Topic information	
Topic title	End of Life
Topic owner	Rachel Sokal
Topic author(s)	Caroline Keenan
Topic quality reviewed	January 2017
Topic endorsed by	Nottingham City Clinical Commissioning Group Long Term Conditions Strategic Group
Current version	2016/17
Replaces version	2012/13
Linked JSNA topics	Cancer, Care Homes, Carers and Dementia

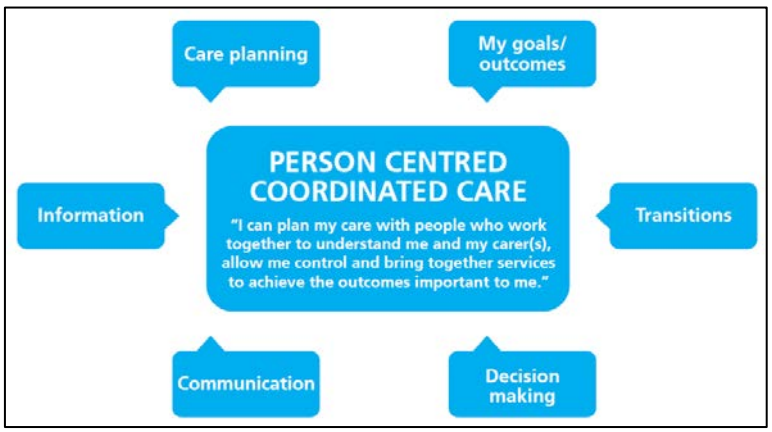
Executive summary

Introduction

This assessment examines end of life care in Nottingham City which encompasses the holistic assessment and management of the full range of physical, psychological, social, spiritual, cultural and environmental needs of patients and their families and carers in their place of choice, during the last years, months or days of life and after death.

End of life care focused on achieving quality of life for patients and their families, friends and carers is provided by a range of people including informal carers, medical, nursing and other health and social care professionals and within a range of settings including people's homes, hospitals, hospices, palliative care units and care homes. End of life care provision must be person-centred and coordinated and commissioning should place citizens at the heart of its approach, as illustrated in Figure 1.

Figure 1: The person centred coordinated end of life care approach



Source: National Voices

The national End of Life Care Strategy (Department of Health, 2008) sets the standard for high quality individual-focused end of life care that enables people to die without symptoms in the company of family, friends and carers in a place of their choosing. The Strategy recognises the importance of coordinated care within teams and between services in primary and secondary care. With 33% of informal carers reporting that hospital services do not work well together with GP practices and other services outside of hospital (Office for National Statistics, 2015c), a whole systems approach to end of life care remains of paramount importance. In Nottingham City major progress has been made towards this approach with the introduction and development of the Electronic Palliative Care Coordination System (EPaCCS).

The Nottinghamshire Guideline for Care in the Last Year of Life acknowledges that end of life care is the responsibility of all health and social care providers that provide for people with less than one year to live, people with a chronic and eventually fatal illness and people diagnosed with a condition from which they will eventually die. The guideline is focused around the five priorities for care of a dying person: promoting recognition of the diagnosis; communicating with patients and their families and carers; achieving choice; provision of support to families and carers; and recording the patient's individual care plan (Nottinghamshire Healthcare NHS Trust, 2015).

This assessment shows that whilst quality and equity of end of life care in Nottingham City is improving there are some areas within which further improvement is required. With projected increases in future demand for end of life care and complexity of the citizens who would benefit from it, it is important that the whole system approach embedded in Nottingham City continues to develop and evolve.

Unmet need and gaps

- Approximately 54% of those able to benefit from end of life care have been identified according to EPaCCS and Quality Outcomes Framework registrations;
- Approximately 55% of those able to benefit from end of life care have accessed one or more formal community end of life care service (defined as access to the End of Life Community and Coordination Service, Macmillan and/ or the Primary Integrated Care Service);
- There is a need to improve the support that enables people to die in their preferred place;
- Evidence suggests that inequity according to diagnosis exists in identification and service provision. In particular, patients with a cancer diagnosis are over represented in identification of end of life through EPaCCS and in access to formal end of life interventions;
- Research indicates a level of inequity in access to services according to ethnicity, sensory impairment, learning disability and vulnerability;
- There is a need for culturally competent practitioners across the spectrum of end of life care;
- Local views call for the introduction of end of life care as soon as it is known that a diagnosis is terminal; and

- Local views support the encouragement and promotion of discussions relating to death from an early age. The culture of not wanting to discuss the subject needs to be overcome.

Recommendations for consideration by commissioners

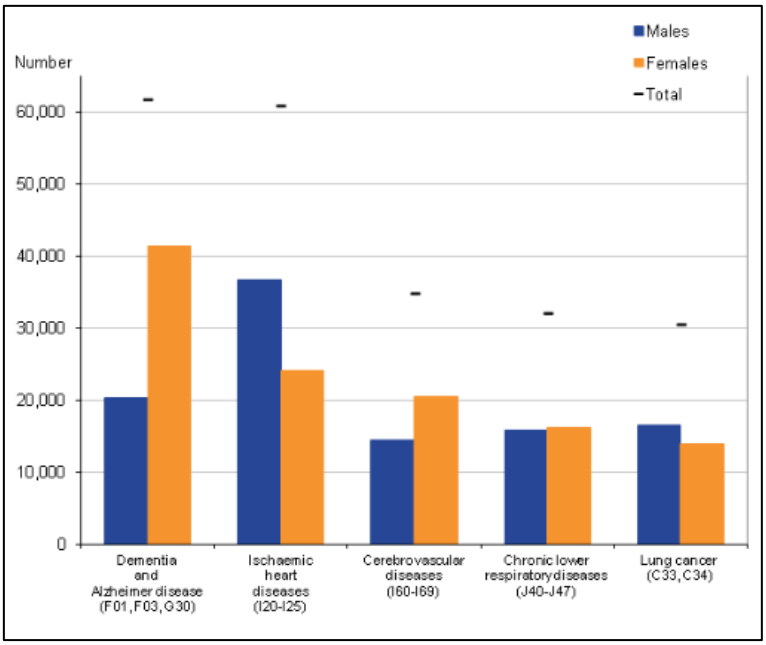
- Conduct an audit focused on end of life identification and access to services with a view to improving both of these factors;
- Increase the recording of preferred place of death and the proportion of deaths that take place in the preferred place through continuing to promote EPaCCS and access to formal end of life care services;
- Improve equity of diagnosis in EPaCCS registrations and access to formal end of life interventions;
- Ensure end of life care provision is equal and proportionate across sensory impairment, learning disability, ethnicity and vulnerability;
- Promote the identification of end of life supported by EPaCCS across all service delivery;
- Create a positive culture in which citizens and practitioners are able to discuss the end of life of themselves, their families and the people they care for in an open and comfortable way;
- Develop an inclusive process by which patients and their families and carers (including those from 'seldom heard' communities) can provide feedback to providers and commissioners about their experiences and implement a robust system to respond;
- Ensure that religion and belief awareness training for practitioners is regular enough to meet both staff turnover and the fluidity of Nottingham's population; and
- There is a need for improved access to EPaCCS amongst both GPs and healthcare professionals in secondary care. Currently, the use of EPaCCS as a tool is limited by a lack of access from certain providers – notably acute services and secondary care. An audit should consider and set quality parameters for transfer of information from one care setting to another.

