Hackney

REPORT OF THE HEALTH IN HACKNEY SCRUTINY COMMISSION

End of Life Care **Health in Hackney Scrutiny Commission** **15th March 2017**	**Classification** Public	**Enclosures**

FOREWORD

End of life care has been much discussed in the news because of the changing age profile within the UK and concern as to how health services are managing this change. Within London the population aged 65+ is expected to rise by over 1.5 million by 2041. Hackney has a younger profile, nevertheless the number of residents aged 85 or over is projected to grow significantly. However, given that this was not an area that we had scrutinised previously we did not restrict the review to care of the elderly.

We made site visits to St Joseph’s Hospice, Richard House Children’s Hospice, Beis Pinchas nursing home, Acorn Lodge Care Centre and attended a Death Café and an NHS Community Voices event “Dying well in City in Hackney” We took evidence in formal scrutiny meetings from the Homerton University Hospital, City and Hackney Clinical Commissioning Group, Marie Curie, Age UK, the Older People’s reference group, Interlink Foundation and the Conscious Aging Trust.

We learned about Co-ordinate My Care a shared electronic system for recording patients’ wishes about their care. We heard concerns about the difficulties when elderly frail patients are suddenly transferred to acute settings. And as always, we heard the need for agencies to work better together.

It’s a timely review, working better together is at the heart of Hackney’s health devolution pilot, which sees the integration of health service and social care budgets. The recommendations for this review can feed in to the pilot.

Our recommendations include additional training for nurses, more support for discussions with patients about their wishes, better awareness of available services, culturally sensitive support and the need to plan for children’s palliative care across a larger area.

I would like to thank all of those who generously gave their time to give evidence to the commission or to host a site visit.

Cllr. Ann Munn
Chair – Health in Hackney Scrutiny Commission

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1. INTRODUCTION

1.1 End of life care refers to the care and support that is provided in the last few months or years of a person who has an incurable illness. The main aim of end of life care and support is to help people to die with dignity while ensuring that they and their families have the right levels of support to enable them to do this.

1.2 End of life care is commissioned locally by councils and clinical commissioning groups and the delivery and quality of services can therefore vary between areas however, a common feature is that care is provided by both specialist and non-specialist services including:

Hospitals	Acute, intensive care units, elderly care, oncology, respiratory and cardiac medicine
Primary care	GPs, community nurses, nursing and care homes
Specialist palliative care	In hospitals, within communities and hospice settings
Social care and additional health care	Social care packages, health and wellbeing initiatives (via PH), support from VCS sector

1.3 A London Council's briefing[1] recently outlined how:

- Despite the majority of people saying they would prefer to die in their own home[2] London has the highest proportion of people dying in hospital of all English regions. Between 2011 and 2013, 49 per cent of deaths in England occurred in hospital compared to 55 per cent in London.

- London has the highest average length of hospital stay for people with a terminal illness compared to other regions in England.

- The 2011 national VOICES survey of bereaved relatives rated overall quality of care across all services lower in London than in any other part of the country.

- The capital's population aged 65+ is projected to rise to over 1.5 million by 2041. With people living longer and with more complex health needs, an increase in demand for palliative care is expected.

- In London, less than half of the people who have palliative care needs actually receive that care. In 2014, over two thirds of hospital specialist palliative care services and over a third of community specialist palliative services were not

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[1] End of Life Care In London, London Councils, Jan 2016

[2] **http://www.dyingmatters.org/overview/why-talk-about-it**

funded to provide 24/7 telephone advice and 9 to 5, seven days a week face-to-face visiting.

Background and drivers for the review

1.4 Rising demand for health and social care is primarily due to a growing population and advances in medicine, so that people live longer with complex, chronic and life-limiting conditions. Many are also living longer healthier lives with consequent demand for services later on. To meet demand there is a need therefore to improve the coordination and integration of services and to work in partnership with individuals and families to empower them to make informed choices about their care, including where the person wishes to die and the quality of care they receive at the end of their lives.

1.5 The first comprehensive strategy to promote high quality care and support for those reaching the end of their life was published by the Department of Health in 2008. Since its publication the way care is provided has shifted with a greater emphasis on person-focused care, integrated services and local decision-making and delivery. In September 2015 a new national framework for end of life care was published which acknowledges the increasing demands placed on those who commission or provide services to improve quality and efficiency with reducing resources.

1.6 The National Framework set out six ambitions to ensure a good end of life experience as well as eight 'building blocks' that need to be in place to enable those ambitions to be achieved including personalised care plans, shared records and involvement of the dying person. These are expanded upon in 5.1.2.

Why do the review now

1.7 National research shows that currently almost half of all deaths (47%) take place in hospital[3]. Nearly 30% of all hospital beds are occupied by someone in their last year of life[4]. The majority of deaths occur following a period of chronic illness such as respiratory disease, heart disease or cancer. Almost 500,000 people die each year in England, two thirds of whom are 75 years or older. With an ageing population, the number of deaths is set to increase by 17% between 2012 and 2030[5].

1.8 In 2015 **53%** of City & Hackney residents died in hospital – around the same as the London average, though higher than the national rate (see Appendix 1). The proportion of deaths occurring in hospital of local residents has fallen by about 10% over the past 10 years with a similar fall evident in national data. **24%** of City & Hackney residents die at home. There are also variations by ward (see Appendix 2). This is similar to the London and national average, and has increased in recent years. The proportion of residents who die in

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[3] National End of Life Care Intelligence Network, 2015

[4] Prevalent cohort study D. Clark et al 2014 reported in CCG evidence to Commission, 5 Oct 2015

[5] Local Preferences and Place of Death in Regions within England 2010, National End of Life Care Intelligence Network (2011).

care homes (**8%**) and hospices (**11%**) have also increased in recent years, though remain below the national average[6]. This is at least partly a reflection of local demographics (a relatively low elderly population, just 7% over 65 and 3% over 75[7]). Each year a further 2.5% of residents who die, die in other places – for example outdoors or in commercial premises.[8]

1.9 One of the four priorities in the refreshed Hackney Health and Wellbeing Strategy 2015-18 is "*Caring for people with dementia, ensuring our services are meeting the needs of the older population*". The Strategy points out that the size of the Hackney population aged 85 and over is projected to grow significantly and by 2020 there are likely to be almost 2,000 people living locally with dementia.[9] In relation to dementia specifically, a Dementia Alliance has been established to bring the Homerton Hospital, East London Foundation Trust and the Alzheimer's Society together to deliver the required improvements. To make this review manageable in the limited time we had available we had to rule certain areas out of scope. We decided not focus on Dementia and Alzheimers issues. We considered both of these are of a scale and complexity to require separate reviews, however issues relating to them did obviously come up in discussions.

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[6] http://fingertips.phe.org.uk/profile/end-of-life/data#page/0/gid/1938132883/pat/6/par/E12000007/ati/102/are/E09000012/iid/91756/age/1/sex/4

[7] Briefing from HUHFT to Commission on 10 Oct 2016

[8] : http://fingertips.phe.org.uk/profile/end-of-life/data#page/0/gid/1938132883/pat/6/par/E12000007/ati/102/are/E09000012/iid/91756/age/1/sex/4

[9] Hackney Health and Wellbeing Strategy 2015-18, p. 10

Core Questions

1.11 Our review set out to answer the following questions:

CORE QUESTIONS

1) With a growing elderly population and more people living with Long Term Conditions, how can the aspiration of most residents to die at home, be met by providers of health and social care in Hackney?

2.) With people now more autonomous than in the past and wishing to exercise patient choice and control in terms of their end of life care, how prepared are local providers to deliver a joined-up 24 hour system, including sufficient late-night care?

3.) With the numbers of adults who could benefit from palliative care known to hospices being just a small minority of the total, how could providers encourage a better take-up of their services and what are the funding implications?

3.) How could the communication skills of medical practitioners in terms of end of life care issues be improved?

4.) How can the public be better informed and educated about end of life care so that they better understand the mix of options generally available in home vs acute care?

5.) Are we over-medicalising end of life care and what might be done to reduce for example the amount of inappropriate medical interventions.

2. EXECUTIVE SUMMARY AND LIST OF RECOMMENDATIONS

2.1 Executive Summary

2.1.1 End of life care refers to the care and support that is provided in the last few months or years of a person who has an incurable illness. This review set out to examine how the mix of options available locally for those at end of life, their families and their carers, might be improved. It sought to address how communication issues between families and medical practitioners and between individual health partners could be improved. We also wanted to explore how to drive up use of our excellent local hospice and how the stigma around death and dying can be reduced, perhaps by community action.

2.1.2 Over the course of eleven different meetings, both formal and informal, and a number of site visits we heard from a range of commissioners and providers as well as from residents who are or have been affected by end of life care issues.

2.1.3 Our report is being published as the new Hackney Devolution Pilot is about to be implemented on 1 April. This will see the bulk of Council's and the CCG's health and social care funding going into one pooled budget overseen by a new Integrated Commissioning Board (ICB). A new Unplanned Care Board is being created underneath the ICB and this we hope will provide an opportunity to make real gains in terms of much needed integration and co-ordination of services. This will build on the *One City and Hackney* pilot which had already made progress on these issues across a number of fronts. The *Co-ordinate My Care* system (an electronic care plan which is accessible to all the care professionals) is central to the CCGs efforts here and we have made a number of recommendations to the CCG's End of Life Care Board, which is currently the hub for planning all end of life care services.

2.1.4 Our recommendations encompass: how to make the new integration work; driving up the use of *Co-ordinate My Care*; improving nurses' training; better alignment of transfers of care between care homes and hospitals; how to improve communication between medical practitioners and families, in particular in relation to having those difficult but necessary conversations; raising awareness of local hospice and other services; how the local community and voluntary sector might play a bigger role in supporting those caring for those at end of life; improving culturally appropriate services and the specific needs of children who are at end of life.

2.1.5. Our review has caused us to question whether there are perhaps unreal expectations about the nature of death and dying mixed in with the current drive by acute providers to ensure that more people die at home. Dying at home is often protracted and needs will escalate and alter over time and therefore the support services need to be both flexible and robust enough to cope. For those who live alone and may not have someone to champion their cause through the complex matrix of services, there is the added danger that they may fall between services. We hope that with devolution and integration real progress can be made on both of these fronts.

2.2 Our recommendations are:

Recommendation One
The Commission recommends that the new Unplanned Care Board use the new Quadrant work stream to ensure that processes for communication with patients at end of life and coordination between agencies are firmly in place, that they continue to be adhered to and that work is undertaken to improve them.

Recommendation Two
The Commission requests the GP Confederation, as operators of the Coordinate My Care system, to:

- **(a) Ensure all health partners are active in ensuring that there is greater uptake of CMC**
- **(b) Ensure that all relevant health and care providers can and do access CMC records for patients in their care**
- **(c) To report back on the pilot whereby social workers were given access to a GP Practice's EMIS system and the viability of extending this.**
- **(d) Explain why patients of children's hospices are not currently included in CMC.**

Recommendation Three
The Commission requests the Chief Nurse of HUHFT to explore how, as part of their initial and continuing training, the Homerton's nurses and Health Care Assistants could learn from going on secondments to Hackney's care homes to share best practice in caring for frail elderly people e.g. in washing, feeding and hydration.
The Commission would also like to be advised how the training modules for geriatric and palliative care have developed of late and what scope there is for increasing joint training with care homes.

Recommendation Four
The Commission recommends that the new Unplanned Care Board work with the City and Hackney EOLC Board to examine how outcomes for frail elderly patients at end of life might be improved if a better co-ordinated system of controlling movement between care homes and acute settings was instigated and care home staff were supported to access advice from other sources where appropriate. Furthermore we request London Ambulance Service to examine their Clinical Triage Process on responding to calls from families of very frail elderly people at end of life stage <u>in care homes</u> where families want the patient transferred to acute care. What are the guidelines here and who do the LAS staff take direction from? Are Paradoc always called out? LAS also to be mindful that advance care plans/CMC records may be in place and these would need to be consulted.

Recommendation Five
The Commission's recommends the CCG's EOLC Board to consider how lines of responsibility can be better communicated to families of EOLC patients so that it is clear to them who is taking responsibility at each stage of the process

Recommendation Six
The Commission requests the Chief Nurse of HUHFT and the Chair of the CCG's EOLC Board to report back on how training of clinicians in having difficult conversations around End of Life Care issues could be improved. This should include the need for Advance Care Planning, Advance Decision to Refuse Treatment, Do Not Attempt CPR plans and the need to get more patients onto systems such as 'Co-ordinate My Care'.

Recommendation Seven
The Commission requests St Joseph's to work with the CCG's End of Life Care Board on increasing awareness of St Joseph's services locally, including working towards equality of access for different communities in the borough and to better signpost other EOLC support in the borough. In particular there needs to be an emphasis on reaching and supporting carers. The plan should also consider how more specialist services, such as St Joseph's Namaste care, for example, can be promoted.

Recommendation Eight
The Commission recommends to the End of Life Care Board to work towards making City and Hackney a 'Compassionate Community' as per Devon's 'Compassionate Community Hub' and report back on how the issues raised in the NCPC report could be taken forward locally. This would involve close working with HCVS, Age UK East London, Older People's Reference Group and Connect Hackney. The Hub would bring together a Caring Network Forum, Peer Support Groups and community engagement activities.

Recommendation Nine
The Commission requests Connect Hackney to consider using part of its funding to <u>increase awareness</u> about End of Life Care issues for older people. This could focus on what is the current local offer and how it might be improved

Recommendation Ten
The Commission requests HCVS and in particular Connect Hackney and Age UK East London to examine how there might be a greater role for the sector locally in <u>facilitating discussions with patients</u> at End of Life stage. This could focus on the desire to die at home, the need for ACPs, the need for a will, the need to consider lasting power of attorney for health and welfare decisions etc. This builds on the work of St Joseph's 'Compassionate Neighbours' volunteers but would have a focus on end of life care planning rather than general support and befriending.

Recommendation Eleven
The Commission requests the Council's Adult Services and the Compassionate Neighbours Co-ordinator at St Joseph's to explore how the Compassionate Neighbour volunteers can better signpost clients into council advice and support services and on the other hand how social workers might be able to refer possible clients who are socially isolated into the Compassionate Neighbours scheme, therefore maximising take-up of it.

