End of Life Care Strategy

Promoting high quality integrated care for all Havering residents

2016-2019

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Links with other documents	Havering H&WBB Strategy This is Havering – JSNA chapter http://www.haveringdata.net/research/jsna.htm. DH 2008 End of Life Care Strategy ..\..\End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2[1].pdf Ambitions to Palliative and End of Life Care ..\Background papers\Ambitions-for-Palliative-and-End-of-Life-Care.pdf Paediatric palliative care Paediatric Palliative Care NHS Standard Contract Havering CCG Commissioning Plan ..\..\HAVERING CCG COMMISSIONING STRATEGIC PLAN 20142015.pdf

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1. Foreword

In England, about 1,300 people die every day. Around 900 of them will have wanted to die at home, but less than half will do so. Some 975 may have needed palliative care to relieve suffering but 469 will not have received it (Dying Matters Coalition 2010). About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there.

People's preferences regarding place of death were summarised within the 2008 National End of Life Care Strategy, in that "most people would prefer to be cared for at home, as long as high quality care can be assured and as long as they do not place too great a burden on their families and carers". Despite this the acute hospital remains the most frequent place of death (54%) for 2,195 people that die every year in Havering.

We know that where a patient has a plan in place, and everyone who is involved in the care of that patient knows about that plan, he/she is much more likely to die in their preferred place. Good community support can realise 70% of deaths at home and halve unplanned hospital admissions (National Council for Palliative Care/Dying Matters Coalition 2011). In order to achieve this, a cultural and behavioural shift in how end of life care is perceived and in how it is delivered is required.

The overall aim of this strategy is to raise the profile and importance of choices in death and dying across all care settings, cancer and non-cancer conditions and across all age groups.

Key stakeholders make up the membership of the Havering End of Life Steering Group, and we are committed to ensuring that the people of Havering have access to high quality end of life care, irrespective of their condition, or where they live.

2. Executive Summary

A working definition for End of Life Care has been developed by the National Council for Palliative Care (2009):

> End of life care is care that helps all those with advanced, incurable conditions to live as well as possible in the last year of life. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

It applies to people who are likely to die within the next 12 months"[1] as a result of

- o advanced, progressive, incurable conditions (including children and young people)[2]
- o general frailty
- o existing conditions if they are at risk of dying from a sudden acute crisis
- o life-threatening acute conditions caused by sudden catastrophic events

It can be identified by using the 'trigger' question – 'would I be surprised if this patient died within the next 12 months?'

Nationally health and social care services for people with end of life care needs have improved considerably over recent years. As people live longer, and with the increasing prevalence of chronic conditions, it is essential that health and social care services collaborate further to meet the challenge of planning and delivering high quality palliative and end of life care for increasing numbers of patients and clients in Havering.

This strategy provides a vision and direction for service planning and delivery, and will be implemented by the Havering End of Life Steering Group. This group consists of representatives from all relevant stakeholders including clinicians; health and social care providers; commissioners and independent and voluntary organisations.

This strategy builds upon a large amount of work that has already been undertaken in Havering, for example, implementation of Gold Standards Framework (GSF) training, the development of a standardised DNR form and the use of electronic EoL Care Plans; the work of existing services such as the local hospices; general practice; and community services.

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[1] NICE . Guide for Commissioners for End of Life Care. 2011.
Available at: https://www.nice.org.uk/guidance/cmg42#12-defining-end-of-life

[2] 2008 End of Life Care Strategy – promoting high quality of care for all adults at the end of life.

The improvement in service delivery that is expected from this strategy will require ownership and leadership from across the system in partnership with patients, carers and the public. This strategy acknowledges the importance of current collaborative arrangements between the statutory, community and voluntary sector agencies; and recognises that going forward these arrangements need to be strengthened through local and regional strategic planning.

The key objectives of this strategy are to embed the recommendations from the National Palliative and EoL Care Partnership ambitions framework[3]. This framework builds on the 2008 Department of Health (DH) Strategy for EoL Care and the improvements and changes that have followed since.