What do we know?

1) Who is at risk and why?

There were 495,309 registered deaths in England in 2015 which equates to 1% of the population (Office for National Statistics, 2015a). The majority of deaths occurred following a period of chronic illness related to conditions including but not limited to heart disease, dementia and Alzheimer disease, cancer, chronic respiratory disease, stroke and other types of cerebrovascular disease (Office for National Statistics, 2015b). Figure 2 shows the leading five causes of death in England and Wales in 2015. These causes account for 41.5% of all registered deaths.

Figure 2: Number of deaths in England and Wales from five leading causes, 2015



Source: Office for National Statistics

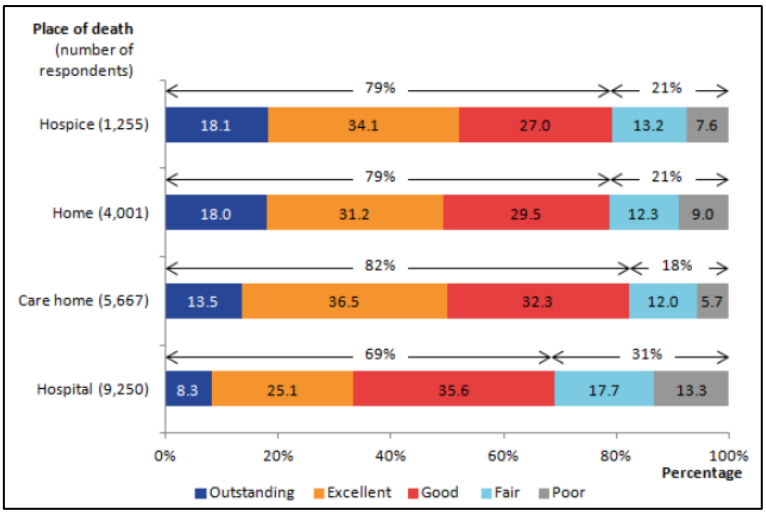
Cause of death statistics inform estimates of the number of deaths that can be anticipated. These estimates help to identify individuals to whom end of life care should be made available. The End of Life Care Strategy (Department of Health, 2008) states that approximately 1% of the population dies each year. Approximately 75% of deaths are not sudden, but expected (National Institute for Health and Care Excellence, 2015), therefore it is estimated that 0.75% of the population is able to benefit from end of life care.

In 2015/16, 0.34% of the population of GP practices in England were registered on the Quality Outcomes Framework palliative care register (NHS Digital, 2016). This suggests a gap in identification and provision between the estimated 0.75% that might benefit from end of life care and the 0.34% identified on the palliative care register.

The National Survey of Bereaved People (Views of Informal Carers – Evaluation of Services, VOICES) is an annual survey reporting information on bereaved people's views of the quality of care provided to friends and relatives in the last three months of their lives. In the latest

results of the survey (Office for National Statistics, 2015e), 75% of respondents rated end of life care as outstanding, excellent or good. Quality of care was significantly higher for females compared to males (44% and 39% respectively). In terms of place of death, more respondents felt that quality of care was outstanding, excellent or good in hospices, care homes and the home whilst significantly fewer reported the same about hospitals. These statistics are presented in Figure 3.

Figure 3: Overall quality of care by place of death in the last 3 months of life, England, 2015



Source: [Office for National Statistics]

2) Size of the issue locally

In 2015, there were 2,446 recorded deaths where Nottingham City was the usual place of residence which reflects the national picture in representing 1% of the population (Office for National Statistics, 2015a). Of these 2,446 deaths, it is estimated that 75% (1,835) were not sudden, but expected and therefore might have benefited from and end of life intervention. The majority of deaths occurred during a period of chronic illness which is also congruent with the national picture (Nottingham City Public Health Team, 2015).

Deaths in Nottingham City predominantly occurred in citizens aged 60 and over (87%, 2015) and were relatively equally distributed across gender (males 51%, females 49%, 2015). However, the volume of deaths varies between males and females as a function of age. Males are more likely to die between the ages of 0 and 60 (males 16%, females 10%, 2015). Figure 4 shows the distribution of deaths in Nottingham City across age group and gender.

Figure 4: Deaths by age group and gender, Nottingham City 2015

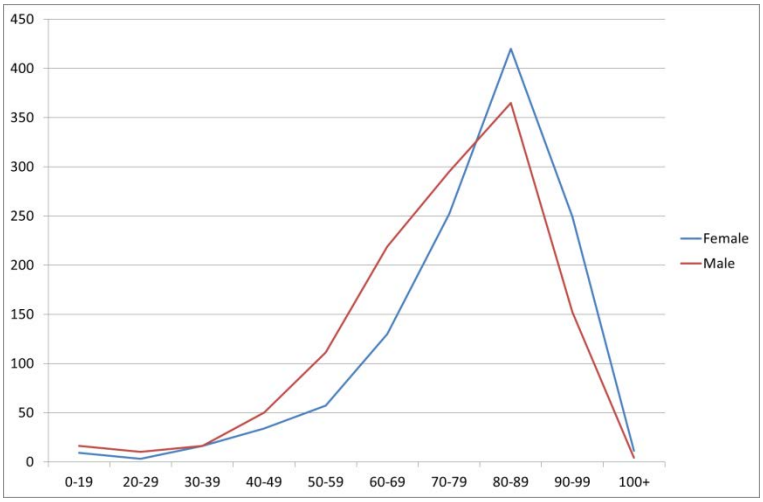


Table 1 shows deaths in Nottingham City broken down by underlying cause of death. The main causes of death were cancer, circulatory disease and respiratory disease which combined represented 70% of all deaths.