Recommendation Twelve

Whilst the Commission supports the current NHS guidance that a patients' right to know and to make their own decisions supersedes the rights of their family, the Commission would like HUHFT and St Joseph's to explain what work they are doing with the Charedi community to address that community's concerns about what they consider as a lack of culturally appropriate end of life care. The Commission also requests St Joseph's to report on progress being made in driving up the use of the hospice by other BME communities where there may be other cultural sensitivities.

Recommendation Thirteen

The Commission recommends the Cabinet Member of Health Social Care and Devolution include the concerns of the children's palliative care sector when considering the reconfiguration proposals underway as part of the NEL STP. This also applies to reconfiguration of Urgent Care and Out of Hours Services. Children's palliative care would benefit from being planned across a larger footprint than is currently the case. Variations in funding and structure of support available across borough boundaries makes it difficult for Children's Hospices to plan their services.

3. FINANCIAL COMMENTS

3.1 There are no direct financial implications for the Council arising from the recommendations contained within this report. Any subsequent costs which emerge for the Council from their implementation will need to be met from existing resources.

4. LEGAL COMMENTS

4.1 Legal has noted the contents of the report. There are no immediate legal implications arising from this report.

5. FINDINGS

5.1 CONTEXT AND INCIDENCE

5.1.1 Evidence for this review was gathered during two commission meetings and five site visits/meetings. The Commission received detailed reports from the commissioners and service providers who are involved and **we will not repeat that information here** but it can be found in the agendas for the 10 October 2016, 29 November 2016 and 16 January 2017. Instead we will draw out the main themes of our findings and the basis for our recommendations.

The National Framework

5.1.2 The first comprehensive strategy to promote high quality care and support for those reaching the end of their life was published by the Department of Health in 2008. Since its publication the way care is provided has shifted with a greater emphasis on person-focused care, integrated services and local decision-making and delivery. Then in September 2015 a new national framework for end of life care was published which acknowledged the increasing demands placed on those who commission or provide services to improve quality and efficiency with reducing resources. The National Framework sets out the following six ambitions to ensure a good end of life experience for patients and their families:

- *Each person should be seen as an individual, and their family and loved ones should be kept informed by the care providers and be given appropriate support.*
- *Each person must get fair access to quality care and support regardless of where they live.*
- *The care provided should be reviewed regularly and adjusted to ensure the person does not get distressed.*
- *Health and care providers must co-operate so that all providers are aware of the person's preferences. Support must also be available 24 hours a day, seven days a week.*
- *All staff are competent, confident and prepared to provide the needed care.*
- *Society is ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*

Moving on from the Liverpool Care Pathway

5.1.3 The public's faith in end of life care treatment has in the recent past been tarnished because of the controversy surrounding The Liverpool Care Pathway. This had been developed by Royal Liverpool University Hospital and Liverpool's Marie Curie Hospice in the late 1990s for the care of terminally ill cancer patients. The LCP was then extended to include all patients deemed dying. It was developed to help doctors and nurses provide quality end of life care. It has since been discredited. It was widely abused as a 'tick box exercise', with patients being casually assessed as terminal, heavily sedated, and denied water so the diagnosis became self-fulfilling. The criticism was also made that hospitals had been provided with cash incentives to achieve targets for the number of patients dying on the LCP.

5.1.4 In July 2013, the results of an independent review into the LCP led by Baroness Julia Neuberger were published. Accepting the review's recommendations, the government advised that NHS hospitals should phase out the use of the LCP over the following 6–12 months, and that "*NHS England should work with CCGs to bring about an immediate end to local financial incentives for hospitals to promote a certain type of care for dying patients, including the LCP".*

5.1.5 Since the controversy over the LCP a wealth of reports have highlighted variable standards of provision across wards and organisations and a lack of co-ordination in services for end of life care. These include: *More Care, Less Pathway: A review of the Liverpool Care Pathway 2013; Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life* and *End of Life Care House of Commons Health Committee report 2015*.

Initiatives in London

5.1.6 In London there has been a cross-sector response to the challenges of end of life care involving directors of social services, the NHS and voluntary sector working together. A number of initiatives are underway and we learned about the operation of these from representatives of Marie Curie. These are:

***Pan London End of Life Alliance* -** set up in partnership with the London Association of Directors of Adult Social Services (ADASS), Marie Curie and NHSE London. The Alliance also has representation that cuts across health, social care and the voluntary sector. The Alliance was tasked with bringing together different partners and stakeholders to ensure that end of life services are integrated. The Alliance's primary aim is to promote patient-centred and coordinated care commissioning and delivery models across London.

***End of Life Care Charter* –** All London directors of adult social services have signed up to the charter which commits social care practitioners to ensuring that a sensitive, appropriate and holistic approach is provided at the right time taking account of the practical, emotional and spiritual needs of people approaching end of life and their carers.

***End of Life Care Network* –** a proactive network with membership from across the sector including a range of statutory and voluntary agencies. The network focuses on a range of issues, for example, how inappropriate referrals to A&E can be minimised for those receiving end of life care. The network also oversees the implementation of the Charter.

London Assembly Health Committee findings on End of Life Care

5.1.7 The London Assembly's Health Committee concluded its own investigation on 'End of Life Care in London' in Sept 2016 and we noted in particular that the London Association of Directors of Adult Social Services' submission to the review identified the following needs:

- End of life training for all social and health care staff in all settings.
- Equal access in all boroughs to community nursing and specialist palliative care.
- Resources shifted from acute to community providers to manage out-of-hospital care.
- Provision of adequate housing to meet the needs of an aging population to enable care to be provided in the home.

5.1.8 The London Assembly Committee made the following findings:[10]

a) "Only 8 out of 33 London Clinical Commissioning Groups (CCGs) scored above the national average for end of life care quality indicators and fewer than half of local authorities include end of life care within their Health and Wellbeing Strategies. CCGs spend a wide range of money on each death, the least spent £540 per death and the most spent £3,740 per death.

b) 70% of hospitals in London cannot provide specialist palliative care services seven days a week and only 24% of London patients accessing palliative care have a non-cancer diagnosis.
c) Around 10% of London households are occupied by a person aged over 65 who lives alone, yet access to services is unequal, with older people, living alone, struggling to access the care they need".

They also recommended to the Mayor of London that he push for all Health and Wellbeing Boards to include end of life care in their Health and Wellbeing Strategies, something we would echo.

5.2 THE COMMISSIONING LANDSCAPE

CCG's End of Life Care Board

5.2.1 Locally end of life care services and support are commissioned by the CCG and the Council and care is provided by both specialist and non-specialist services.

5.2.2 The CCG has a responsibility for commissioning the health element of End of Life Care for the residents of City and Hackney and has an End of Life Care Board. It meets 3-4 times a year and its membership includes all relevant stakeholders, including the Homerton University Hospital Foundation Trust, St

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[10] http://www.london.gov.uk/assembly-publications/end-life-care

Joseph's Hospice, Marie Curie, GP Confederation and East London Foundation Trust. The CCG has an end of life care clinical lead and an end of life care lead manager (commissioner).

5.2.3 Nationally CCGs are required to deliver on the NHS *Five Year Forward View* and the new Sustainability and Transformation Plans. NHSE's *Actions for End of Life Care* (2014/16 NHS England), *NICE Quality Standard for End of Life Care (2011)* and the findings of the London Assembly's Health Committee on *End of Life Care in London* (February, 2016) set the context for their work.

5.2.4 The Board set themselves the following priorities for 2016/7:

- Earlier identification of people approaching end of life
- Coordination of care
- Preparing patients and families for end of life
- Improved quality of end of life care
- Improved collection of patient experience and engagement of communities
- Ensuring staff feel confident and competent to have difficult conversations about end of life care

5.2.5 In our meeting with the Chair of the EOLC Board we learned about some of their key challenges such as:

Consistent care pathway: Ensuring that there is a consistent approach across the borough so that all patients receive access to the same level of care.

Unmet needs amongst vulnerable and hard to reach groups: Understanding unmet need. Some BME groups for example are not accessing palliative care as much as they should and a project has begun with St Joseph's.

Access to interpreting and advocacy: Ensuring patients for whom English is not their first language can have open conversations about their diagnosis and planning end of life care.

5.2.5 As regards earlier identification of end of life care issues they have the following in place:

Training for GPs/other community staff: run by Homerton geriatricians, 1 day training, simulation based, including raising topic of dying with patient, encouraging them to express wishes, dealing with family, writing and recording advance care plan.

Enhanced Service Contract with GPs: identify patients in last year of life, offer conversations about Advance Care Plans and Do Not Attempt Resuscitation plans, creation of Co-ordinate My Care records, as appropriate

CQUIN[11] with Homerton: commenced in September 2015. To include: information on patient discharges from Elderly Care Unit, conversations about ceilings of treatment, prompting GPs to start/continue conversations on advance care planning and assisting GPs in identifying patients who are approaching end of life.

5.2.6 The CCG also developed the *One Hackney and City* pilot on Integrated Care. This has now concluded. It is being replaced by the incoming Quadrant Model which is part of the new Hackney Devolution Pilot which involves a pooled budget and the creation of a new Integrated Commissioning Board. In terms of end of life care issues however the One Hackney and City pilot did make a lot of progress and was successful in:

- Involvement of St Joseph's on the One Hackney and City provider board
- Extra Clinical Nurse Specialist (CNS) capacity (1 per quadrant), involvement in Multi-Disciplinary Teams (MDT) and GP Practice meetings, better identification of patients, earlier involvement of CNSs, better access to St. Joseph's services
- Improved 24/7 access and advice: extra Marie Curie night nursing capacity, St Joseph's Hospice 24/7 advice and information line, more District Nurse capacity and Out of Hours (OOH) cover (including 24/7 telephone access line for patients), work with Out of Hours provider.

5.2.7 The CCG commissions a range of end of life care related services including specialist palliative care 24 hrs a day and 7 days a week. Here is an overview:[12]

Provider	***Service***
St Joseph's Hospice	Services include a wide range of palliative care including, inpatient, day and community care offering, nursing and medical care, emotional support, practical advice, physical and psychological therapies, spiritual care, social and creative activities. Contract value: £2,362,581
Mildmay Mission Hospital UK	Provision of specialist services to people with HIV across the following strands: Neuro-cognitive impairment and complex physical rehabilitation; Respite and End of Life care; Day services Contract value: £308,498
Marie Curie	Provision of palliative night nursing service in the community (registered nurses and health care assistants). This service is managed by the Homerton Hospital. Contract value: £30,000 (through the Homerton)
Richard House	Children's palliative care (inpatient and day care) for those aged 0-19 years. Services for those with life-limiting and life threatening conditions and have complex health care needs. Richard House are working with commissioners to develop their outreach model to best support the

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[11] Commissioning for Quality and Innovation is a standard NHS performance target

[12] Extract from briefing to 5 October 2016 meeting with the Commission

	needs of local families. They work collaboratively with the Community Children's Nurses at the Homerton and St Joseph's. Young people may also have access to short breaks (respite through leisure activities) funding from the council (criteria is middle or high level disability living allowance) or from the CCG's commissioned providers (KIDS Adventure Playground or the Huddleston for swimming) should they require Nursing support during these activities Contract value: £71,965
Specialist palliative care within acute trust	Within the wider acute contract with the Homerton there is provision and funding for palliative care.
Extra spend on continuing healthcare and community nursing within the Adult Community Nursing contract	There are a range of elements of service within continuing care and the Community Health Service (CHS) block contract with the Homerton that make provision for palliative care
EOLC contract across GP practices operated by the GP Confederation (including Co-ordinate My Care)	The CCG commissions the GP Confederation to deliver this service. GPs actively identify patients within their practice who may be considered to be in their last year of life using the SPICT[13] tool or other appropriate tool. The service entails the GP talking to patients who they consider are in the last year of life and placing them on the palliative care register and if appropriate on the **Co-ordinate My Care** system. The GPs also attempt to discuss with the patients and their relatives (as appropriate) advanced care planning including how to achieve a quality end of life care and DNACPR. The GP talks with the patient (and relatives where appropriate/with consent) regarding their condition(s) and then enters the patient's details onto the QOF palliative care register. The GP also talks with the patient (and relatives where appropriate/with consent) regarding Advanced Care Planning (ACP) and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR). Contract value: £161,700 per annum
Triangle	This service provides rapid access to domiciliary services of personal care and respite care to individuals at home. Contract value: £125,000 per annum
Other	Additionally, the CCG provides funding for support bereavement counselling, which includes bereavement for families and carers of patients who are identified as End of life, who were not under the care of St Josephs. Such a service is also provided by St Joseph's Hospice for the carers and families of patients under the care of St Josephs. There are community nurses dedicated to palliative care funded through One City and Hackney

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[13] The SPICT™ is a validated tool used to identify people at risk of deteriorating and dying with one or more advanced conditions for palliative care needs assessment and care planning

5.3 OUTCOMES

5.3.1 Nationally, survey data suggest that more people would, given the choice and conditions being right, prefer to die at home and fewer wish to die in hospital than is currently the case. Latest ONS data shows that 46.9% of people died in hospital, although the proportion of people dying at home or in care homes continue to increase (based on Q3 data 2015/16).

5.3.2 Supporting people to die in their preferred place of choice and reducing the number of deaths in hospital is a key focus of the NHS and for CCGs in developing *Sustainability and Transformation Plans*. The importance of end of life care is further highlighted by its incorporation under 2.2 (Patient Experience) in the Mandate to NHS England[14].

5.3.3 There are around 1000 deaths in City and Hackney across all age groups each year. The majority of these are in hospital but the proportion of them is decreasing over time. A higher proportion die in hospital in City and Hackney than nationally however. The National VOICES survey showed that relatives of people who died in hospital rated overall quality of care significantly worse than any other place of death. Locally a higher proportion than the national average die outside of hospital but the majority in Hackney still die in a hospital. One City & Hackney had a performance measure: “% of deaths outside of hospital”. This was achieved for 2015, increasing from 43% to baseline to 45%. The latest data available on proportion of patient who die in hospital is Q3 2015/16. The table below shows City & Hackney and its comparator CCGs. C&H has a higher rate that the England average, but lower than the average of our comparator CCGs in north east London.