Strategic Objectives

Ensure each person approaching end of life is seen as an individual

Ensure that each person gets fair access to care

Improve care planning and maximise patients' comfort and wellbeing

Have co-ordinated care across the health and social care system

Ensure services are prepared and offer high quality care Ensure we build compassionate and resilient communities that will cope better and help each other in times of crisis and loss

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[3] Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. www.endoflifecareambitions.org.uk

3. Introduction

This strategy was developed in collaboration with Havering statutory and voluntary partners and local stakeholders, and sets out a vision for high quality care across Havering for all adults and children approaching the end of life.

This local strategy reflects national and local policies including the National End of Life Care Strategy 2008 and Ambitions for Palliative and End of Life Care: A national framework for local action (2015 -2020).

The purpose of this strategy is to respond locally to both national and local drivers for change, and to commission and develop services for patients with end of life care needs, regardless of diagnosis.

This strategy will be implemented through the End of Life Steering Group and will report to the Havering Clinical Commissioning Group (HCCG) and the Havering Health and Wellbeing Board (HHWBB).

4. National Context

Actions for End of Life Care: 2014-16 – sets out NHS England's commitments for adults and children. It is one component of a wider ambition to develop a vision for end of life care beyond 2015. This can only be achieved in partnership with all those in health and social care. The 2008 Strategy managed to reverse the upward trend of people dying in hospital. We now need to ensure that living and dying well is the focus of end of life care, wherever it occurs. This is the challenge: together we can and must achieve it.

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Directors of Adult Social Services, charities and groups representing patients and professionals, has developed a framework for action.

This framework is aimed at health, social care and community leaders. It builds on the Department of Health's 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

This national framework for action sets out six 'ambitions' – principles for how care for those nearing death should be delivered at local level. These have been adopted as our key strategic objectives.

5. Vision and Strategic Objectives to Deliver Improvements for End of Life Care

Building on the progress and work already undertaken locally, the vision for End of Life care will be to:

- Provide compassionate care that meets agreed national standards in a consistent and coordinated way for all Havering residents approaching the end of their life; and,
- Commission services that will enable and support our residents to live and die with dignity and in the place of their choice.

Strategic Objectives

Ensure each person approaching end of life is seen as an individual

Ensure that each person gets fair access to care

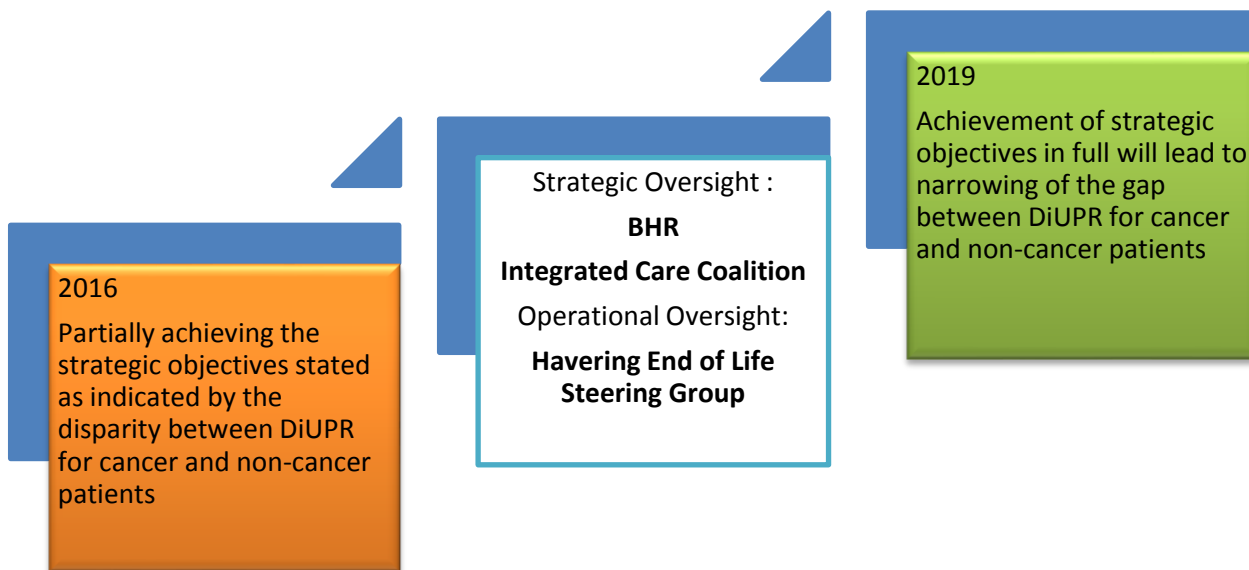Improve care planning and maximise patients' comfort and wellbeing