Table 1: Underlying cause of death in Nottingham City, 2015

Underlying Cause of Death	Number of Deaths	% of Deaths
Neoplasms	685	28%
Diseases Of The Circulatory System	644	27%
Diseases Of The Respiratory System	366	15%
Mental And Behavioural Disorders (including Dementia)	216	9%
Diseases Of The Digestive System	168	7%
Diseases Of The Nervous System	87	4%
External Causes Of Morbidity And Mortality	67	3%
Endocrine, Nutritional And Metabolic Diseases	44	2%
Diseases Of The Genitourinary System	32	1%
Symptoms, Signs And Abnormal Clinical And Laboratory Findings, Not Elsewhere Classified	28	1%
Certain Infectious And Parasitic Diseases	24	1%
NULL	24	1%
Diseases Of The Musculoskeletal System And Connective Tissue	16	1%
Diseases Of The Blood And Blood-Forming Organs And Certain Disorders Involving The Immune Mechanism	8	0%
Congenital Malformations, Deformations And Chromosomal Abnormalities	4	0%
Diseases Of The Skin And Subcutaneous Tissue	4	0%
Certain Conditions Originating In The Perinatal Period	1	0%
Diseases Of The Ear And Mastoid Process	1	0%

In 2015/16, 0.35% of Nottingham City's registered GP practice population was on the palliative care register (NHS Digital, 2016) which, in line with the national picture, is considerably less than the 1% of the population that dies each year and the 0.75% of the population for whom death is not sudden, but expected.

There were 989 Nottingham City patients registered on the Electronic Palliative Care Coordination System over a year (October 2015-September 2016), which represents 40% of annual deaths and 54% of annual deaths that are not sudden, but expected. Furthermore, approximately 1,000 individual patients accessed one or more formal end of life care service over a year (February 2016-January 2017, defined as accessing the End of Life Community and Coordination Service, Macmillan and/ or the Primary Integrated Care Service), which equates to 41% of annual deaths and 55% of deaths that could be anticipated.

National evidence has revealed differences in access and quality of care across a number of factors including diagnosis, age, ethnic background, and social circumstances. A recent review has shown that these differences continue to present a challenge to the provision of equitable care (Care Quality Commission, 2016). These factors are discussed in more detail below.

Age

Local assessments have shown that the majority of deaths occurred in residents over the age of 60. In 2015, Nottingham's Directly Age Standardised Mortality Rate (ASMR) was significantly higher than England for all ages and specifically for the 0-64, 65-74 and 75-84 age groups but not those aged 85 or more (Public Health England, 2016). This evidence shows that people die comparatively younger in Nottingham and that end of life care in Nottingham City is an issue across the age range.

People with a cancer and non-cancer diagnosis

In Nottingham City, 51% of patients registered on the Electronic Palliative Care Coordination System and approximately 46% of patients accessing community end of life services have a cancer diagnosis. Given that cancer causes 28% of all deaths in Nottingham City, these statistics indicate that people with a cancer diagnosis are over represented in identification through EPaCCS registration and in access to formal end of life interventions.

People with dementia

The timing of planning for end of life care is crucially important for citizens with dementia and Alzheimer's disease. Nottingham's prevalence of dementia in citizen's over 65 is higher than it is in England (5.35% and 4.27% respectively, Public Health England, 2016). Work is ongoing around advance care planning to support dementia patients at a much earlier stage than a prognosis of the last 12 months of life.

People with Learning Disabilities

People with learning disabilities may experience difficulties in accessing end of life care that meets their specific needs. This can be due to failure to diagnose advanced disease early enough to plan and prepare for end of life care and communication difficulties with healthcare professionals (Keenan & Macintosh, 2000). Current communication models designed to assist healthcare professionals in breaking news of serious illness and poor prognosis do not meet the specific needs of people with learning disabilities (McEnhill, 2008). This results in the risk of excluding people with learning disabilities from making informed choices for their future care at the end of life.

Black and minority ethnic groups

The 2011 Census shows Nottingham City's black and minority ethnic population is 35% and this proportion is projected to increase (Nottingham Insight, 2016). A recent national report identified a number of disparities and unmet needs from analysing end of life care provision in terms of access to and receipt of care. Issues included scarcity of information about hospice services and lack of cultural awareness and understanding (Calanzani, Koffman & Higginson, 2013).

Religion and belief

Understanding and awareness of religion or belief is recognised as crucial to care at the end of life and death. Examples of best practice include spiritual and religious support for the patient, family and carers in the patient assessment (Thomas and Lobo, 2011).

Socio-economic status

Socio-economic deprivation is a risk indicator for health inequalities and has been identified as a risk indicator for poor end of life care outcomes (Gomes & Higginson, 2006). In the National Survey of Bereaved People (Office for National Statistics, 2015c), significantly more people of the most deprived quintile rated end of life care as poor compared to those of the least deprived quintile (29% and 22% respectively). Nottingham ranks 8th most deprived out of the 326 districts in England according to the Indices of Deprivation (Office for National Statistics, 2015d) which poses a challenge to ensuring positive outcomes.

Vulnerable groups

Groups at risk of experiencing health inequalities also include people in prison, homeless people and people living alone or without a carer. Detailed data related to end of life care needs is not available at a local level for some of these groups suggesting a significant need to work with vulnerable groups to ensure provision of services to support people in the community who are at the end of life to exercise their choice in preferred place of care and death.

3) Targets and performance

End of Life Care Profiles

End of Life Care Profiles (Public Health England, 2016) are available to inform improvements and benchmark performance in end of life care. The profiles are available at the Nottingham City geography and are grouped by the following domains:

- Place of death;
- Underlying cause of death;
- Mortality rates;
- Death in usual place of residence;
- Dementia and Alzheimer's disease; and
- Other relevant indicators.

For information relating to underlying cause of death, mortality rates, dementia and Alzheimer's disease and other relevant indicators see section 2 of this assessment. Place of death and death in usual place of residence are discussed in this section.

In Nottingham, the most common place of death is hospital (57%), followed by home (24%), care home (17%), other places (2%) and hospices (0%). Whilst this is consistent with the national picture in terms of ranking, there are some significant differences in place of death between Nottingham and England. Nottingham citizens are significantly more likely compared to England to die in hospital (47% and 57% respectively) and significantly less likely to die in care homes (17% and 23% respectively). Statistics on deaths in hospices are not included here because Nottingham City provides community beds instead of hospice beds. In light of evidence that quality of end of life care is considered best in hospices, the

home and care homes as opposed to hospitals; these statistics suggest improvements are required to reduce the proportion of hospital deaths in Nottingham.