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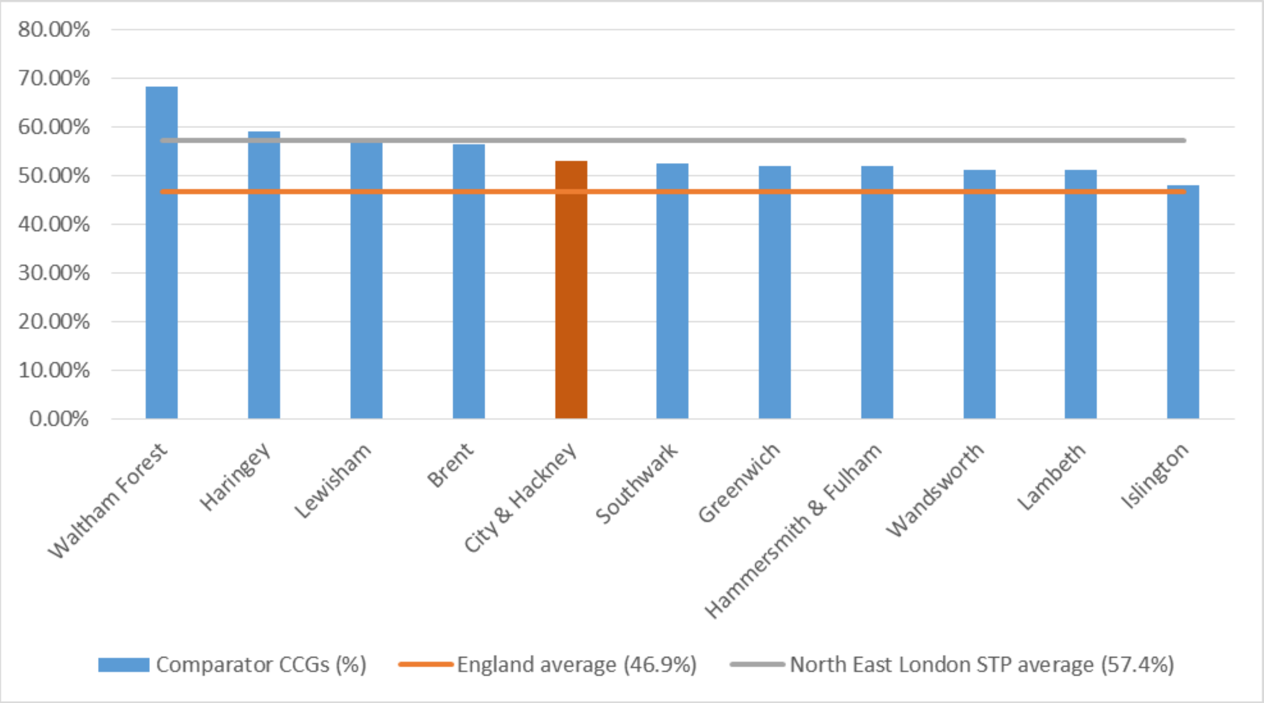
[14] https://www.gov.uk/government/publications/nhsmandate-2016-to-2017

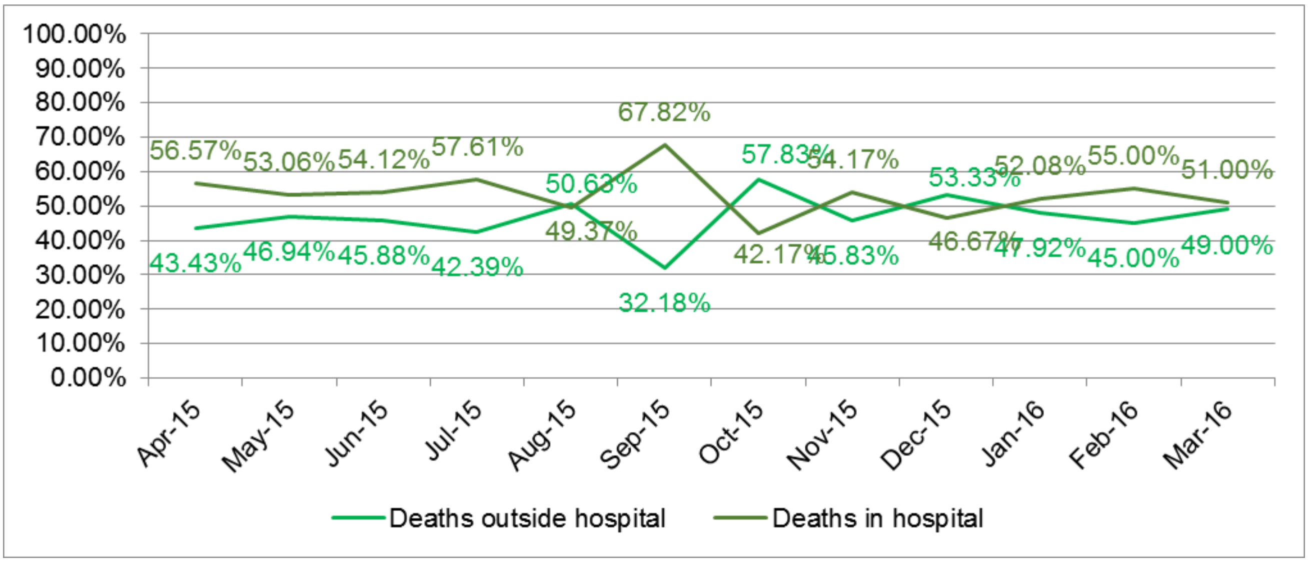
Chart 1: Percentage of deaths that take place in hospital (Q3, 2015/16)



Source: http://www.endoflifecareintelligence.org.uk/data_sources/place_of_death.

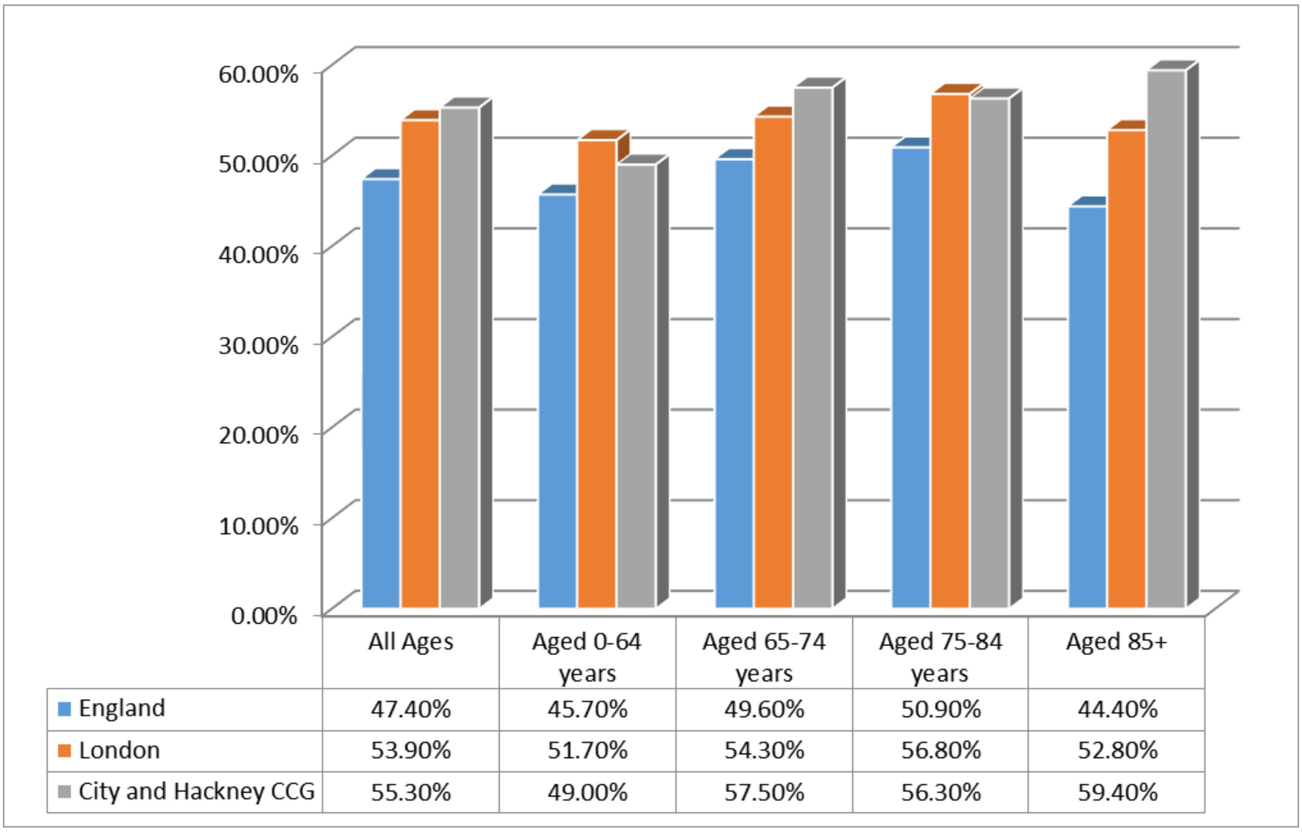
5.3.4 Looking at data over time, we are seeing a reduction in the number of deaths taking place in hospital.

Chart 2: Deaths that take place in and out of Hospital in City & Hackney



Source: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

Chart 3: Hospital Deaths by Age (2014): C&H compared with England and London

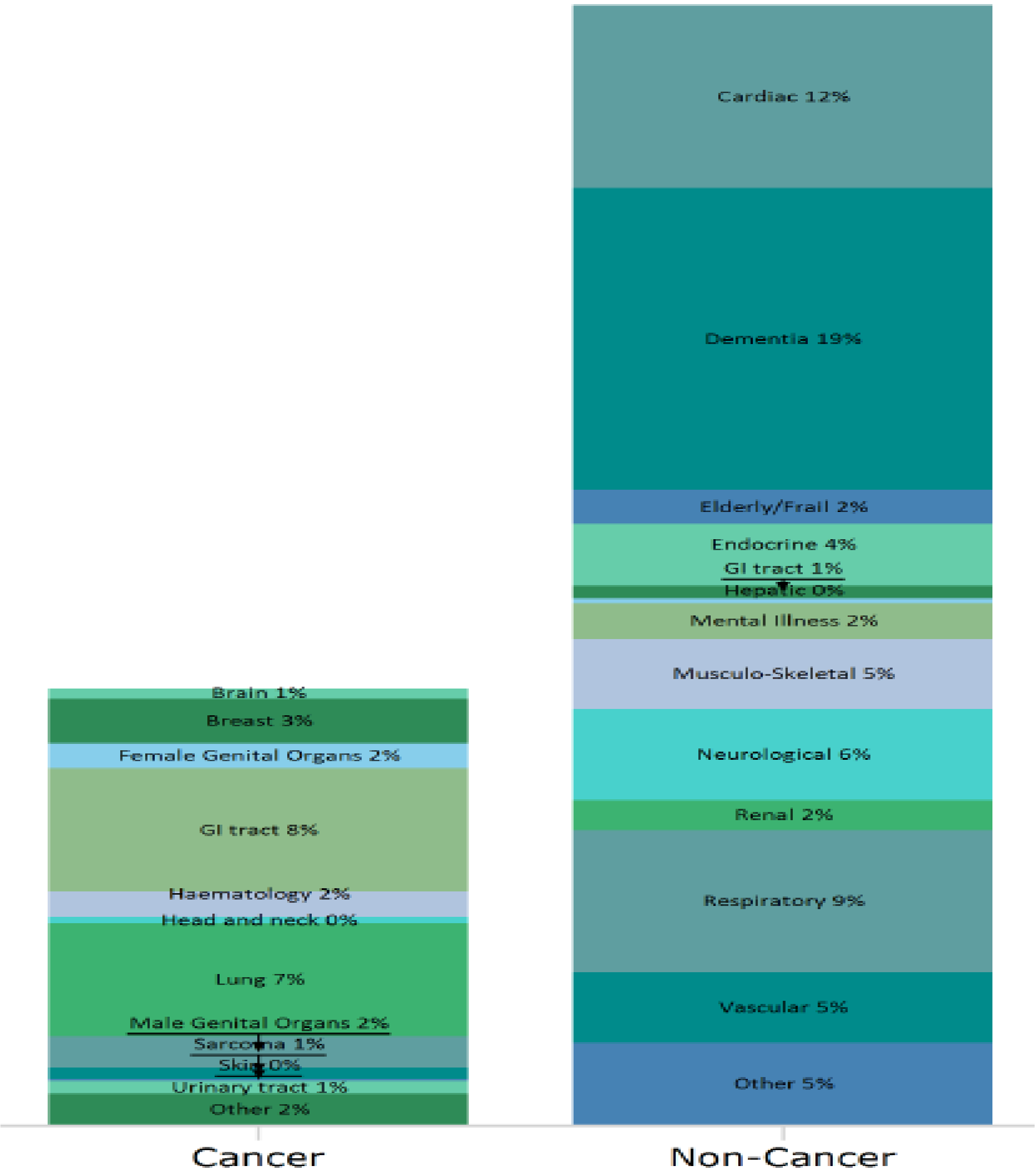


	All Ages	Aged 0-64 years	Aged 65-74 years	Aged 75-84 years	Aged 85+
■ England	47.40%	45.70%	49.60%	50.90%	44.40%
■ London	53.90%	51.70%	54.30%	56.80%	52.80%
■ City and Hackney CCG	55.30%	49.00%	57.50%	56.30%	59.40%

Source: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death;

5.3.5 We also noted a range of data from the CCG from those GPs registered with the Co-ordinate My Care system. This information now also includes preferred place of death. Date presented to us in September suggested that 72% of people recorded on CMC died in their preferred place of death. Over the 12 months to September, the number of patients at the end of life that have been registered on the CMC system had increased from 548 to 741 (35% increase). The introduction of the End of Life Care contract in primary care is seen as one of the main drivers for the increase in activity relating to the co-ordination of care plans for this patient group over the last year.