Have co-ordinated care across the health and social care system

Ensure services are prepared and offer high quality care Ensure we build compassionate and resilient communities that will cope better and help each other in times of crisis and loss

The scope of this strategy encompasses:

- o Care provided in all settings (e.g. home, residential/care home, nursing home, hospice, acute hospital, prison or any other institution)
- o Care provided to adults and children with any advanced, progressive, incurable illness
- o Care given in the last year of life
- o Patients (adults and children), carers, the public, family members and staff (including care after bereavement)

Fig. 1   Strategic Vision

2016
Partially achieving the strategic objectives stated as indicated by the disparity between DiUPR for cancer and non-cancer patients

Strategic Oversight :
BHR
Integrated Care Coalition
Operational Oversight:
Havering End of Life Steering Group

2019
Achievement of strategic objectives in full will lead to narrowing of the gap between DiUPR for cancer and non-cancer patients

6. Local Context

6.1. Commissioning End of Life Care

Currently, HCCG commissions all health based end of life care services in Havering. Contractual relationships exist with GPs, Barking Havering Redbridge University Trust (BHRUT), London Ambulance Service (LAS), St Francis Hospice, North East London Foundation Trust (NELFT) Community Health Services and PELC (out of hours service).

End of Life Care is a priority for Havering as reflected in the

o   Havering Health and Wellbeing Strategy - to ensure informed choice on end of life care through robust information and guidance for patients and carers.

o   HCCG commissioning plan (2014/15) - to improve end of life care through an integrated approach with the local authority using Integrated Case Management (ICM) and community nursing. This will include increasing identification of EoL patients and patients dying in their preferred place of choice, and fully implementing the Gold Standard Framework in all nursing homes and GP practices.

o   Better Care Fund - to provide training for domiciliary care providers, long-term care homes, together with strengthening co-ordination of end of life care services.

- The BHR Integrated Care Coalition, established as an Advisory Board to oversee strategic change across health and social care, is supporting the development of a Frailty programme with the purpose of avoiding unnecessary hospital admissions including at the end of life.

6.2. Local Need

Key messages

- Havering has an ageing population. In the next ten years (2015-2025), we would expect an increase of 20% in those aged 5-10, 26% in those aged 11-17, 13% in those aged 65-84 and 25% in those over 85 years of age[4]. As the population ages there is an increase in the incidence of long term conditions and their complications; and consequent hospitalisations and need for palliative and end of life care.
- Fortunately deaths are uncommon in children and young people in Havering with the majority occurring during the neonatal period.
- Although one of the most ethnically homogenous places in London, Havering is expected to become more ethnically diverse with the proportion of BAME groups doubling from 5% (2015) to 10% in 2030. Approximately 1% of the population die in Havering each year (on average 2,195 people)[5.] On average mortality (rates) in Havering is lower than England and similar to London. The directly age-standardised rate of mortality from all causes for the period 2009-13 is 238 per 100,000 persons aged less than 75 years but with significant variation within borough. The major causes of death are cancers, circulatory diseases, and respiratory diseases.
- People in Havering are living longer, including those with learning difficulties. As a result many will have multiple co-morbidities including dementia, and so may have more complex palliative and EoL care needs.
- People with a Learning Disability make up an estimated 1-3% of the population. Whilst the EoLC needs of people with a learning disability may be no different from those of the general population, the way in which these needs are met should take account of this. Based on the Death in Usual Place of Residence (DiUPR) indicator measured over the period 2013-2015, more people are dying in their place of residence 40.2%, which equates to an 8.3% improvement. Based on this indicator it