Significantly fewer deaths take place in the usual place of residence in Nottingham compared to England (41% and 46% respectively). This difference is due to more deaths away from the usual place of residence for citizens aged 85 and older (48% and 54% respectively), citizens with circulatory disease (39% and 45% respectively) and citizens with dementia and Alzheimer's disease (62% and 71% respectively). These statistics suggest improvements in end of life care should be focused on older citizens and those with dementia, Alzheimer's disease and circulatory disease.

Outcomes are significantly improved for Nottingham City patients registered on the Electronic Palliative Care Coordination System (EPaCCS). Death took place in the usual place of residence for 74% of these patients which provides evidence to continue to promote EPaCCS.

The Nottingham City Vulnerable Adults Plan (2012-15)

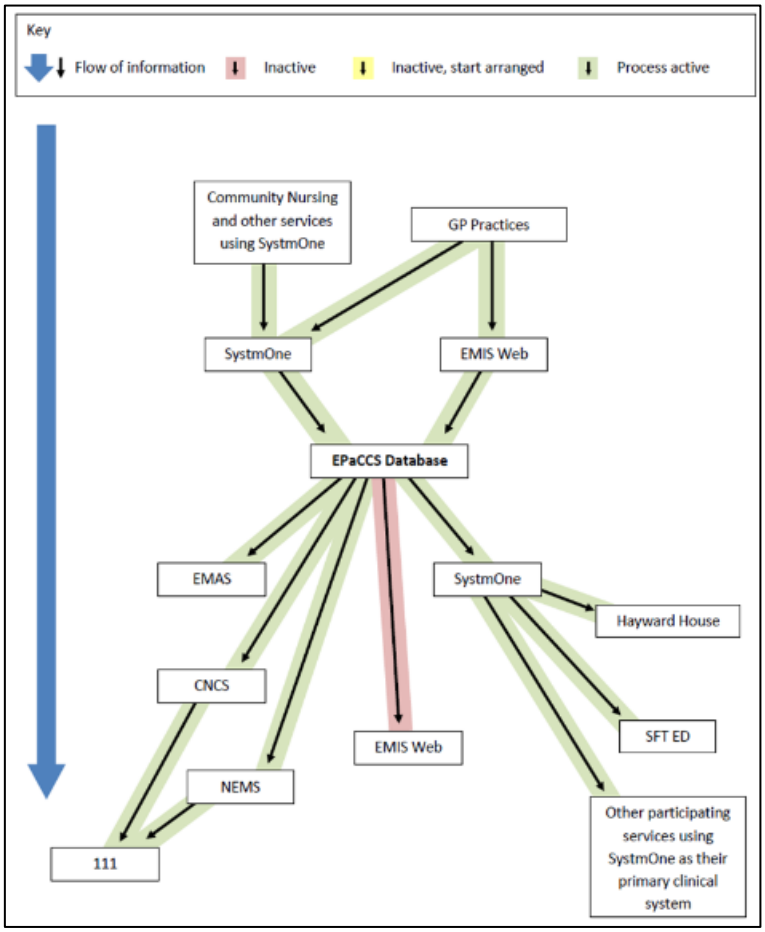
The Nottingham City Vulnerable Adult's Plan 2012-2015 (Nottingham City Council, 2012) has citizens who require health, social care or other specialist support services within its scope. This includes older people with long term conditions, degenerative chronic or neurological diseases. A primary outcome of the plan is to ensure that vulnerable adults have support, advice and information to live with choice, control and dignity in a place of residence that seeks to meet individual needs. A refresh of the plan is under development.

4) Current activity, service provision and assets
Activity

Electronic Palliative Care Coordination System

The Electronic Palliative Care Coordination System (EPaCCS) has been used to coordinate end of life care within and between health and social care providers since it was introduced in Nottingham City in September 2014. The system enables the recording and sharing of information about people's end of life care preferences which leads to better informed practitioners and efficiency savings in time spent creating duplicate records whilst negating the need for patients having to repeat previous conversations. Flow of information with EPaCCS is shown in Figure 5.

Figure 5: Flow of information with EPaCCS (as at April 2015)



Source: http://www.e-paccs.co.uk/sharing-through-epaccs/

Evidence suggests the use of EPaCCS increases the proportion of people dying in their preferred place of death, reduces hospital deaths and increases deaths in the home and in hospices (Public Health England, 2013). In the first year of activity, 779 Nottingham City patients were registered in EPaCCS which increased by 27% (989 patients) in the second year (October 2014 – September 2015 and October 2015 – September 2016 respectively), indicating a substantial increase in utilisation of the system.

Approximately 75% of patients registered on EPaCCS had a do not attempt cardiopulmonary resuscitation status (DNACPR). Local intelligence suggests that an improved rate of DNACPR is representative of improved communication between the practitioner and patient about the potentially traumatic and invasive procedure. The preferred place of death for patients registered to EPaCCS in the last year is shown in Table 2, for 47% of patient registrations the preferred place of death was home.

Table 2: Preferred place of death of Nottingham City patients registered in EPaCCS, October 2015-September 2016

Preferred Place of Death	Number of Registrations	% Registrations
Home	466	47%
Residential, nursing or care home	242	24%
Hospice	21	2%
Other	8	1%

In December 2016 there were 845 active patients of Nottingham City recorded in EPaCCS which represents 30% of the expected number of annual deaths. Of the 845 active patients, 51% had a cancer diagnosis, 76% had a long term condition diagnosis and 28% had both a cancer and long term condition diagnosis. 74% of deaths took place in the usual place of residence or the patients' preferred place of death.