5.3.6 Data from Coordinate My Care also provided the CCG with information about the primary condition of patients identified as palliative care. The chart below highlights diagnoses in two categories, those with cancer and those with non-cancer for City &Hackney. The latest data available, shows that of the palliative care patients registered with CMC, 28.1% have cancer and 71.9% are non-cancer related conditions. This challenges a common misconception that cancer predominates in the area of palliative care.



National VOICES[15] survey 2015

5.3.7 The Department of Health administers a validated national survey of bereaved relatives and carers called *VOICES or View of Informal Carers – Evaluation of Services*. Among the findings from the latest survey in 2015 we noted the following:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.

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[15] The VOICES (Views of Informal Carers – Evaluation of Services) is a validated survey of bereaved relatives and carers administered nationally by DoH and locally by CCGs

- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%).
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

The latter highlights a point also raised in our review which is that while most people want to die at home when the realities of the situation become apparent they will more often opt for a hospital death. There is a disconnection here between the perception of dying at home and the reality.

Local VOICES Survey City and Hackney 2015-16

5.3.8 In addition CCGs can carry out local versions of this research. City and Hackney's local VOICES survey[16] was funded through the CCG's Innovation Fund in 2015 and completed in October 2016. The project was managed by St Joseph's Hospice and was overseen by a steering group which comprised all local stakeholders with an interest in palliative care. The purpose of the project was to help identify areas of need and improvement in the end of life care within City & Hackney through seeking views from carers, following the deaths of a family member. Those who ran the survey acknowledge that it does have some limitations (small sample size and those having positive experiences had been more likely to complete it) but it nevertheless provides very valuable local data on end of life care.

Below are some of the key findings we noted:

- The overall quality of healthcare dying patients received within City and Hackney was rated above the national average.
- Across the different settings, hospice care was rated the highest and other care services were in line with national averages. Hospital care was perceived to require some improvements. The report suggest that this could be because of challenges specific to Hackney's community profiles which are more diverse than those found across other CCG areas.
- Ratings for dignity and respect were above the national averages
- Pain management was more successful in in-patient care than in community and home care settings and this is in line with national results
- Almost all felt that patients and carers were treated with dignity and respect during the last two days of life.
- The need to break bad news sensitively was highlighted as one of the prime areas with need for improvement.
- Care provided by doctors was rated higher than that of nurses (although it doesn't provide insight into whether other professions such as health care assistants might have influenced the perception of nursing care)
- Almost all were happy with level of involvement in decision making.

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[16] VOICES Survey – City and Hackney 2015-16, City and Hackney CCG/Homerton University Hospital/St Joseph's Hospice, November 2016

- Only a minority of patients died in their preferred place of death
- The provision of information about bereavement services is limited across most care providers
- Bereavement services could be more accessible and responsive to the challenges bereaved carers and relatives face in the lead up to and after the death of a relative/friend

5.3.9 To bring another dimension to this the Royal College of Physicians recently surveyed[17] acute providers on the quality of their end of life care provision. They found the following in relation to communication and treatment decisions:

- *Where there was an advance care plan, the team took the contents into account when making decisions (91%) and it was reviewed (79%); however only **4%** (415/9302) of patients had documented evidence of an advance care plan made prior to admission to hospital.*

- *A do not attempt cardiopulmonary resuscitation (DNACPR) order was in place for 94% (8711/9302) of patients' notes at the time of death. Where sudden deaths are excluded, discussion about CPR by a senior doctor with the patient was recorded in **36%** (2748/7707). Overall, for **16%** (961/6072) there was no reason recorded why a discussion did not take place. Discussion about the CPR decision with the nominated person(s) important to the patient was documented in 81% of cases.*

- *It was recorded that 32% of patients had opportunities to have their concerns listened to and, of these, 94% were given the opportunity to have questions answered about their concerns.*

The fact that only 4% had Advance Care Plans made prior to admission to hospital and that only 36% recorded discussions with a doctor about CPR are areas of concern.

5.4 INTEGRATION ISSUES

5.4.1 It is not uncommon in Scrutiny reviews to find high standards of work being done by health and social care providers and we always welcome that but a common theme we find in many of our reviews relates to shortcomings in integration and partnership working. As health care gets more complex inevitably there is a danger that nobody is looking out for the whole person as they are so focussed on delivering their own important part of the jigsaw. This is evident in end of life care and it means that patients often do need a personal champion to ensure that a loved one can navigate the systems. The problems become exacerbated when we are dealing with often very frail elderly people at end of life stage. A common issue we heard about was criticisms about what was thought of as often unnecessary hospitalisation and poor standards of basic nursing care in acute settings. On discussing this with the Chief Nurse of the Homerton we acknowledged that what was at issue here was not the need for new processes or procedures in the treatment of the

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[17] *End of Life Care Audit – Dying in Hospital*, a national report for England, Royal College of Physicians/Marie Curie; 2016

elderly, but a commitment to a higher standard of general nursing care for old people with a particular a focus on hydration, feeding and washing, all of which much take more effort and are more complex for the old.

5.4.2 The number of players involved obviously makes it difficult but the result can often be poor case handling of frail elderly people between care homes and acute settings. We heard about cases when talking to the care homes and we also considered the issues raised in a recent Safeguarding Adults Review.

A Safeguarding Adults Review Panel case history

5.4.3 We were grateful that the Chair of the City and Hackney Safeguarding Adults Board (CHSAB) drew to our attention a recent Safeguarding Adults Review (SAR) relating to an individual known as Mr GH which they were currently considering and which had a direct bearing on our review. Each year we consider the CHSAB's annual report and hold them to account on their performance and this provided a useful opportunity to use insight from that Board to enhance a scrutiny review.

5.4.4 The purpose of a Safeguarding Adults Review Panel is to commission evidence from all relevant agencies involved in the case under review, to asses and analyse that evidence and to make judgements about the lessons learnt. Mr GH, aged 80, died in St Joseph's Hospice in Aug 2015, ten days after he had been admitted. Prior to this he had lived alone in a one bedroom first floor flat in a sheltered housing scheme. He had a number of longstanding and complex health problems and the following 6 agencies were involved in his care:

- GP surgery
- Adult community nursing (provided by HUHFT)
- Acute health care (first in Homerton then in St Joseph's)
- Adult social care (care package also Safeguarding, Occupational Therapy)
- Care agency (delivering the care and support package)
- Housing association (sheltered housing)

Informally involved in his care were his sister, who lived in the south of England but who did some advocacy for him, and a private cleaner whom he had engaged and who was quite involved in his support.

5.4.5 The report of the SAR Panel, as the Chair of the Safeguarding Board pointed out to us[18], found instances of good practice by all agencies involved but also that the agencies did not keep pace with Mr GH's changing needs as he approached the end of his life. Although there was liaison, the overall coherence and coordination of care planning was missing. There were failures in communication as well as shortcoming in how some agencies responded to his needs and no one agency took a holistic view of his situation and there was no concerted approach to accommodating his changing needs speedily and effectively. As a result, they concluded, the quality of life that he

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[18] Memo from Chair of CHSAB to Cllr Munn 10 Dec 2016

experienced in his final weeks was not as it should have been and he was unable to remain at home as he had wished. The SAR made a series of recommendations for individual agencies regarding coordination and leadership when someone has complex health and social care needs. As part of the next stage of that SAR review there will be a communications strategy, an action plan and reviews of progress made in implementation.

5.4.6 It was interesting to note how effective his housing manager was in raising concerns in this case and they have to be commended for this. We also noted how his GP appeared very slow in referring him to Palliative Care. Perhaps Mr GH’s expressed wish for no more intervention and to remain at home was taken as a reason for limited further interventions. It would seem however that the complexity of his health and care needs were probably too severe for him to be cared for effectively at home, considering he lived alone and even without the few failures listed in this report, the option of St Joseph’s or another appropriate nursing environment should perhaps have been discussed earlier. In terms of learning from the case we would argue that the expressed desire of the majority of people to die at home has to be seen in the context of their changing medical need and that dying at home is not always practical or desirable particularly for those living alone, even if they’re in sheltered accommodation.

5.4.7 The case of Mr GH and our discussions with the various care agencies in our own evidence gathering made us reflect on the workings of Multi-Disciplinary Team meetings. The challenge is that while every member of a team fulfils their duty, who in the end ‘owns’ a case like this is vital particularly for those who might have nobody to speak up for them. The Commission suggests that partners would benefit from a more focused, collective, reflection of these issues by for example introducing regular, EOLC case review exercises to act as a multi-agency learning process. Such reviews would we suggest need to involve sufficiently senior staff from each partner to ensure that issues are taken back at a sufficiently high level to be implemented.

5.4.8 The health and social care system in Hackney is about to undergo one of its most important transformations in a generation with the creation of the Hackney Devolution Pilot. At its essence this involves the pooling of most of the health and social care budgets between the CCG and the Council and the creation of an Integrated Commissioning Board. These new arrangements replaced the One Hackney and City programme which itself was a pilot. A new Unplanned Care Board replaces One Hackney and City as, among other things, the key coordination vehicle for care of older people at end of life. We learned that there are both **GP Practice MDT** (multi-disciplinary team) meetings focusing on case management and **Quadrant MDT meetings** focusing more on case review processes. Our first recommendation therefore focuses on the need to use the opportunity the new structures provide to ensure better co-ordination of end of life care support. A key issue here is establishing clarity for patients, carers and families as who the ‘Responsible Individual’ is at each stage as this does not seem to be clear to service users.

Recommendation One
The Commission recommends that the new Unplanned Care Board use the new Quadrant work stream to ensure that processes for communication with patients at end of life and coordination between agencies are firmly in place, that they continue to be adhered to and that work is undertaken to improve them.

City & Hackney GP Confederation's End of Life Contract

5.4.8 The desire to better coordinate care for patients at end of life is at the heart of the CCG's *Co-ordinate My Care* system. All 43 GP Practices in City and Hackney are signed up to deliver the End of Life Contract. The aim of this CCG contract which is provided by the GP Confederation is to encourage GPs to identify those patients who may be in the last year of life and to offer them an opportunity to create an Advance Care Plan (ACP) and to record the details of this on the *Coordinate My Care (CMC)* system, if the patient agrees. The process of care planning impacts positively on the quality of care received by patients and carers.

5.4.9 CMC is an electronic care plan that is accessible to a number of healthcare professionals including London Ambulance (LAS), Out of Hours services (OOH), the Homerton A&E, the Adult Community Nurses such as District Nurses and Community Matrons. Evidence from CMC suggests that those patients who have an ACP are more likely to die in their preferred place of death and to avoid unnecessary hospital admissions. The service aims to reduce the number of emergency admission at end of life, to reduce the length of stays in hospital at end of life and to increase the proportion of patients dying in their preferred place of death. Practices were asked to actively identify those patients who may be in the last year of life (using the Supportive & Palliative Care Indicators Tool, known as SPICT) as well as by other means. GPs were to offer patients information about their disease trajectory (if appropriate), and offer them the opportunity to create an ACP which as a minimum should include the following:

- Preferred place of care;
- Preferred place of death;
- A discussion about resuscitation and the circumstances in which the patient and/or the health care professional feel it would not be appropriate. This could result in a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form on CMC;
- Any other patient wishes

5.4.10 We learned that GPs have active oversight of the patients on the palliative care register, they are discussed at the monthly practice Multi-Disciplinary Team (MDTS) meeting which are ideally attended by the Adult Community Nursing teams and the Palliative Care Clinical Nurse Specialist, they are visited regularly or as necessary and their carers' and/or family are consulted and engaged.

5.4.11 Advance Care Planning is key to making the patient's and carers' experience be as good as it can be in the circumstances. ACPs involve having those difficult conversations with the patient and their carer (if appropriate and relevant) and, crucially, sharing this information with other care providers, such as the hospital, the community nursing teams and other health care professionals who are involved in the patient's care.

5.4.12 The GP Confederation stressed to us that good advance care planning happens when all those involved in the patient's care are able to *speak* to each other so that the patient's changing needs are understood in real time. As they pointed out Health IT systems do not lend themselves to being able to *speak* to each other. GPs in Hackney use *EMIS*, whilst the hospital uses *Cerner* and the District nurses use *RIO*. CMC offers a solution, whereby, information recorded by the GP on the CMC care plan, can be viewed, and if necessary, updated, by other health care professionals who may have seen the patient in another setting, such as the hospital, or at home by the district nurse. The aim is to ensure that all patients on the end of life register have a CMC care plan. We learned that further IT developments are required to have this system fully operational at all levels, but it is expected that this will be achieved within the next year.

5.4.13 We learned that since the linking of CMC to the wider GP Confederation's End of Life contract, Hackney has steadily progressed in the national CMC league tables[19]: City & Hackney is now 14th in the national rankings, has added 195 more patients to CMC in September 2016 and has been the top performing CCG each month from June 2016. This is as a result of GP practices consistently creating care plans on CMC for those patients who have consented.

5.4.14 We learnt too that the Confederation has instigated quarterly MDT training sessions where they use a case study to aid learning. We would encourage more of this and all attempts to engage all the stakeholders (acute, primary, social care, voluntary sector) in these sessions.

5.4.15 While we acknowledge that CMC is an excellent innovation we did come across some instances of poor awareness of it and we'd ask the Confederation to focus on these. HUHFT described how patients often are going on their own Treatment Escalation Plans too late e.g. when too ill or lacking capacity, so there is a need to stress the importance of people thinking of End of Life Care issues while still able. GPs also need to encourage more Advance Care Plans and Do Not Attempt CPR plans among their patients where appropriate. The Commission also heard concerns from Richard House Children's Hospice about why children were not included in CMC.

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[19] End of life care report to HiH meeting on 29 November 2016 from City & Hackney GP Confederation

Recommendation Two
The Commission requests the GP Confederation, as operators of the Coordinate My Care system, to:

(a) Ensure all health partners are active in ensuring that there is greater uptake of CMC
(b) Ensure that all relevant health and care providers can and do access CMC records for patients in their care
(c) Report back on the pilot whereby social workers were given access to a GP Practice's EMIS system and the viability of extending this.
(d) Explain why patients of children's hospices are not currently included in CMC.