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[4] This is Havering; a demographic and socioeconomic profile 2015

[5] Based on the number of deaths over 3-year period (2011-2013) – 6,585 (Data source: ONS PCMD)

means that approximately 878 deaths occur in their usual place of residence and 1317 occur in hospital each year. There is also evidence that there is variation in DiUPR across wards in Havering.

- o The national (VOICES) survey of bereaved people found that three out of four (75%) of bereaved people rate the overall quality of end of life care for their relative as outstanding or good; with 10% rated as poor. The relatives of people who died in hospital rated overall quality of care significantly worse than any other place of death. There is also evidence of significant variation in access[6] and quality of end of life care that people receive. [7]   Havering has been selected for CQC End of Life Care fieldwork review[8] for 2015. The findings of this review will be used to update the implementation plan.
- o GSF training is offered to all GP practices with 90% uptake at the time of writing. There was a 62% uptake of training provided by SFH to nursing homes. Work on the use of electronic EoL care plans is progressing and are accessible to local service providers. In addition a standardised DNR proforma has been locally agreed.

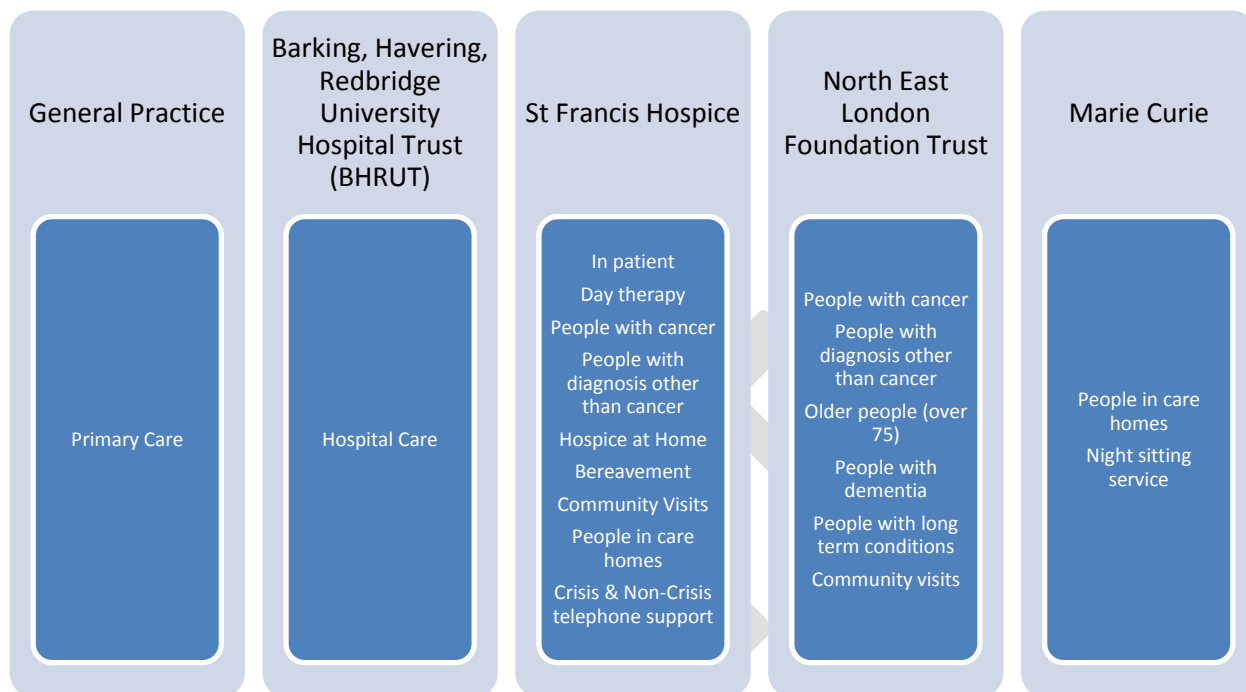## 6.3 Current End of Life Care Provision

A synopsis of current arrangements is shown in the following diagram. Once patients are identified with EoLC needs they have access to a range of services that provide both urgent and supportive care at home, in the community and in hospital.