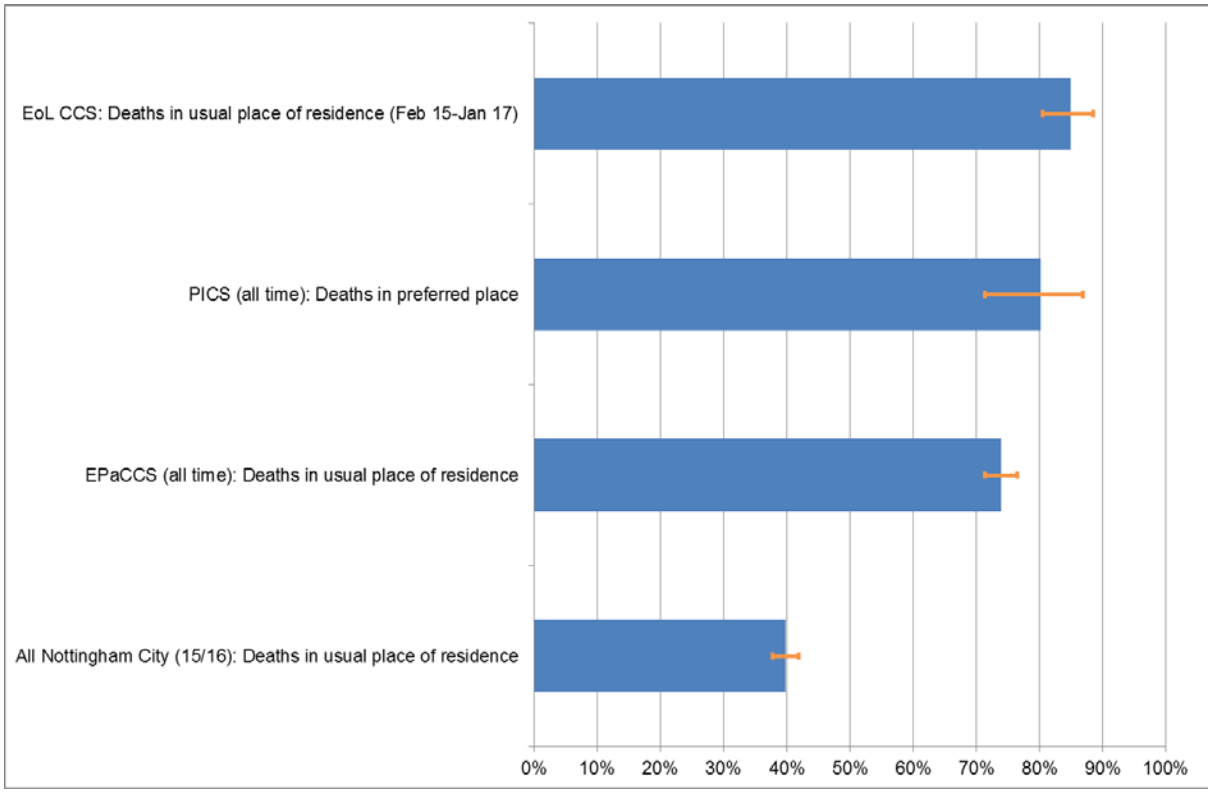
Service Provision

Current provision and outcomes

It is estimated that approximately 1,000 patients are supported by one or more formal end of life service per year. Over a 12 month timeframe, 1,010 patients accessed the community and coordination service, 110 patients accessed the Primary Integrated Care Service and 369 patients accessed Macmillan. Many of the patients who accessed the community and coordination service also accessed the Primary Integrated Care Service or Macmillan.

Where outcome data was available, outcomes for patients registered on EPaCCS and/ or supported by the Primary Integrated Care Service (PICS) or Community and Coordination Service (EoL CCS) are significantly improved compared to outcomes for the City overall, as shown in Figure 6.

Figure 6: Outcome comparison



Community and Coordination Service

The Community and Coordination Service is commissioned for adult Nottingham City GP practice patients and their family and carers. The service is available for people deemed to be in the last twelve months of life and for any diagnosis. The service consists of the following elements:

- Coordination service: a single point of access for referrals from practitioners for end of life care;
- Response service: nursing support for patients and their families and carers twenty-four hours a day and seven days a week;
- Planned palliative care: twenty-four hours a day seven days a week nursing and social support for patients and their families and carers including hospice at home and day therapy services;
- Palliative care beds: for residential respite care; and
- Pre and post death bereavement services.

Best practice education and training, specialist clinical advice and support, coordination of planned care and management of the EPaCCS system is provided in neighbourhood teams.

Key aims of the community and coordination service are to embed person-centred coordinated care and to reduce avoidable hospital admissions and deaths which evidence has shown are often less favourable for patients and their families and carers.

CityCare and Nottinghamshire Hospice collaborate to support patients by sharing information and aid transition between providers. EPaCCS enables practitioners to access the patients' care preferences in real-time.

A palliative rehabilitation service including dietetics, occupational therapists and physiotherapists was integrated with the community end of life care offer in December 2016. This represents an opportunity to further develop the whole system approach to end of life care.

Other palliative care services dedicated to specific diagnoses including respiratory disease, heart failure, liver disease and cancer are also commissioned in Nottingham City and delivered by the Primary Integrated Care Service and Macmillan.

Improvements in the sharing of information and administration and the associated efficiency savings have led to an opportunity to increase and extend the remit of the integrated community offer. Where efficiencies can be found these will be converted to a clinical resource to improve quality and extend the reach of end of life care services.

Care homes

In Nottingham City there are approximately 1,500 GP registered citizens in non-specialist care homes for older people. There are approximately 80 care homes, 54 of which are for older citizens. Given that 17% of deaths in Nottingham City took place in care homes in 2015, this segment represents a considerable proportion of citizens in need of end of life care and support. A separate chapter regarding care homes residents in Nottingham City is available at Nottingham Insight.

Medicines management and community pharmacists

Nottingham City Care Partnership (Wilson, 2014) reported that up to 90% of all identified palliative care occurs within the patient's home environment and the majority of patients and their family and carers prefer a home death. Due to common difficulties in swallowing medication it is often the case that symptom control medication must be administered through subcutaneous injection. It is therefore recommended that GPs prescribe medication in advance of deterioration.

The condition of those reaching the end of life can change rapidly, thereby requiring an urgent response. The End of Life Care Strategy (Department of Health, 2008) found that one of the major challenges in relation to the delivery of high quality end of life care in the community includes difficulty in accessing palliative care medication outside routine working hours.

Palliative care medication is available from a network of community pharmacies in Nottingham City as a means of improving access to medication. This requires the pharmacy to maintain the required stock of palliative care medication in line with the agreed list. Where requested, the pharmacist will provide advice to the health care professional regarding the prescribing or dosage of palliative care medications that should be administered to a patient. The pharmacist will also provide information and advice relating to the use of palliative care medication to patients and carers. There are currently twelve community pharmacies in Nottingham City providing this service.

Guidance for healthcare professionals to aid prescribing for symptom control and anticipatory prescribing in the last days of life is available from: http://www.nottsapc.nhs.uk/media/1079/end-of-life-prescribing-guidance.pdf.