5.5 CARE AND QUALITY OF SERVICE

5.5.1 We heard some concerns about instances of poor care for frail and elderly patients at HUHFT particularly around hydration and help with feeding and washing. Our research is not quantitative and claims we hear are anecdotal but they nevertheless do raise concerns that a successful Trust like the Homerton must address confidently. When discussing this with the Chief Nurse she agreed that this was about the general standard of good nursing care and not about any specialist treatment and we acknowledge this response. We do acknowledge too the challenges of providing care for frail and confused elderly patients in a general acute setting but would ask that there is a need for the Homerton to keep a focus on training of nurses and Health Care Assistants (HCAs) and to be more responsive to claims of insufficient nursing care when these do occur. In January 2017 the CQC has published national ratings on its CQC inpatient survey and we noted with some concern that the Homerton came out with the lowest scores in England for two questions: *Did you have confidence and trust in the nurses treating you?* And *Overall, did you feel you were treated with respect and dignity while you were in the hospital*?'[20]

5.5.2 How to improve and better align nurse training across the acute, nursing home and care home sectors became an issue in our review. There are 4 nursing homes in Hackney with a total of 226 beds: Acorn Lodge Care Centre (98), Beis Pinchas (44), St Anne's Home (34) and Mary Seacole (50). For this review we made site visits to two: Acorn Lodge and Beis Pinchas. We learned that while there is some joint training taking place however we want to encourage more initial and continuing training for nurses and HCAs with both care homes and hospices. Care Home managers expressed criticism of the condition of frail elderly people who had been returned to them from acute hospitals. It was suggested to us that Homerton's nurses, like all in acute hospitals had a relative lack of experience of washing and feeding very frail elderly people. We acknowledge the pressures on general nursing staff and all the other training calls on them and the fact that nursing home staff too

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[20] Quarter 2 Quality Report to CCG Governing Body meeting 27 Jan 2017 reporting on results of CQC Inpatient Survey 2015. Agenda pp 127-132.

have the benefit of working in a specialist sphere, but we would suggest that the professional silos that appear to have built up between acute providers and nursing homes need to be surmounted in the interests of delivering higher standards for patients.

Recommendation Three

The Commission requests the Chief Nurse of HUHFT to explore how, as part of their initial and continuing training, the Homerton's nurses and Health Care Assistants could learn from going on secondments to Hackney's care homes to share best practice in caring for frail elderly people e.g. in washing, feeding and hydration.

The Commission would also like to be advised how the training modules for geriatric and palliative care have developed of late and what scope there is for increasing joint training with care homes.

5.5.3 We heard concerns from a local care home about recurring issues relating to the protocols of London Ambulance Service in transferring frail, elderly patients to A&E at the request of family members. There were concerns about the attitude of staff and derogatory comments made by LAS staff about care homes in the presence of the family members who instigated the calls. As the Care Home Manager said to us "*A & E also does not question the transfer and by admitting the resident the perception of the family is that the Home did not deliver adequate care".*

5.5.4 We acknowledge that dealing with anxious family members at the end of life stage is a significant problem for all care providers but we would argue there appears to be a lack of leadership in evidence here. If a care home manager feels strongly that the case for transferring a very frail elderly person to an acute hospital is not justified surely that needs to be made strongly to the GP who is the Responsible Individual here and the various parties then need to abide by the GPs judgement call and respect the decision made and not communicate mixed messages to anxious families. Instead, distressed or anxious family members force a situation, which is not ideal for the patient, because of a poor spirit of partnership working between the care home, the ambulance service, the acute hospital and the GP.

5.5.5 Allied to this problem is that when such frail elderly people then arrive in A&E, because of the current pressures on these services, they can often be required to wait for long periods where their condition will deteriorate. By the time they are seen they are dehydrated, with criticism falling back on the care home, when the reason the patient is dehydrated is because they have been waiting to be admitted. It is obvious to all that a busy acute setting is not the best place for a very frail elderly and confused patient, unless there is a major medical emergency, therefore the question arises - why is such a patient in an A&E in the first place and who is making the decision? It is challenges like these that we hope will be alleviated by the new integrated care system and we would hope when we revisit our recommendations after six months that there will be some tangible evidence of improvement.

Recommendation Four
The Commission recommends that the new Unplanned Care Board work with the City and Hackney EOLC Board to examine how outcomes for frail elderly patients at end of life might be improved if a better co-ordinated system of controlling movement between care homes and acute settings was instigated and care home staff were supported to access advice from other sources where appropriate. Furthermore, we request London Ambulance Service to examine their Clinical Triage Process on responding to calls from families of very frail elderly people at end of life stage in care homes where families want the patient transferred to acute care. What are the guidelines here and who do the LAS staff take direction from? Are Paradoc always called out? LAS also to be mindful that advance care plans/CMC records may be in place and these would need to be consulted.

5.5.6 The issue for carers of how to manage large volumes of medications in End of Life Care to ensure sufficient quantities are available out of hours, known as anticipatory prescribing, is a growing problem. Poorly controlled symptoms can lead to considerable distress for the dying person and an individualised approach to anticipatory prescribing should ensure that the drugs prescribed are appropriate to the anticipated needs of the dying person, and prevent distressing hospital admissions and waste of medicines. We observed a key stakeholder meeting on the issue which arose because the CCG’s Prescribing Board had received concerns from some GPs.

5.5.7 The meeting involving all the key stakeholders included some very useful input from carers/patient advocates, those with direct experience of dealing with pain management crisis with loved ones often in the middle of the night and at weekends. The NHS appears to have gone from low levels of anticipatory prescribing 10 year ago to a situation now where there is too much waste of expensive medications and hence the concern. We learned that GP Out of Hours providers (in Hackney CHUHSE) can no longer keep controlled drugs and this has led to the need for more anticipatory prescribing for end of life care patients.

5.5.8 In addition the Dr Harold Shipman case has also led to new national regulations which prevent medical staff from removing unused controlled drugs from a deceased person’s home and families often do not appreciate this. This has to be done in a special procedure under a Home Office licence. We also learned that Pharmacists generally no longer have space to keep large stocks of controlled drugs and furthermore they are not reimbursed for loss of out of date medicines, which makes them less likely to keep stocks high. Could they be commissioned to keep approved lists of medicines in stock, we wondered? Also is there a need to give some patients a safe for controlled drugs if they have a family member in the home who has a drug misuse problem? Could there be an Out of Hours pharmacist for dispensing controlled drugs in each of the 4 new Quadrants is another issue? It became clear that so many of the issues here would be alleviated by better take up of the Co-ordinate My Care System and progress being made by the new Unplanned Care Board.

5.6 COMMUNICATION WITH PATIENTS AND FAMILIES

5.6.1 The effectiveness of communication with patients and families is key to improving the quality of end of life care. It comes out in every discussion but we first looked at what the NHS was doing formally about this issue.

5.6.2 The CCG described how the key issues coming out of the various Patient and Public Involvement groups over the past two years were:

- Informed consent
- Shared decision making and involving patients in care planning
- Need for clear information
- Consideration for patients' individual circumstances and the importance of patient choice
- Involving carers and family in discussions and decisions
- Ensuring that patients with no carers or family members have access to other support.
- Ensuring sufficient training for clinicians

5.6.3 The CCG has commissioned Healthwatch to run the *NHS Community Voice* which is a series of monthly discussions on health related topics. Recommendations, questions and comments from these meetings are collated and shared with relevant services and commissioners who are asked to respond accordingly. We learned that their meeting on End of Life Care raised the following:

- Services should devise a mechanism to monitor effective and timely information sharing between health professionals.
- Carers should be included in planning and decision making.
- Need for better information about different services including One Hackney and City; extended appointments with GPs; the role of GPs as the holders of a person's medical information and advanced decision making support through *My Life My Decision*.
- Clear information for carers and advocates on where people can go if they want to challenge decisions made about their needs assessment when at end of life.
- Provision to be made for advocates/befrienders/community champions for people without family who are approaching end of life. Patients felt that there is a lot of focus on family but where is the support for those without family?
- Where do those who choose not to follow medical advice around their condition go for support?

5.6.4 In response to these we noted that the CCG explained that additional support including additional appointments with GPs were available under the existing End of Life Care contract. Where families want to challenge the decisions that their family member has made they are encouraged in the first instance to speak with the services concerned or to contact the PALS service which offer confidential advice and support. We acknowledged that this is a very challenging area.

5.6.5 The CCG also highlighted the following initiatives as key:

- *Compassionate Neighbours*: via St Joseph's Hospice. About 50 volunteers already trained and matched with clients in the community to

  offer support on end of life issues. Patients referred in by GPs and care providers
  - *VOICES survey*: carried out locally (see 5.3.8 above)
  - *Dying Well Charter*: Hackney was chosen as 1 of 9 national pathfinders and the only one in London. This was focused on improving communication, coordination and joint responsibility and the previous CEO of St Joseph's led on this.
  - *Project by St Joseph's* to engage communities which access less hospice care than others.

5.6.6 The CCGs own Patient and Public Involvement Committee is a formal sub-committee of the CCG's Governing Body. Membership of it comprises patient and service user representatives, Healthwatch, representatives of local community and voluntary sector groups as well as patient experience teams within the providers. They focused on Coordinate My Care in their recent discussions on EOLC but also on developing a CQUIN on 'shared decision making'.

5.6.7 The CCG's 'Planned Care Programme Board', 'Patient and Public Involvement' team and the Homerton Hospital developed a patient experience CQUIN (Commissioning for Quality and Innovation) to ensure that shared decision making is embedded within the relevant treatment pathways at end of life care. CQUINs are incentives which are built in to the various treatment pathways as part of the contract between the CCG/NHSE and the provider. Reaching the target then delivers financial rewards to the provider. The CCG told us that in their discussions on developing this incentive the following interesting issues arose:

- What is the role of carers if the patient is not deemed to have the capacity? (Doctor makes the decision but always in consultation with carers and family members)
- The importance of having discussions about Treatment Escalation Plans while acknowledging that it takes a long time to change people's behaviour and mind set
- Was there a potential role for community and voluntary sector organisations around facilitating some of these discussions with people? Could representatives of community and voluntary sector be trained to have these discussions?

We noted the last point with interest and develop this further in 5.9 below.

5.6.8 On Coordinate My Care the CCG's PPI committee noted that the current patient groups were chosen as they were most likely to be admitted to hospital unexpectedly and it is thought that patients with complex needs would benefit most from staff having access to their care planning records. The Committee explored what happens if patient hasn't got the capacity to give consent? Who can act of patients' behalf? Can they be pressurised into making decisions they don't want to make or decisions that have implications they can't understand? And were cultural considerations taken into account?

5.6.9 We noted with interest the key co-ordination issues which are being discussed in the 4 Quadrant Multi-Disciplinary Teams such as the Duty Doctor system being available in each GP practice, having District Nurses based in GP practices again, having the Charedi Jewish ambulance service added to CMC or the need to align different IT systems, noting that Elsdale GP Practice for example was piloting giving social workers access to EMIS (the GP Practices' patient records system). The latter roll-out to other GP Practices may be prevented, we learned, because of concerns about information governance rules, which all GPs must comply with. This issue needs resolving.

5.6.10 The Commission found that while each partner has well developed End of Life Care plans, there is a lack of alignment which can sometimes lead to a lack of leadership. The Homerton's Treatment Escalation Plans, though excellent, appeared very internally focused. We do appreciate however that TEPs are shared with GPs when a patient is in their Elderly Care Unit. A key issue was who needs to take the initiative and responsibility for having difficult conversations with patients and families and then making key decisions at the End of Life Care when someone is being cared for in the community, a care home or an acute setting. While we appreciate that is it the GP in the former two and the lead hospital clinician in the latter, lines of responsibility are often not clear enough to families. There are two issues here: How the Homerton can better support GPs about which patients might best benefit from an ACP and then ensuring that families and carers understand what is going on.

Recommendation Five
The Commission's recommends the CCG's EOLC Board to consider how lines of responsibility can be better communicated to families of EOLC patients so that it is clear to them who is taking responsibility at each stage of the process

5.6.11 Training in 'difficult conversations' around death and dying remains limited as does the overall limited amount of time which clinicians and staff spend on learning how to talk to and support end of life care patients and their families. The current staff pressures in the NHS also make it much more difficult for nurses and doctors to be spared from the front line for the repeated and necessary training calls that are on them. We would therefore argue that initial training is probably the best time to get these messages across.

Recommendation Six
The Commission requests the Chief Nurse of HUHFT and the Chair of the CCG's EOLC Board to report back on how training of clinicians in having difficult conversations around End of Life Care issues could be improved. This should include the need for Advance Care Planning, Advance Decision to Refuse Treatment, Do Not Attempt CPR plans and the need to get more patients onto systems such as 'Co-ordinate My Care'.

5.7 RAISING THE PROFILE

5.7.1 We heard a range of views about the ongoing communications challenge of increasing the profile of hospice services generally and the need to improve signposting of residents to the range of support which is currently available locally in end of life care. This is an ongoing challenge for the Hospice sector. We think there is a need to link in this work with what could be developed in Connect Hackney and the local VCS as well as to build on the GP Confederation’s work on ensuring that GPs get better at referring appropriate patients to St Joseph’s earlier.

5.7.2 The borough is lucky to have a long established centre of excellence in hospice care, St Joseph’s, located here and we commend the breadth of work they do. They care for and support people affected by life-limiting conditions and terminal illness providing nursing and medical care, emotional support, practical advice, physical and psychological therapies, spiritual care as well as social and creative activities. At the hospice on Mare St they provide in-patient wards, respite wards, day hospice, out-patients clinic and a very well used community space. In the community they provide care in patient’s homes, in care home and in other residential settings. They have c.300 staff, 400 volunteers and provides 42 beds across three wards. We were somewhat surprised on our visit however to note spare in-patient capacity, considering the complaints we hear from every section of the NHS about overcrowding pressures. We would seek assurance from St Joseph’s that this is because their Community Palliative Care Team and the Community Nursing Service are successfully dealing with lower acuity patients in a community setting. We heard that those being admitted were increasingly of higher acuity, which would fit this pattern.