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[6]Dixon J, King D et al .Equity in the Provision of Palliative Care in the UK: Review of Evidence.2015

[7] http://www.cqc.org.uk/sites/default/files/20150415%20Inequalities%20in%20EOLC%20project%20briefing%20updated.pdf

[8] http://www.cqc.org.uk/content/themed-review-end-life-care

Figure 2   Current End of Life Care Provision in Havering

General Practice	Barking, Havering, Redbridge University Hospital Trust (BHRUT)	St Francis Hospice	North East London Foundation Trust	Marie Curie
Primary Care	Hospital Care	In patient Day therapy People with cancer People with diagnosis other than cancer Hospice at Home Bereavement Community Visits People in care homes Crisis & Non-Crisis telephone support	People with cancer People with diagnosis other than cancer Older people (over 75) People with dementia People with long term conditions Community visits	People in care homes Night sitting service

7.   Specific needs

7.1 End of Life Care for Children

Infants, children and young people with life-limiting conditions, including those who are approaching the end of their life, need high-quality treatment and care that supports them to live as well as possible and to die with dignity. Providing such treatment and care often involves decisions that are complex and emotionally distressing, especially towards the end of their lives.

Together for Short Lives[9] states that most adults only need palliative care at the end of their lives, but many infants, children and young people with life-limiting conditions need palliative care over a much longer period. During this time their condition may fluctuate and there may even be times when it is difficult to determine if death is imminent.

Those who are unlikely to be cured by treatment are offered palliative care. Palliative care for young people is not simply end-of-life care[10] but focuses on enhancing the quality of life.

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[9] Together for Short Lives - A guide to end of life care

[10] Marie Curie Cancer Care and Together for Short Lives (2012).Don't let me down: ensuring a good transition for young people with palliative care needs.

7.2 End of Life care for people with a Learning Disability

Getting it right' for people with intellectual disabilities has huge advantages for palliative care services (or any other mainstream services). The skills needed to meet the norms in this White Paper are transferable. The way in which palliative care is provided for people with intellectual disabilities could thus be a benchmark for all service provision.

In addition there are a significant number of people with LD who live at home with elderly parents who have not ever been supported by services. When the elderly parent becomes terminally ill/dies the person with LD often has to be placed in extremely expensive placements, for they often lose their parent and their home at the same time, which is not helpful for the person with LD. If, when people are terminally ill and they have a vulnerable person they care for, it would be very useful for this to be highlighted so supportive services can be put in touch to assist the vulnerable person to make their loss and bereavement less painful and more planned.

7.3 End of Life Care for people from BAME groups

The available evidence suggests that people from Black, Asian and Minority Ethnic (BAME) groups are less likely to use/have access to end life care services[11]. Potential explanatory factors for the low uptake included lack of referrals, lack of knowledge about services or about what palliative care involves and religious traditions and family values in conflict with the idea of palliative/hospice care. Other factors included structural barriers such as geographical location of inpatient hospices and social segregation, previous bad experiences when in receipt of care.

This research found that ethnic monitoring was inconsistent so that it is difficult to make comparisons over time and to identify where specific needs are not being met. This report also highlighted the fact that BAME groups tend to be labelled 'hard to reach' with the implication that it is people from BAME groups that are not accessible rather than the service. There was also a lack of awareness that ethnicity is something that everyone possesses and that the professionals' beliefs and values underpin attitudes.