Nottingham University Hospitals NHS Trust

Clinicians must give consideration to end of life at discharge from hospital and, in collaboration with families and carers, share information appropriately with primary care and other care providers. Advance care planning should be documented in discharge information.

Hayward House is a specialist palliative care unit located within the City Hospital grounds. The unit provides holistic palliative care to patients and their relatives/carers. Patients are cared for by a specialist medical team including a pain management specialist. Complementary therapies and counselling are provided as well as activities including arts and crafts and access to pets.

Nottingham University Hospitals NHS Trust provides practical and emotional support to patients and their families and carers or staff through a number of services:

- The Child Bereavement Team;
- Pre-bereavement support in conjunction with the Butterfly Project;
- Bereavement support with maternity; and
- Macmillan Cancer Information and Support Centre.

Nottingham Emergency Medical Services

Nottingham Emergency Medical Services (NEMS) provides a GP 'out of hours' service for patients in cases where care cannot safely wait until GP practices are open. The sharing of care preferences and advance care planning through EPaCCS enables the service to tailor care provision. Information is updated every 24 hours.

End of life care for children and young people

The Nottingham City Integrated Community Children and Young People's Healthcare Programme supports young people, their parents and carers with life limiting and life threatening conditions and illness. This includes those who would benefit from palliative and end of life care. The Programme's scope consists of community and acute paediatric nursing services as well as therapy services. (Nottingham City Clinical Commissioning Group, 2015).

East Midlands Ambulance Service

As with NEMS and other services, access to patients' advance care planning is available to East Midlands Ambulance Service (EMAS) through EPaCCS. However, due to the limitation in the number of characters available for providing information on patient call outs, only the resuscitation status is currently included. There are plans for the clinical assessment team desk to have access to a read-only version of EPaCCS in the future.

Assets

Financial Assistance

When an individual has less than six months to live they may apply for Attendance Allowance or Personal Independence Payment through a fast track application available via www.direct.gov.uk.

Support for Carers

Carers may require enhanced support at end of life and a number of options are in place to meet this requirement including Hospice at Home, day and residential care in a hospice, hospital or care home setting. A statutory Carer's Assessment should also be completed by a social worker.

Other Support

Other national and local support for patients and families and carers is available from the following organisations.

Local Support:

- Maggie's Centre;
- SPIRAL for children and young people aged 15-17 years following the loss or someone important;
- Multi-ethnic groups/religions at Hayward House
- Self Help Nottingham maintains a directory listing all groups and support agencies in Nottinghamshire; and
- Black and Ethnic Minority Carers of Nottingham and Nottinghamshire.

National Support:

- Macmillan provides support to people affected by cancer from diagnosis, through treatment and beyond;
- Marie Curie for care and support through terminal illness;
- Winston's Wish for families and carers of bereaved children;
- Cruse Bereavement Care for bereaved people in England; and
- Hope Again for young people living after loss.

The Royal College of Psychiatrists provides a comprehensive list of national organisations offering support and advice to people who have been bereaved.

5) Evidence of what works

National strategy, policy and guidance by date of publication

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 sets out six ambitions for improving palliative and end of life care:

1. Each person is seen as an individual;
2. Each person gets fair access to care;
3. Maximising comfort and wellbeing;
4. Care is coordinated;
5. All staff are prepared to care; and
6. Each community is prepared to help.

What's important to me. A Review of Choice in End of Life Care (2015) describes the results of a Government commissioned review into the quality and experience of care for adults at the end of life.

The Gold Standards Framework for Palliative Care provides training to practitioners providing end of life care including guidance on advance care planning. Its key principles, listed below, inform the Nottinghamshire Guidance for Care in the Last Year of Life (2015):

1. Communication;
2. Coordination of a person's care;
3. Control of symptoms;
4. Continuity of care;
5. Continued learning;
6. Carer support; and
7. Care of the dying.

Commissioning Person Centre End of Life Care: A toolkit for health and social care (2016) is an NHS England publication for the commissioning of person-centred coordinated end of life care.

Our Commitment to you for end of life care (2016) is the Government response to its 2008 strategy. The document sets out the commitment to deliver end of life care and how this will be done through:

1. A more personalised approach;
2. Improving quality in all settings;
3. Learning from innovation;
4. Leadership and system-wide commissioning;
5. Improving knowledge and skills;
6. Working in partnership; and
7. Strengthening accountability and transparency.

End of Life Care and Human Rights: A practitioner's guide (2016) published by the British Institute of Human Rights is a 'dip in and out' guide designed to assist practitioners to support and involve patients and family and carers in end of life planning and development.

End of Life Care: Helping people to be cared for and die at home (2016) published by the Housing Learning and Improvement Network outlines an approach for combining the resources of clinical commissioning groups, healthcare and GP leads for end of life care with those of housing, public health, social care and support.

Every Moment Counts (2015) describes success factors and outcomes in end of life care. The document is the result of a collaborative project between National Voices and The National Council for Palliative Care. It focuses on quality of life and death, honest discussions and planning, physical, emotional and spiritual needs, responsive support and people important to the patient (defined as family, friends and other contact including carers).

Actions for End of Life Care (2014-2016) acknowledges that whilst significant improvement has been made since the publication of the End of Life Care Strategy (2008), there are

further improvements to be made. The document sets out a framework of four interdependent components consisting of engaged and informed patients, families and carers, practitioners committed to partnership working, organisation and supporting processes and commissioning.

One Change to get it Right (2014) outlines five priorities for care of the dying person:

1. The possibility of death is recognised and communicated clearly. Decisions and actions reflect the patient's wishes and are regularly reviewed;
2. Communication between practitioners and the care of the patient and their family and carers is sensitive;
3. The patient and their family and carers are involved in decisions about treatment and care;
4. The needs of family and carers are explored, respected and met as far as possible; and
5. Plans for care are tailored to the individual; include food and drink, control of symptoms and psychological, social and spiritual support.

Commissioning End of Life Care (2011) is a guidance document for commissioners based around the need to act early to avoid negative outcomes.

End of Life Care: Achieving quality in hostels and for homeless people – a route to success (2011) sets out the challenges posed by the End of Life Care Strategy (2008) in relation to homeless people.

The End of Life Care Strategy (2008) sets out the national vision for a whole systems approach to end of life care.

NICE quality standards and guidelines by date of publication

End of life care for infants, children and young people with life-limiting conditions: planning and management NICE guideline [NG61], December 2016
This guideline sets out the need to involve young people and their families in decisions and planning for end of life care.