5.7.3 The range of support both to patients and their families and carers is impressive but the ongoing challenge is getting the message out to the community that it is there and tackling the stigma which unfortunately still persists around hospices. On our visit we spoke to some in-patients and the issue of general support for carers came up. We noted the diverse range of support which St Joseph’s provide including: information and support, complementary therapies, physiotherapy, occupational therapy, dietetics, speech and language therapy, psychological therapies, social work services, welfare and benefits support and spiritual care and support. Complementary Services are crucial part of the mix but sadly receive no statutory funding and so have to be funded totally from their charitable side. On top of this they have a Live Well Information and Support Service which is specifically for those affected by a life-limiting but not necessarily terminal condition. We also learned about more specialist services such as Namaste care for people with dementia.

Recommendation Seven
The Commission requests St Joseph's to work with the CCG's End of Life Care Board on increasing awareness of St Joseph's services locally, including working towards equality of access for different communities in the borough and to better signpost other EOLC support in the borough. In particular there needs to be an emphasis on reaching and supporting carers. The plan should also consider how more specialist services such as St Joseph's Namaste care, for example, can be promoted.

5.7.4 The need for a community development approach to death and dying became more apparent to us as we proceeded with the review. While there is much that the statutory sector can do there are limits in terms of how they can begin to change behaviours and attitudes. Likewise in the community it is often down to community and voluntary sector to deliver the support and advice to improve end of life care. Key players here are Age UK and Marie Curie, both of whom we spoke to.

5.7.5 Age UK East London told us about their *My Life My Decision* programme which was delivered by them locally and funded from 2014-16 by the Big Lottery Fund. The aim was to support people aged over 50 to think about and plan their care in advance and help to ensure they have the death that is right for them. Age UK's national research revealed that while 82% of people have strong views about what treatment they would want or refuse to accept at end of life, only 4% of adults have made Advanced Care Plans or Lasting Power of Attorney for Health and Welfare[21]. The programme tested new ways of engaging people and communities, they developed person centred support, delivered one-to-one support and improved models of partnership between health services and voluntary organisations allowing healthcare professionals to refer patients to the programme to plan for their own care. The programme also provided training and awareness raising for professionals. The programme claimed a return on investment of 1:2.24, calculated on savings in unnecessary future hospital admissions or treatment and they made a strong case for such a programme to be replicated more widely to save more for the public purse.

5.7.6 We also heard from the Conscious Ageing Trust about a project they were running in Bridport in Devon on working with one locality to support them to develop what that called a Compassionate Community Hub. This comprised a Caring Network Forum, peer support groups and a range of community engagement activities including the 'Before I Die Wall', a 'mourning café and a social media platform. These 'Diealog Compassionate Community Hubs' as they are called use an approach which they term "grassroots up participatory development" i.e. citizen led participation in developing a community response to end of life care.

5.7.7 Closer to home we found a thriving example of this with the phenomenon of the 'Death Cafés. These community gatherings which invite people to tea

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[21] Extract from *Summary learning from My Life, My Decision*, Agenda for Commission meeting 29 Nov 2016 p.121

parties where there are informal discussions about death and dying have spread all over the world (already 3,600 in 37 countries) and we met with their founder Jon Underwood, who is based in Hackney. We also took the opportunity to visit one which was held in St Joseph's. This attracted a packed crowd of over 100 people and combined a panel of interesting opening speakers who provided very useful information for participants, with a focus group like discussion (about 10 tables x 10) which was not moderated. These discussions then evolved organically and with the audience being a mix of interested local residents, the recently bereaved and some professionals, they provided a useful space for people to unburden and share experiences. A signature feature of Death Cafés is that the never direct people to any course of action and are always respectful of different attitudes to death and dying. Written guidelines are provided on how to set them up but they are not centrally controlled. They do not apply for funding as they do not collect data on those who attend which of course would be a requirement.

5.7.8 The National Council for Palliative Care and Hospice UK produced a key report entitled '*Each Community is Prepared to Help – Community Development in End of Life Care*' which outlined a public health approach to end of life care. The aim was to build on the National End of Life Care Strategy 2008 and in particular Ambition Six ('each community is prepared to help') of the *Ambitions for End of Life Care 2015-2020.* The approaches outlined are based on the principle that care at end of life should be done with and not to people and that death, dying, loss and care are complex social events of which the medical component is only one aspect. Solutions to the problems facing people such as social isolation, carer fatigue, stigma and fear are not the sole responsibility of professionals, it argues. Everyone has a role to play and these issues will only be truly tackled if a whole community approach is taken. One typical concern for example is about the over-medicalisation of the process of dying and Advance Care Planning may help health and social care partners to resist the reflex recourse to hospitalisation and people may therefore choose non-hospital deaths more often.

5.7.9 Building on the NCPC's *Each Community is Prepared to Help* report, Age UK's '*My Life My Decision'* project (the funding for which ended in 2016) and examples such as the 'Diealog Compassionate Community Hubs' in Devon, the Commission is asking the End of Life Care Board to examine the feasibility of developing something similar in Hackney.

Recommendation Eight
The Commission recommends to the End of Life Care Board to work towards making City and Hackney a 'Compassionate Community' as per Devon's 'Compassionate Community Hub' and report back on how the issues raised in the NCPC report could be taken forward locally. This would involve close working with HCVS, Age UK East London, Older People's Reference Group and Connect Hackney. The Hub would bring together a Caring Network Forum, Peer Support Groups and community engagement activities.

5.8 SUPPORTING VOLUNTARY AND COMMUNITY SECTOR

5.8.1 As we learned with Age UK East London and Marie Curie for example the community and voluntary sector has a key role in developing and improving end of life care working with providers and commissioners and the statutory sector. We learned about Connect Hackney which is a project led by older people, for older people in Hackney. It is managed by HCVS and has won a five-year funding package from the Big Lottery Fund's *Ageing Better* programme, which aims to prevent and reduce social isolation among older people.

5.8.2 Connect Hackney's primary focus obviously is in organising a programme of activities which help reduce social isolation for elderly people and we commend the work they've been doing and the principles of co-production which drives their activity. As they are dealing with older people we would consider them an important vehicle for reaching this group with messages about thinking ahead and perhaps making plans for end of life care. They could be instrumental for example in helping to break down the stigma that exists in talking about these issues and, as part of the general support they provide this age group, they would be a perfect vehicle for increasing the awareness of what help is available for those caring for partners at end of life and what support is available for the bereaved.

5.8.3 To this end we are asking the Connect Hackney Steering Group and its partners in HCVS to consider taking forward the Compassionate Community Hub concept locally. As is done elsewhere such activity could explore what options are currently available to families and carers, the importance of hospices and the need for Advance Care Plans, making a will, funeral planning, plans for care of pets after death, digital legacy, organ donation etc. We would like to request Connect Hackney if it might consider establishing event(s) which would combine the best elements from Age UK seminars on end of life care with the 'Death Café' events i.e. combining practical support/information with a discussion on people's emotional responses to death and dying.

Recommendation Nine

The Commission requests Connect Hackney to consider using part of its funding to <u>increase awareness</u> about End of Life Care issues for older people. This could focus on what is the current local offer and how it might be improved.

5.8.4 In addition we would also like to echo the suggestions which emerged from the CCG's Patient and Public Involvement Committee on whether there might be a role for the wider community and voluntary sector organisations around facilitating discussion with people at End of Life stage. Could representatives of the relevant local community and voluntary organisations be trained to have these discussions? This might be particularly fruitful within BME communities where the take up of hospice services is poor.

5.8.5 We learned from St Joseph’s about their excellent Compassionate Neighbours programme. This is a free community-led support for anyone living with or caring for a person with a serious, long-term or terminal illness, or a person who is frail and/or isolated. Compassionate Neighbours are a network of trained volunteers who are willing to offer their time, companionship and support to people living in their own community. The scheme is growing rapidly and has been highly commended as an example of best practice for others to follow.

5.8.6 Our suggestion about encouraging volunteers in local VCS organisations to facilitate (most likely group) discussions on end of life would be separate from but complement Compassionate Neighbours. It would focus on helping people with the practicalities of end of life care planning (the basics of Advance Care Planning) rather than the more one-to-one befriending support which Compassionate Neighbours provides. It was clear from the large numbers attending the Death Café for example that there is a demand in the community for a space to talk but also a place to go and hear what you need to be doing, should you have dying relative or friend.

Recommendation Ten

The Commission requests HCVS and in particular Connect Hackney and Age UK East London to examine how there might be a greater role for the sector locally in <u>facilitating discussions with patients</u> at End of Life stage. This could focus on the desire to die at home, the need for ACPs, the need for a will, the need to consider lasting power of attorney for health and welfare decisions etc. This builds on the work of St Joseph’s ‘Compassionate Neighbours’ volunteers but would have a focus on end of life care planning rather than general support and befriending.

5.8.7 We learned that a key issue for the volunteers who work in St Joseph’s Compassionate Neighbours scheme is that they can often get heavily involved in attempting to sort out their client’s welfare rights issues. Often problems are far too acute for a Compassionate Neighbours volunteer to manage. We also learned that the potential of the scheme was perhaps not as fully appreciated as it could be within Adult Social Care. We’d like to suggest that there is scope therefore for St Joseph’s and Adult Services in the Council to liaise here to their mutual benefit.

Recommendation Eleven

The Commission requests the Council’s Adult Services and the Compassionate Neighbours Co-ordinator at St Joseph’s to explore how the Compassionate Neighbour volunteers can better signpost clients into council advice and support services and on the other hand how social workers might be able to refer possible clients who are socially isolated into the Compassionate Neighbours scheme, therefore maximising take-up of it.

5.9 CULTURAL SENSITIVITY

5.9.1 End of life care issues are very much linked to culture and traditions. These vary between communities and we acknowledge how challenging it is for the Homerton or St Joseph's to tailor their services to suit a highly diverse borough such as Hackney. We heard from the local Charedi community and we visited their key nursing home Beis Pinchas in Stamford Hill. In our discussions with community representatives we heard about instances whereby Charedi families appeared to be reticent to raise legitimate complaints about treatment of their loved one during end of life at the Homerton Hospital because they felt that the complaint might trigger post mortems or autopsies to which they have specific cultural objections. They therefore worried that a complaint from them could lead to the body of a loved one not being released for burial immediately after death, which is a key religious requirement for them.

5.9.2 Interlink Foundation has been very active in progressing these issues with local providers. They have already recommended in various forums and committees that Palliative Care Teams need to be trained in Charedi ethical principles around end of life care and Charedi patients should be advised to seek advocacy support when admitted to mainstream services. They recommend that Palliative Care Teams have a good dialogue with experts in Jewish law and the clinical aspects of end of life. They also argue that the 'Duty of Care' has to cover basic care needs of nutrition, hydration and medication. They explained that according to Jewish law, a number of factors would be taken into account including how seriously ill a patient was and momentary pain versus long term pain. They also talked to us about the need for greater sensitivity in conveying information to patients' where there is a terminal prognosis.

5.9.3 We were contacted by Interlink North West in Salford where they have developed a project called "Chayim Aruchim"[22] (Hebrew for long life) which comprised a team of 10 Rabbis, 2 retired GPs and legal advisors. The project developed a bespoke advance directive amongst the core team so they could better support Jewish families with end of life or crisis care. Again they pushed for 'Care advocates' to support families in case meetings so as to lower tensions. They also described how they got their Community Nursing Team to provide subcutaneous drips to their patients, including with glucose added, which they say has significantly reduced the need for hospitalisations for these people at end of life.

5.9.4 We noted a report they produced in October 2014 for Healthwatch Hackney and the CCG entitled *Community Insight Report – Patient Centred Care* which contained some specific recommendation on End of Life Care. Here again they raised concerns about disclosing a terminal prognosis arguing that they "put a great emphasis on the sanctity of human life and conveying positive

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[22] *Chayim Aruchim – 7 key points to know when caring for Orthodox Jewish Palliative or Hospice Care Patients*, Interlink North West, 2016.

message to inspire hope and recovery"[23]. They add that "*there is a culture within the NHS and social care of openness and sharing of information with patients which does not sit comfortably with Charedi culture. Often relatives may request that the patient should either not be told or be protected from the full impact of the diagnosis, which is often disregarded by clinicians. Family wishes are disregarded in the name of the protocol*"[24] they argued. They object to the words 'hospice' or 'end of life care' being used in the presence of the dying patient and to staff providing a prognosis with explicit timelines of life expectancy. Whilst we appreciate there are cultural sensitivities here, as a Commission we support the current NHS guidance that a patients' right to know and to make their own decisions supersedes the rights of their family in these situations.

5.9.5 Interlink also made some useful recommendations on better flexibility in use of allocated care hours (to accommodate cultural factors) and they asked if greater thought could be given to the importance of commissioning specific Charedi provision alongside general provision.

Recommendation Twelve

Whilst the Commission supports the current NHS guidance that a patients' right to know and to make their own decisions supersedes the rights of their family, the Commission would like HUHFT and St Joseph's to explain what work they are doing with the Charedi community to address that community's concerns about what they consider as a lack of culturally appropriate end of life care. The Commission also requests St Joseph's to report on progress being made in driving up the use of the hospice by other BME communities where there may be other cultural sensitivities.

5.10 CHILDREN'S PALLIATIVE CARE

5.10.1 We visited Richard House in Beckton which is London's first children's hospice, supporting families whose children (babies, children, young adults) are life limited, life threatened or have complex health conditions. The majority of their patients have congenital or genetic conditions e.g. muscular dystrophy, Duchene syndrome, congenital heart conditions, brain injuries (accident or premature birth). They deal with few oncology cases as these require urgent treatment in specialist cancer centres. Their focus is primarily respite care rather than long stay and their work is more akin to Long Term Conditions treatment. They look after families and also provide ante-natal care. They currently have 4 beds and 2 family flats. They provide holiday short breaks (respite for families) and step down care from hospital and they work closely with Children's Community Nurses to put in place a package of care

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[23] *Community Insight Report – Patient Centred Care*, Oct 2014, Interlink Foundation for Healthwatch and CCG, p.17.

[24] ibid

5.10.2 We learned from them about the recent national survey of children's palliative care[25] which found that:

- The number of babies, children and young people with life-limiting or life threatening conditions is increasing and the demand for services is growing
- Statutory funding for children's palliative care charities in England is declining and is patchy
- Short breaks are essential to families and local authorities have a duty to make sure they are provided to disabled children, yet many have cut funding for children's palliative care charities
- Over half of charities would have to cut services if the children's hospice grant was removed
- There is a need for parity with adult services for seriously ill children all over the UK, (they also argue that Scotland appears to have got the balance right).