The Commission for Racial Equality[12] uses the term 'ethnic minorities', believing that cultural and religious differences are important. Thus there is a tendency to use the notion of 'ethnicity' rather than race in relation to common features such as language, religion and origin. Many religious groups will have their own philosophical and social systems. It is important to recognise the distinct differences in culture between people from different communities. Each situation is unique and will require creative and flexible responses. Staff

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[11] Natalia Calanzani, Dr Jonathan Koffman, Irene J Higginson. Demographic profile and the current state of palliative and end of life care provision for Black, Asian and Minority Ethnic groups in the UK. King's College London, Cicely Saunders Institute June 2013

[12] Together for Short Lives - A guide to end of life care

must be prepared to acknowledge and respect an individual's beliefs and values, even though they may not understand or share them. It is helpful for staff to have some knowledge of the beliefs and rituals associated with death and dying, particularly in relation to issues immediately following death and in care of the body.

7.4 End of Life Care for people with Dementia

People with dementia who are dying should have the same access to end of life care services as those without dementia. However, treatment decisions for people with dementia differ from decisions for other people approaching end of life because:

- The time from diagnosis to death is usually much more difficult to predict and dementia may last several years, or just days because of concurrent illness.
- The deterioration in communication skills for people with dementia prevents them from expressing their views and wishes later in the disease pathway.

It is important that people with dementia and their carers receive information and support that helps them think and plan early for future care. Therefore, health and social care providers should ensure that early diagnostic and assessment services for people with dementia are available, and that they provide good quality information about dementia.

A considerable transformation programme in relation to the diagnosis and treatment of those with dementia in Havering is currently underway, with the implementation of a memory screening clinic and an ageless dementia service. Refocusing services to enable more diagnosis, treatment, care and support in primary and community services requires a trained workforce[13]. End of life care will of course be pivotal to these work streams.

7.5 Bereavement Support

It is well recognised that the period in which EoLC is needed ranges from a few years to a matter of months, weeks or days, and into bereavement[14].

People closely affected by a death should feel that information and support was available to them around the time of death and afterwards, which was appropriate for them and offered at the right time. As such partners involved in the delivery of EoLC need to ensure that there are accessible bereavement support that includes sensitive communication and provision for

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[13] Joint Havering Dementia Strategy 2014

[14] NHS England. Actions for End of Life Care: 2014-16

immediate and on-going emotional and spiritual support appropriate to their needs and preferences.

Bereavement support is provided but there is evidence of variation in access[15] and quality[16] and we need to improve the local offer to patients, carers and families in Havering.

8. Issues for consideration

8.1 Financial

Achieving the aims and objectives of this strategy requires a re-examination of the financial investment in end of life care. To advance a strategic approach to investment there must be greater engagement in discussion about death and dying across the Havering population; improved communication; better provision of operational and financial information; the establishment of an end of life pathway; improved community based end of life care and support; and greater IT interaction to identify and support the coordination of care to end of life patients. This approach will enable service gaps to be filled and duplication of response to be removed, leading to more efficient use of resources.

8.2 Demography

The need for ever improving and more cost efficient end of life care is further highlighted by the Havering population projections, particularly in the over 65 age group. As the population lives longer, the proportion of people with various long term conditions continues to rise and the End of Life Care pathway needs to adjust to these changes appropriately.

The services implementing the strategy will take account of the increasing ethnic diversity of people in Havering and the considerable life expectancy variations between the most affluent and most deprived parts of the borough.

8.3 Public Awareness

In current UK culture, death and dying are not widely talked about. This is to the detriment of people with dementia. If death and dying were more widely discussed, and planning for end of life was routine practice among the general public, there would be clear plans in place so that most people would not reach the end of their lives and not have their wishes known. The national strategy recognises that as a nation we face multiple challenges in responding to the needs and preferences of people who are approaching death. Focus is therefore clearly placed on improving and changing the way in which we respond to end of life care and how we communicate difficult news and information. This strategy acknowledges the need to develop new approaches and initiatives which can initiate a cultural change and

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[15]Dixon J, King D et al .Equity in the Provision of Palliative Care in the UK: Review of Evidence.2015

[16] http://www.cqc.org.uk/sites/default/files/20150415%20Inequalities%20in%20EOLC%20project%20briefing%20updated.pdf

enable patients, friends, relatives and carers of patients approaching the end of their life's to openly discuss their personal needs and preferences and choices.

