options being considered such as increasing District Nurses. It would also be helpful to have had a clearer definition of what is meant by 'Hospice at Home', as it is a bit confusing and appears to overlap with community based palliative care. – Clarification would be appreciated.

Issue 3: Reducing health inequalities and social exclusion

- We welcome the standardisation of access to psychological and bereavement services. However we hope that this also means increased support. From our members experience we know that caring for someone at the end of their life takes a huge toll on carers mental health and wellbeing. If palliative care is to be more community based then there should be even greater psychological support for carers both before and after bereavement.
- The model proposed and the idea of the common core offer is equitable.
- Detail is needed on how this links in to other local services e.g. IAPT (improving access to psychological therapies) particularly for those with complex needs
- Provision to improve access to hospice outpatient services will reduce inequalities across the area
- Respite is a key means of supporting carers and we are very pleased to see it included in referral criteria as a reason for inpatient bed admission. This service will need to be planned, with sufficient beds, so that carers can rely on admissions and not see them cancelled for other clinical priorities. We hope that carers will be given choice about where the respite will be given so that they and other family members can visit.

- We are concerned that permanent closure of the Pembridge inpatient beds will worsen health inequalities due to distance needed to travel, and it is difficult to make further judgements on this without knowing where the proposed enhanced end of life care beds will be located

Issue 4: Integrated delivery of care and making care more joined up and easier to navigate

- Standardising access to a 24/7 helpline for palliative care will certainly improve this
- Thought needs to be given to how patients and carers will know how to access the helpline, particularly if not already known to specialist palliative care services
- Staff will need clear information on how to appropriately signpost and support when a patient is not already known to services
- Hospice at Home services will only provide single handed care (one carer), needing to join up with existing services where double handed care (two carers) is needed. These sounds like care will be less joined up and harder to navigate. We know that a plethora of carers can be very confusing for both patients and their families – was there any consideration of a key worker?
- Has the review considered how information will be provided to patients and their carers e.g. updates patient's leaflets?
- Perhaps it may be better to provide double handed Hospice at Home visits or put this funding into Continuing Healthcare budgets?

Issue 5: Responding to feedback and engagement and building on the valuable learning and feedback received from previous reviews of palliative and end of life care services and ongoing engagement

- We welcome the priority given and work done in improving access to anticipatory medications, and on using Universal Care Plan to record Advance Care Planning decisions
- The community have repeatedly called for the re-opening of the Pembridge inpatient service and we are not convinced that there is sufficient evidence that these beds are not needed.

Issue 6: Making sure our services are aligned to nationally recommended standards and evidence

- Consideration needs to be given to ensuring services are also in line with the NHS Net Zero ambition.

Issue 7: How financially sustainable is community based palliative care now and in the future?

- Sadly we known this remains an ongoing issue
- Support to care homes is mentioned, and we would hope arrangements are put in place for payment if NHS/charitable organisations are providing training and support care homes as private providers commissioned to provide end of life care
- The review states that the 54 enhanced end of life care beds "will be located in existing community bed services (for example nursing homes and community bedded units) and predominantly staffed by existing nurses and health care assistants, who will be upskilled in palliative and end-of-life care."
- We question who is currently using these beds and which services will no longer be being provided in the community in order for them to become enhanced end of life care beds
- How are these enhanced beds accessed and what is the length of stay?
- More information is needed about location of these beds and the impact of creating them on current services.
- Finance – The review states that affordability is one of the criteria in assessing which service options are deliverable. Clearly a great deal of hard work has taken place in developing this model; surely affordability should be a major consideration to ensure that the model is deliverable.

Issue 8: Recruiting and retaining a skilled workforce now and in the future

- This issue extends well beyond the scope of this review, but certainly ensuring equality of pay and conditions between NHS and hospice/charitable employed staff would be essential.
- It is not clear from the review if staffing is to come from existing staff or indeed if more staff are to be recruited. It would have been helpful to see a workforce plan or to have given some idea of the roles and numbers of staff.

Thank you for giving us an opportunity to submit these comments.

We hope that you will find our questions and comments useful and look forward to receiving your response

Eve Turner

On behalf of Ealing Save our NHS

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