5.10.3 Richard House made the case to us that specialist care for children ideally needs to be planned on a larger footprint than is currently the case and this is because there is too much disparity between funding and commissioning arrangements across neighbouring boroughs. They are therefore fully supportive of any moves which the NEL STP might make in redesigning support for children's palliative care around a larger footprint. Similarly they asked us if any reviews of Urgent Care and GP Out-of-Hours Services could also encompass acute and community care of children at end of life, so as to get more children out of acute hospitals sooner.

5.10.4 They also reminded us that it is important to challenge thinking that a hospice is seen as 'giving up'. A typical scenario would be that a patient receiving children's palliative care would be likely to pass away in c.3 years, so the focus would be what can be done in the interim to enhance the quality of the time they have left.

Recommendation Thirteen

The Commission recommends the Cabinet Member of Health Social Care and Devolution include the concerns of the children's palliative care sector when considering the reconfiguration proposals underway as part of the NEL STP. This also applies to reconfiguration of Urgent Care and Out of Hours Services. Children's palliative care would benefit from being planned across a larger footprint than is currently the case. Variations in funding and structure of support available across borough boundaries makes it difficult for Children's Hospices to plan their services.

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[25] *On the brink: a crisis in children's palliative care funding and commissioning in England 2015/16*, Together for Short Lives, November 2016. www.togetherforshortlives.org.uk

CONCLUSION

6.1 The recent local VOICES survey of bereaved relatives and carers in City and Hackney[26] found that end of life care in Hackney was generally rated 'very good' or 'good' across all providers. We always need to learn however from those who felt that care could be better and these respondents expressed a desire for better communication and coordination between services, more compassion from healthcare staff and easier access to out of hours services, as well as better pain control, in particular for patients receiving care at home. After our review we would echo all these points and ask local commissioners and providers to look more closely at these aspects.

6.2 It was interesting to note that while two thirds of the respondents to the local VOICES survey wished their family member to die at home yet only half actually did. There are a number of possible reasons for this. Firstly 42% of the aged 65+ population in Hackney are in single person households[27] and this is rising. There are also links between the proportion dying in hospital and general levels of deprivation (see Appendix 2) with poorer wards having higher rates of hospital deaths. The reason here is that poorer people are more likely not to have the level of support at home which could sustain them throughout a lengthy period of decline and death.

6.3 The review caused us to question whether there are unreal expectations about the nature of death and dying mixed in with the current drive by acute providers to ensure more people die at home. It became clear to us that if rates of dying at home are to be increased there needs to be in place a range of provision so that care can be escalated when needed. Dying at home can be messy and painful for both the patient and carer, who are often old and frail themselves. It is also protracted and needs will escalate and alter. There is a need to plan for these changes so that there are no sudden admissions to hospital when a carer is simply no longer able to cope. This brings us to the long term problem of patients being moved to hospices at too late a stage.

6.4 The Safeguarding Adult Review case of Mr GH demonstrated that he was referred to St Joseph's too late. It also underlined the importance for patients, particularly single people living alone, of having a champion who can navigate the complex matrix of health, social care, community nursing, sheltered housing support which the person is receiving and apply pressure when it is needed. "Who owns the case" became the conclusion of that case review and we understand it is a common theme in others. The answers to this are too often not satisfactory.

6.5 Hackney is fortunate to have a major, highly regarded, hospice like St Joseph's at our doorstep and they are rightly commended for the diverse range services they provide. How to drive up use of the hospice and how to tackle the stigma that still surrounds hospices is an ongoing challenge

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[26] VOICES Survey – City and Hackney 2015-16, City and Hackney CCG/ Homerton University Hospital/ St Joseph's Hospice, November 2016

[27] Briefing from HUHFT to HiH on 10 Oct 2016

however. While they are making great strides in attracting referrals from people from our local BME communities there is always more to be done. We hope that expansion of the Compassionate Neighbours scheme will be a conduit for driving up use of the hospice in the future.

6.6 We learned how St Joseph's, Age UK East London and other providers suffer from the fact that their funding tends to be short term and fragmented and this proves a real hindrance to their ability to plan and grow. They are not alone in this. A typical scenario is that they receive pump priming for an important new initiative which is being trailed, they put in the investment, start it up, and then funding ends and initiatives can't be sustained, but soon along comes another new but slightly amended variation of the same thing. This short termism wastes both time and money and it is unfortunate for example at Age UK's very useful *My Life My Decision* project has ended.

6.7 Both the care homes we visited had an interesting and persuasive perspective on promoting the concept of dying at home. From their point of view they seek to create a 'home' for their residents where these people live and die with the medical support they need around them. They argue that we need to remain more open-minded and flexible in considering what constitutes "home".

6.8 Poor communication with patients, carers and families and the struggle to ensure there is sufficient take up of the necessary training for clinicians and health care workers remains a problem. At its simplest the choice of words is key when communicating with patients about end of life care and it is vital to ensure that patients do not feel abandoned or feel that care is being withdrawn. Knowing when to have the "difficult conversation" with patients, their families and carers and crucially, feeling confident in holding these conversations, is key and more efforts need to be made by bodies such as Health Education North Central and East London (HENCEL) to expand learning opportunities for these "soft skills". On the flip side of that there is the need too for medical staff to avoid unnecessary or unwanted escalations of care because of a lack of confidence in dealing with anxious families.

6.9 As with all our reviews we came across the problems arising from the fragmentation of health and social care as it gets more complex. As budget pressures get more severe there is a need prevent cost shunting across the health and social care partners and a need to prevent a culture of blame from emerging. This can be inevitable when everyone at each stage of the pathway is feeling under pressure but tackling this must be a priority for the new the new integrated care model under the Hackney Devolution Pilot.

6.10 Looking to the future it is clear that GPs, the Homerton, St Joseph's and Adult Social Care will be fully engaged in improving this area of care. GPs in particular via Co-ordinate My Care have taken on the IT challenge of creating shared care plans. The journey to fully integrated care plans shared across all sectors is not yet achieved and may take some time to be fully implemented, but in the meantime, the CMC platform is acknowledged as the best option available to improving communication amongst health care professionals involved in end of life care and so improving the care provided to patients at the end of life.

7. CONTRIBUTORS, MEETINGS AND SITE VISITS

7.1 The review's dedicated webpage includes links to the terms of reference, findings, final report and once agreed, the corporate response. This can be found at http://www.hackney.gov.uk/end-of-life-care-review

7.2 Evidence was gathered at the following meetings:

1.) Site visit to NHS Community Voices event 'Dying well in City & Hackney' at CLR James Library on 20 October 2015
Attending: Cllrs Sales and Snell

2.) **Site visit to DEATH CAFÉ held at St Joseph's Hospice on 11 May 2016**
Attending: Cllrs Munn, Patrick, Peters, Potter, Sales, Snell

3.) Site visit to ST JOSEPH'S HOSPICE – 22 September 2016
Attending: Cllrs Munn, Patrick, Peters, Potter, Sales, Snell

Met with: Mary Flatley (Lead Nurse, In-patient Unit), Beverley John (Information and Support Service Assistant), Micaela Loveridge (Clinical Governance Lead), Carly Attridge (Volunteer Services Manager), Ann Hines (Volunteer), Libby Fry and Sarah Mooniamah Salem (Compassionate Neighbours Volunteers), Sally Muylders (Compassionate Neighbours Programme Manager), Dr Libby Sallnow (Palliative Care Specialist), Marianne Mestern (Community Nursing Lead), Ruth Bradley (Interim Chief Executive), Linda McEnhill (Interim Director of Care), Diane Laverty (Nurse Consultant Respite Care) and Dr Sam Edward (Medical Lead and Consultant in Palliative Medicine).

4.) Site visit to CITY AND HACKNEY CCG/Dr Max Mackay-James/Jon Underwood (founder of 'Death Cafes') on 5 October 2016 at CCG office.
Attending: Cllrs Munn, Hayhurst, Patrick, Peters, Potter, Sales, Snell

Met with: Dr Meena Krishnamurthy (Lead GP for End of Life Care, CCG), Jan Annan (Head of Outcomes and Evaluation, CCG), Dr Max Mackay-James (Conscious Ageing Trust), Jon Underwood (founder Death Cafés). Apology from Jennifer Walker (Programme Director, One Hackney and City), input added via Jan Annan.

5.) Site visit to ACORN LODGE CARE CENTRE on 6 October 2016
Attending: Cllrs Munn, Patrick, Peters, Potter, Sales, Snell

Met with: Diane Jureiden (Home Manager) and Julie Cornish (Administration Manager)

6.) Site visit to BEIS PINCHAS NURSING HOME on 6 October 2016
Attending: Cllrs Munn, Patrick, Peters, Potter, Sales, Snell

Met with: Mrs Ita Symons and other staff

7.) Commission Meeting on 10 October 2017.
Attending: Cllrs Munn, Hayhurst, Patrick, Peters, Potter, Sales, Snell

Evidence from: Sheila Adam (Chief Nurse and Director of Governance and Honorary Professor of Nursing Leadership, Homerton University Hospital NHS Foundation Trust (HUHFT)), Dr Martin Kuper (Medical Director, HUHFT), Dr David Feuer (Consultant, HUHFT), Linda Athey (Lead Nurse Cancer and Palliative Care, HUHFT), Leanne James (Lead Nurse Cancer and Palliative Care, HUHFT), Margaret Howat (User Engagement Forum, HUHFT), Genette Laws (AD Commissioning, Adult Social Care, Hackney Council), Alexis Howsam (Divisional Business and Service Development Manager, Marie Curie Care/Pan London End of Life Alliance) and Rachael Chapman (Service Innovation and Improvement Lead, Marie Curie Care/ Pan London End of Life Alliance)

8.) Site visit to RICHARD HOUSE CHILDREN'S HOSPICE 28 Nov 2016
Attending: Cllrs Munn, Potter and Sales.

Met with: Caroline O'Connor (Director of Finance) and Hazel Ryan (Statutory Partnerships Manager). Also input from Peter Ellis (Chief Executive).

9.) Commission Meeting on 29 November 2016
Attending: Cllrs Munn, Hayhurst, Patrick, Peters, Potter, Sales, Snell

Evidence from Amaia Portelli (Practice Support Manager, GP Confederation), Dr Stephanie Coughlin (Board Member and local GP, GP Confederation), Deborah Hayes (Director of Individual Services, Age UK East London), Philip Adams (Project Co-ordinator, Age UK East London), Shirley Murgraff (Chair, Older People's Reference Group), Sarah Weiss (Interlink Foundation), Ita Symons (Agudas Israel Housing/Beis Pinchas Nursing Home)

Also attended:

10.) Older People's Reference Group at CCG on 10 June 2016
O&S Officer attended on behalf of the Chair. Observed meeting of the Advisory Group of the Older People's Reference Group (i.e. its Executive Committee) chaired by Cynthia White. Group comprises about a dozen Hackney residents.

11.) Managing Medicines at End of Life held at CCG on 10 November 2016 O&S Officer attended to observe, on behalf of the Chair, a stakeholder review meeting on 'Anticipatory Prescribing and End of Life Care'. This meeting arose because the CCCs Prescribing Board had received concerns about this issue from various GPs. This is on-going performance improvement work led by the CCG and involving all the key partners.

8. MEMBERS OF THE SCRUTINY COMMISSION

8.1 The following served on the Commission during this review

Councillor Ann Munn (Chair)
Councillor Ben Hayhurst (Vice Chair)
Councillor Sharon Patrick
Councillor James Peters
Councillor Clare Potter
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Overview and Scrutiny Officer:	Jarlath O’Connell ☎ 020 8356 3309
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For this review:	
Lead Group Director:	Anne Canning, Group Director - Children, Adults and Community Health
CCG Lead:	Paul Haigh, Chief Officer
Lead Cabinet Member:	Cllr. Jonathan McShane, Cabinet Member for Health, Social Care and Devolution

9. FURTHER READING

9.1 The agenda pages for the Commission meetings on 10 October 2016, 29 November 2016 and 16 January 2017 on the Hackney Council website contain minutes of the evidence sessions, background briefings/papers submitted and notes on the site visits.