Care of dying adults in the last days of life NICE guideline [NG31], December 2015
This guideline focuses on improving care in the last days of life through communication and involvement of the patient and their family and carers.

End of life care for adults Quality Standard [QS13], November 2011
The quality standard defines clinical best practice for all settings and services in which end of life care is provided.

Improving supportive and palliative care for adults with cancer [CSG4], March 2004
The key recommendations of this guidance are:

- People affected by cancer should be involved in developing cancer services;
- There should be good communication, and people affected by cancer should be involved in decision making;
- Information should be available free of charge;

- People affected by cancer should be offered a range of physical, emotional, spiritual and social support;
- There should be services to help people living with the after-effects of cancer manage these for themselves;
- People with advanced cancer should have access to a range of services to improve their quality of life;
- There should be support for people dying from cancer;
- The needs of family and other carers of people with cancer should be met; and
- There should be a trained workforce to provide services.

Palliative care for adults: strong opioids for pain relief [CG140], May 2012
This guidance aims to clarify the clinical pathway for pain management.

6) What is on the horizon?

Demand for end of life care

Approximately 470,000 people die in England each year and projection estimates show that this is expected to increase by 20% over the next twenty years. It is anticipated that in the future people will die at an older age and they will have more complex needs. (NHS Finance and Operations, 2016)

Local estimates suggest that in Nottingham City the population of citizens aged 60 years or more will increase by 7% by 2021 (from 48,800 in 2015 to 52,300) and this age group accounts for 87% of deaths. An increase in complexity will further exacerbate the demand for end of life care and national projections of dimensions of complexity illustrate this increase for people aged 65 and over:

- Limiting long term illness will increase by 10% between 2015 and 2020 for those whose day to day activities are limited a little and by 11% for those whose day to day activities are limited a lot;
- Dementia will increase by 15% between 2015 and 2020;
- The proportion of citizens who are unable to manage at least one activity on their own will increase by 13% between 2015 and 2020; and
- Moderate or severe learning disability will increase by 8% between 2015 and 2020.

Source: Projecting Older People Population Information System

Increased pressure on health and social care provision

Increased pressure on funding and performance has and will continue to impact upon health and social care provision, including end of life care.

Sustainability and Transformation Plan

The draft Nottingham and Nottinghamshire Sustainability and Transformation Plan 2016-21 was published in November 2016. One of the plan's five high impact areas is to strengthen primary, community and social care and carer services. It commits to improving end of life care planning and through doing so increasing the number of people dying in accordance with their wishes and reduce the number dying in hospital.

Academic research

The Nottingham Centre for the Advancement of Research into Supportive, Palliative and End of Life Care (NCARE) is undertaking a research project to identify the barriers and facilitators of improved support at home for patients of serious, life-limiting and terminal illness and their families and carers. This study will commence in March 2017.

7) Local Views

Patients and their family and carers

In consultation with the Greater Nottingham Cancer Forum the following key issues emerged for end of life care:

1. Timely and tailored care
   Individually tailored end of life care should be available to patients and their families and carers as soon as it is known that the condition is terminal.

2. Use of directives
   Directives should be mandatory and regularly reviewed with practitioners.

3. Quality of life
   Service delivery should be focused on the patient's quality of life and a good death.

4. Impact on family and carers
   Negative experiences at end of life can have significant and lasting effects on the individual's family and their carers. This should be recognised and efforts be made to avoid this.

5. Culture change
   There is a need to encourage people and particularly young people to talk about end of life and death from an early age. This will help family members and carers to cope with the death of a loved one and to prepare for end of life themselves.

6. Financial vulnerability
   Many individuals experience financial anxiety during end of life and this could be alleviated by better communication about the help that is available.

7. A 'whole team' approach
   Psychological support assists patients and their families and carers to cope and prepare for end of life. Death should be seen as a team event to reduce feelings of isolation.

In 2015 a collaborative project focused on cancer patients and carers of the Deaf Community was undertaken by The Greater Nottingham Cancer Forum and Jane Beech Trust. During a focus group with four male and nine female patients and carers the following issues relevant to end of life care were raised:

1. Diagnosis
   'For 18 months I was told I was OK. There needs to be more pre cancer information for bowel, kidney and lung. It is now in my glands. The first thing people say is how long have you got, but I don't know. I was just told terminal. There is barely any

information apart from geneticists' information looking at lung, but I sometimes feel like a guinea pig.'

2. Information and communication
   Most focus group participants felt that there was not enough information available in British Sign Language (BSL) and that access to interpreters was challenging for the following reasons:
   - Hospital and GP practices not booking interpreters in time for appointments;
   - Outpatient appointments running late and interpreters having to leave before the patient is seen. A suggestion that Deaf people could be given the first appointment at an out-patient session could be easy to implement;
   - Deaf carers being refused an interpreter as they are not the patient;
   - Getting a different interpreter each time – lack of continuity;
   - Same sex interpreter not being available i.e. male interpreter for breast cancer patient;
   - Lack of medical practitioner ability in the skill of explaining medical terms in a layperson's language and to refer to pictures;
   - Lack of access to medical information in the Deaf community has led to the situation where linguistically appropriate BSL signs have yet to be created to be used within the language; and
   - Lack of interpreter knowledge about how to translate medical terms.

Practitioners

Local practitioners have raised the following matters:

- Care packages are sometimes delayed due to capacity issues which can cause undue distress to patients and their family and carers; and
- An increase in the provision of hospice at home would be beneficial.

What does this tell us?

8) Unmet needs and service gaps

- Approximately 54% of those able to benefit from end of life care have been identified according to EPaCCS and Quality Outcomes Framework registrations;
- Approximately 55% of those able to benefit from end of life care have accessed one or more formal community end of life care service (defined as access to the End of Life Community and Coordination Service, Macmillan and/ or the Primary Integrated Care Service);
- There is a need to improve the support that enables people to die in their preferred place;
- Evidence suggests that inequity according to diagnosis exists in identification and service provision. In particular, patients with a cancer diagnosis are over represented in identification of end of life through EPaCCS and in access to formal end of life interventions;
- Research indicates a level of inequity in access to services according to ethnicity, sensory impairment, learning disability and vulnerability;

- There is a need for culturally competent practitioners across the spectrum of end of life care;
- Local views call for the introduction of end of life care as soon as it is known that a diagnosis is terminal; and
- Local views support the encouragement and promotion of discussions relating to death from an early age. The culture of not wanting to discuss the subject needs to be overcome.