Havering Death Café events were held in 2015. Each 'café' provided the opportunity for interested persons to discuss issues that are relevant to them. We aim to expand this programme based on the learning from the events.

8.4 Electronic Care Plans

Electronic Palliative Care Co-ordination Systems (EPaCCS) enable the recording and sharing of people's care preferences and key details about their care with those delivering their care. The systems support co-ordination of care. The use of EPaCCS began with eight locality pilot sites in 2009-2011 and roll-out across England has progressed since then.

8.5 Workforce Implications

Workforce development plays an integral role in the delivery of high quality, responsive end of life care. As part of both national and local reviews it has been recognised that there are major deficiencies in the knowledge, skills, attitudes and behaviours of staff groups who come into frequent contact with people at the end of their lives.
In response to these shortfalls, we have begun to identify current and future training needs in line with the national strategy guidance. Everyone should be GSF trained

9. Strategy Implementation

An action plan (Table 1) will be developed by the End of Life Care Steering Group. It will outline the prioritised actions to be implemented within the next three years. The implementation plan will take into account the responses from the 2014 EoLC conference and the CQC visit in Oct 2015. The plan will be reviewed annually and amended where necessary to ensure that the actions put in place achieve high quality care.

The EoLC Steering Group will review and update this plan on an annual basis, or more frequently if required.

The key performance indicators listed in Table 2 will be used by the EoLC steering group to monitor the progress of this strategy.

Table 1: ACTION PLAN

Action Plan 16-17	Activity	Outcome	Owner	Timescale
End of Life care Quality Assessment tool	Complete the self - assessment- consider and agree	Baseline of true position of quality and capacity across Havering	EoLC Steering Group- partners	Aug 2017
Electronic Care Plans				March 2017
GSF Training	Training sessions for professionals	All GPs and Care Homes GSF trained	TBC	March 2017
Awareness raising with BAME groups	Focus groups	Better understanding of the needs/views of BAME groups	TBC	Dec 2017
Withdrawal At Home			TBC	
Death Café's		Raised awareness and opportunities to discuss death and dying	Dr Saini	
CQC Visit- Out of Hours Provision			Bob Barr	
GP Education	PTI Session to present EoLC Strategy; EoLC Plans Medications/Scripts	Increased awareness of Havering approach; more complete EoLC registers; Improved pain management	Dr Saini	
Bereavement service-		local service specification developed in partnership with acute, community, voluntary and private sector providers and local authorities		

Table 2: EOLC DASHBOARD

Strategic Objective	Key Performance Indicator	Baseline 15/16	Target 16/17	Comments
Ensure each person approaching end of life is seen as an individual	Number of people with EOLC who are identified EolC registers	TBC		
Ensure that each person gets fair access to care	Gap in the in DiUPR between cancer and non-cancer patients	TBC		EoL Profiles 2012-2014 Place of death by cause: (biggest gap by condition cancer and respiratory) <table><tr><td></td><td>Hospital</td><td>Home</td></tr><tr><td>Cancer</td><td>37%</td><td>30%</td></tr><tr><td>Respiratory</td><td>68%</td><td>14%</td></tr></table>
Improve care planning	Proportion of patients with EOLC needs that have a completed care plan	TBC		Based on GP registers?
Have co-ordinated care across the health and social care system	Proportion of people with EoLC plan who is known to all agencies	100%		Partial roll out of electronic records; will need to ensure that new providers have access to plans
Ensure services are prepared and offer high quality care	Proportion of eligible health and social care staff GSF trained	TBC		
Ensure we build compassionate and resilient communities that will cope better and help each other in times of crisis and loss	Awareness raising activities: Death Cafe	2 sessions	6	