9.2 The following documents have also been relied upon in the research:

National:

- *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*
- *Transforming end of life care in acute hospitals: The route to success 'how to' guide (NHSE Dec 2015)*
- *NICE guideline on care of dying adults in the last days of life*
- *Actions for End of Life Care 2014/16, NHS England*
- *One Chance to Get it Right: the Leadership Alliance for the Care of Dying People, June 2014*
- *More Care, Less Pathway: A review of the Liverpool Care Pathway 2013*
- *Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life*
- *End of Life Care - House of Commons Health Committee report 2015*.
- *End of Life Care Audit – Dying in Hospital*, *an national report for England* (Royal College of Physicians/Marie Curie; 2016

Note: The National Palliative and End of Life Care Partnership's *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* is aimed at local health and 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

Local/ sub-regional:

- Draft Hackney Health and Wellbeing Strategy 2015-18
- City and Hackney Health and Wellbeing Profile: Our Joint Strategic Needs Assessment, 2011/12, updated 2016. Hackney Council and City of London
- End of Life Care in London, Report of London Assembly's Health Committee, February 2016

9.3 The following web resources are also useful.

e-ELCA e-learning for end-of-life care
End of Life Care for All (e-ELCA) is an e-learning project for the NHS, commissioned by the Department of Health and delivered by e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland. It was developed to support the implementation of the Department of Health's national End of Life Care Strategy.
www.elfh.org.uk/projects/end-of-life-care

Gold Standards Framework for Community Palliative Care
Offers primary healthcare teams an evidence-based programme with the tools and resources to help improve the planning of palliative care for their patients in the community. The National Gold Standards Framework (GSF) Centre in End of Life Care is the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life. www.goldstandardsframework.org.uk

General Medical Council (GMC)
Treatment and Care Toward the End of Life: good practice in decision-making; 2010. www.gmcuk.org/guidance/ethical_guidance/end_of_life_care.asp

NICE: End of Life Care Quality Standard
This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. http://guidance.nice.org.uk/QS13

Palliative Care Matters
Palliative Care Matters is a website intended for health-care professionals working in palliative care or related fields. It includes the Palliative Care Handbook. www.pallcare.info

RCGP End of Life Care Resources
This provides useful information and links to resources on end of life care www.rcgp.org.uk/end_of_life_care/home.aspx

Charitable organisations

Macmillan Cancer Support
Offer practical advice and support for patients and families affected by cancer. www.macmillan.org.uk

Marie Curie Cancer Care
Offer practical advice and support for patients and families affected by cancer. www.mariecurie.org.uk

Hospice UK
Champions and supports the work of member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life limiting conditions, and support their families. www.hospiceuk.org

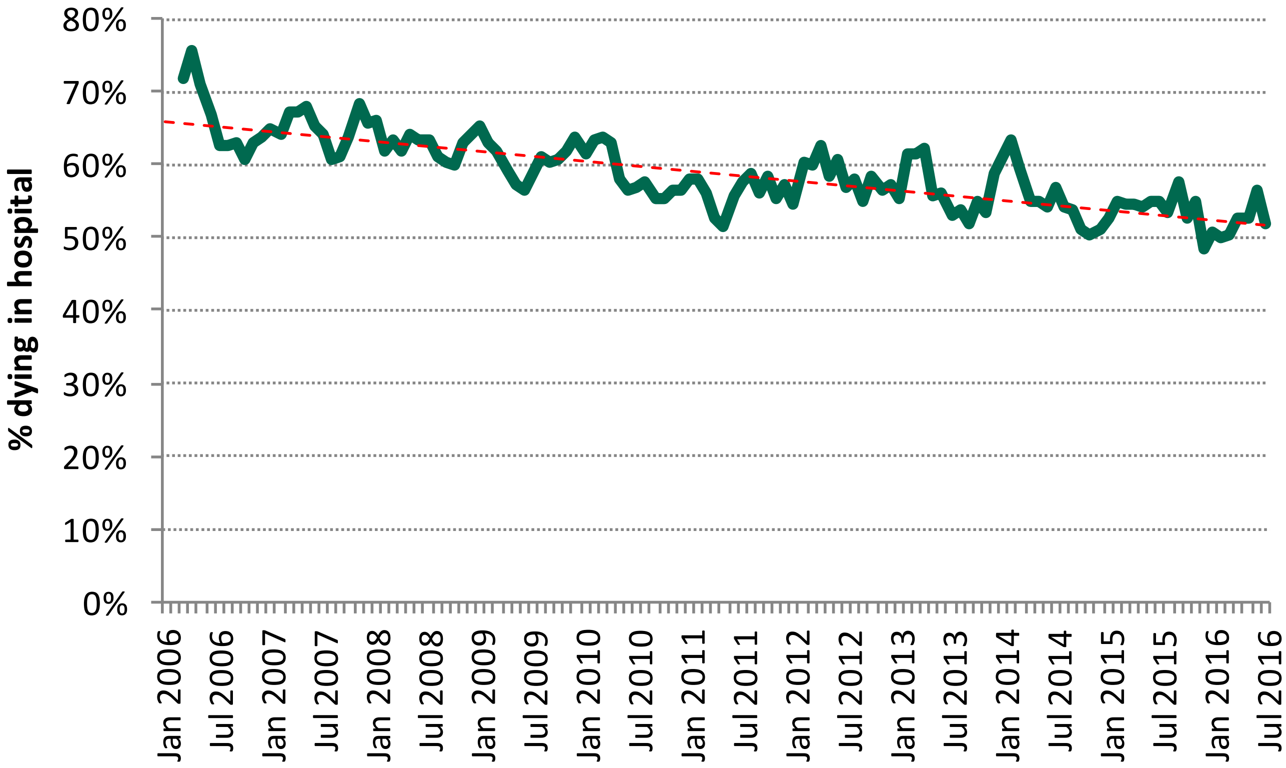
10. GLOSSARY

Acorn Lodge	Is a 98 bed nursing care home in Clapton which is also able to accommodate residential, respite and palliative care needs. It is one of 4 homes which are part of the Lukka Homes Group.
Advance Care Plan	Advance Care Planning is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future. If the person wishes to they can set on record choices about their care and treatment (known as Advanced Statement) and/or an Advance Decision to Refuse a treatment in specific circumstances. These choices can then be referred to by those responsible for care and treatment (whether professional staff or family carers) in the event that the person loses capacity to decide once their illness progresses.
Advanced Decision to Refuse Treatment	This is a legally binding refusal of medical treatment in advance of a time that you lose capacity.
Advance Statement	This allows you to write down your wishes and preferences in case you become unwell and need care or medical treatment.
C&H CCG	NHS City and Hackney Clinical Commissioning Group
Beis Pinchas Nursing Home	Is a nursing home in Stamford Hill for the Charedi community which is part of Agudas Israel Housing Association. They have 43 residents in sheltered housing and 43 in nursing care as well as some respite beds.
CHSAB	City & Hackney Safeguarding Adults Board
CHUHSE	City and Hackney Urgent Healthcare Social Enterprise is the organisation which has the contract for providing GP Out of Hours Services
City and Hackney Together	This is a consortium run by HCVS focusing on helping local third sector organisation, which lack the capacity, to win contracts on their own. It also encourages joint bids as joint working becomes more central to tendering.
CMC	An online care planning platform for frail elderly patients and those patients at the end of their lives. It is commissioned by the CCG and run by the GP Confederation.
CNS	Clinical Nurse Specialist
Compassionate Neighbours	Compassionate Neighbours is free community-led support for anyone living with or caring for a person with a serious, long-term or terminal illness, or a person who is frail and/or isolated. They are a network of trained volunteers who are willing to offer their time, companionship and support to people living in their community.
Connect Hackney	Connect Hackney is a project led by older people, for older people in Hackney. It is managed by HCVS and has won a five-year funding package from the Big Lottery Fund's *Ageing Better* programme, which aims to prevent and reduce social isolation among older people.
CQUIN	CQUIN stands for commissioning for quality and innovation. The system was introduced in 2009 to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care. CQUINs sets an agreed target against which the health provider achieves rewards on reaching an agreed set of outcomes. These are used in the NHS to drive up performance.
Death Café	Death Cafes are informal, facilitated conversations around death and dying using a tea party format.
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DNAR	Do Not Attempt Resuscitation
GP Confederation	City and Hackney GP Confederation is made up of a membership of all 43 City & Hackney GP practices The Confederation provides true population coverage, mitigating against uneven service provision. In other words, the Confederation works with practices to provide help and support as well as direction, to ensure

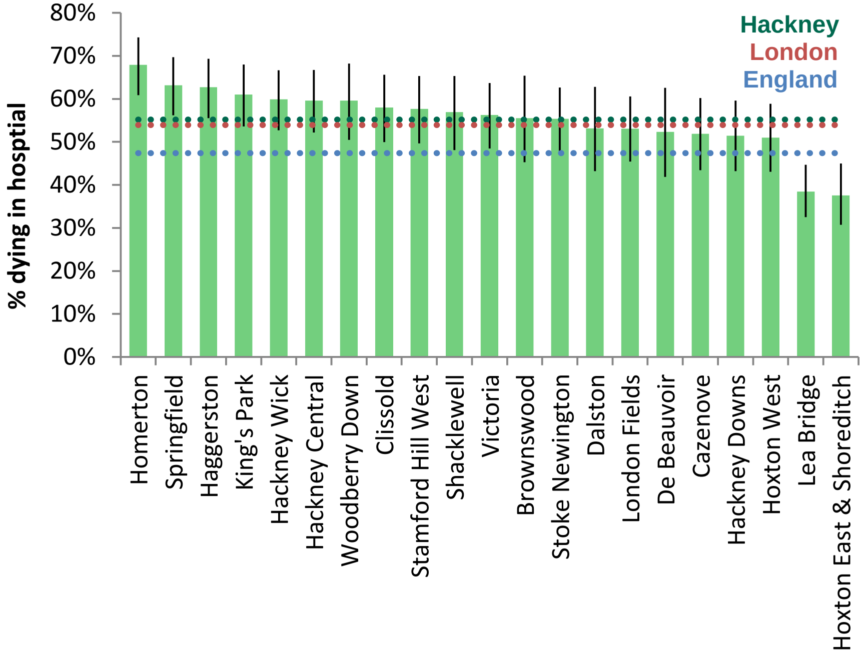
	that all practices deliver care and services of equal high quality.
HENCEL	Health Education England (HEE) is the national NHS organisation responsible for the education and training of all current and future NHS employees. HEE exists for one reason: to improve the quality of care delivered to patients. Health Education North Central and East London (HENCEL) is one of 13 local committees of HEE known as a Local Education and Training Boards (LETBs). HENCEL is responsible for ensuring that high quality education and training is provided to all health professionals including the next generation of doctors, dentists and nurses in North Central and East London.
HUHFT	Homerton University Hospital NHS Foundation Trust
Lasting Power of Attorney	LPAs give someone your trust the legal power to make decisions on your behalf in case you later become unable to make the decisions for yourself. They are registered with the Ministry of Justice's OPG. There are two types: LPA for Property and Financial Affairs LPA for Health and Welfare
Namaste Care	Namaste Care™ is a program designed to improve the quality of life for people with advanced dementia. Namaste, is a Hindu term meaning "to honour the spirit within" and was selected to describe a program that brings honour to people who can no longer tell us who they are or who they were or care for themselves without assistance.
NEL STP	North East London Sustainability and Transformation Plan is one of 33 national plans to reconfigure the NHS. Its footprint covers the CCG areas of: City and Hackney, Tower Hamlets, Newham, Waltham Forest, Barking & Dagenham, Redbridge and Havering.
One Hackney and City	One Hackney and City was a pilot to provide more co-ordinated services for the most vulnerable, high risk patients in City and Hackney. Integrated Care Teams, provided care that crossed the boundaries between primary, community, voluntary, acute and social care services.
OOH	Out of Hours. Used in context of GP Out of Hours services.
Richard House	Richard House in Beckton is London's first children's hospice, supporting families whose children (babies, children, young adults) are life limited, life threatened or have complex health conditions.
St Joseph's	St Joseph's Hospice cares for and supports people affected by life-limiting conditions and terminal illness. They provide nursing and medical care, emotional support, practical advice, physical and psychological therapies, spiritual care as well as social and creative activities. At the hospice on Mare St they provide in-patient wards, respite wards, day hospice, out-patients clinic and a community space. In the community they provide care in patient's homes, in care home and in other residential settings. It has 300 staff, 400 volunteers and provides 42 beds in three wards.
Unplanned Care Board	One of the new bodies under the Integrated Commissioning Board, the others will cover Planned Care, Prevention, Early Years & Children. This takes on the work of the One Hackney and City Pilot which has come to an end.

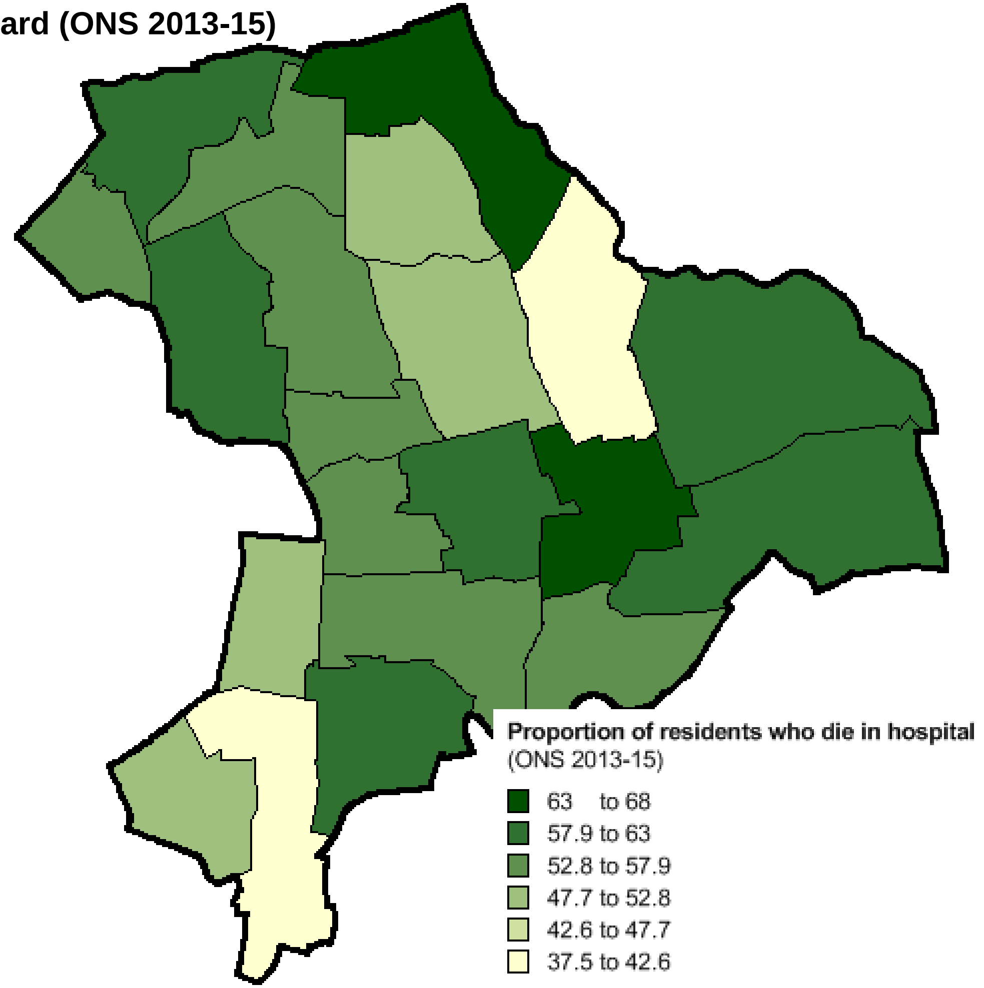
11. APPENDICES

Appendix 1: Proportion of City & Hackney residents who die in hospital – 3 month rolling averages, January 2006 to July 2016 (ONS)



Appendix 2: Proportion of residents who die in hospital, by Ward (ONS 2013-15)





Appendix 3: Proportion of City & Hackney resident deaths in hospital by cause of death (ONS 2013-15)