9) Knowledge gaps

- There appears to be lack of feedback from patients and their families and carers about what is working and what can be improved in end of life care. This gap will be improved in part following the results of an NCARE research project about improving medicines management in the home.

What should we do next?

10) Recommendations for consideration by commissioners

- Conduct an audit focused on end of life identification and access to services with a view to improving both of these factors;
- Increase the recording of preferred place of death and the proportion of deaths that take place in the preferred place through continuing to promote EPaCCS and access to formal end of life care services;
- Improve equity of diagnosis in EPaCCS registrations and access to formal end of life interventions;
- Ensure end of life care provision is equal and proportionate across sensory impairment, learning disability, ethnicity and vulnerability;
- Promote the identification of end of life supported by EPaCCS across all service delivery;
- Create a positive culture in which citizens and practitioners are able to discuss the end of life of themselves, their families and the people they care for in an open and comfortable way;
- Develop an inclusive process by which patients and their families and carers (including those from 'seldom heard' communities) can provide feedback to providers and commissioners about their experiences and implement a robust system to respond;
- Ensure that religion and belief awareness training for practitioners is regular enough to meet both staff turnover and the fluidity of Nottingham's population; and
- There is a need for improved access to EPaCCS amongst both GPs and healthcare professionals in secondary care. Currently, the use of EPaCCS as a tool is limited by a lack of access from certain providers – notably acute services and secondary care. An audit should consider and set quality parameters for transfer of information from one care setting to another.

Key contacts

Caroline Keenan
Insight Specialist – Public Health
Nottingham City Council
Caroline.Keenan@nottinghamcity.gov.uk

Simon Oliver Simon.Oliver@nottinghamcity.nhs.uk
Commissioning Manager
Nottingham City Clinical Commissioning Group

References

Calanzani, N., Koffman, J., & Higginson, I.J. (2013). *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK*, King's College London: Cicely Saunders Institute.

Care Quality Commission (2016). *A different ending: addressing inequalities in end of life care.* Newcastle upon Tyne: Care Quality Commission.

Department of Health (2008) *End of Life Care Strategy – promoting high quality care for all adults at the end of life*, London: COI for the Department of Health.

Department of Health (2009) Religion or belief: A practical guide for the NHS, London: COI for the Department of Health.

Gomes, B. & Higginson, I.J. (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. British Medical Journal. 2006. vol. 332 (7540), 515-521.

NHS Finance and Operations (2016). *Our Commitment to you for end of life care: the Government Response to the Review of Choice in End of Life Care.* London: NHS Clinical Services.

Keenan, P & Macintosh, P. (2000) Learning disabilities and palliative care. Palliative Care Today, 2000. 9(3) 11-13.

McEnhill, L. S. (2008) Breaking bad news of cancer to people with learning disabilities. British Journal of Learning Disabilities, 2008. 36(3) 157-164.

National Institute for Health and Care Excellence (2015) New guidelines to improve care for people at the end of life, Available at: https://www.nice.org.uk/news/article/new-guidelines-to-improve-care-for-people-at-the-end-of-life (Accessed: 26th January 2017).

NHS Digital (2014). *Health Survey for England – 2013 [NS].* [Online] Available from: http://content.digital.nhs.uk/catalogue/PUB16076. (Accessed 12th December 2016).

NHS Digital (2016). *Quality Outcomes Framework (QOF) -2015-16*. [Online] Available from: http://www.content.digital.nhs.uk/catalogue/PUB22266. (Accessed 12th December 2016).

Nottingham and Nottinghamshire (2016) *The Nottingham and Nottinghamshire Sustainability and Transformation Plan,* Available from: http://beta.nottinghamcity.gov.uk/health-and-social-care/adult-social-care/sustainability-and-transformation-plan-stp/ (Accessed: 1st December 2016).

Nottingham City Clinical Commissioning Group (2015). *Nottingham City integrated community children and young people's healthcare (ICCYPH) programme*. Nottingham: Nottingham City Clinical Commissioning Group.

Nottingham City Council (2012). *Vulnerable adults plan for Nottingham City 2012-2015.* Nottingham: Nottingham City Council.

Nottingham City Public Health Team (2015). Mortality *from key causes* [Online] Available from: https://nottinghaminsight.org.uk/IAS/dataviews/. (Accessed: 12th December 2016).

Nottinghamshire Healthcare NHS Foundation Trust (2015) *The Nottinghamshire Guideline for Care in the Last Year of Life*, Nottingham [Online] Available from: http://www.nottsapc.nhs.uk/media/1078/end-of-life-guidance.pdf. (Accessed: 6th December 2016).

Nottingham Insight (2016). *Joint Strategic Needs Assessment Demography and Social and Environmental Context*. [Online] Available from: http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottingham-JSNA/Related-documents/Demography-2016.aspx. (Accessed 13th December 2016).

Office for National Statistics (2015a). *Death registrations summary tables – England and Wales.* [Online] Available from: http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationssummarytablesenglandandwalesreferencetables (Accessed: 26th October 2016).

Office for National Statistics (2015b). *Deaths registered in England and Wales (Series DR): 2015.* [Online] Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015#breast-cancer-remains-the-leading-cause-of-death-for-women-aged-35-to-49-in-2015 (Accessed 12th December 2016).

Office for National Statistics (2015c). *National Survey of Bereaved People (VOICES): England 2015.* [Online] Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#preferences-and-choice-at-the-end-of-life. (Accessed: 12th December 2016).

Office for National Statistics (2015d). *English indices of deprivation 2015.* [Online] Available from: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015. (Accessed: 12th December 2016).

Office for National Statistics (2015e). *National survey of bereaved people (VOICES): England, 2015.* [Online] Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#background. (Accessed: 14th December 2016)

Public Health England (2013). *Electronic palliative care co-ordination systems (EPaCCS) in England: Survey of clinical commissioning groups (2013) by the National End of Life Care Intelligence Network.* London: Public Health England.

Public Health England (2016). *End of Life Care Profiles*. [Online] Available from: http://fingertips.phe.org.uk/profile/end-of-

life/data#page/0/gid/1938132901/pat/6/par/E12000004/ati/102/are/E06000018/iid/91843/age/279/sex/4. (Accessed: 12th December 2016).

Thomas, K. and Lobo, B. (2011) *Advance care planning in end of life care*, Oxford: Oxford University Press.

Wilson, Mark on behalf of Nottingham CityCare Partnership (2014) *Anticipatory Supply of Palliative Care Medications for Adults Policy: 8 November 2012,* Nottingham: Nottingham CityCare Partnership.