Nottinghamshire Health & Wellbeing Board

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Executive summary

Dying is a part of life. For everyone, death is a unique experience which is shaped by many factors; notably an individual's physical condition, their mental and spiritual well-being, and the care provided to them. A "good death" is not easily defined given subjectivity, however *The End of Life Care Strategy* (1) defines it as being treated as an individual, with dignity and respect, being free of pain and other symptoms, being in familiar surroundings with your family and friends.

End of Life care aims to offer individuals choice around symptom control, their care and their preferred place of care (PPC) and death. People reaching the end of their life may experience a range of needs. Managing these needs requires a multidisciplinary approach encompassing teams across the health, social and voluntary care sectors. Offering patients care centered on their preferences, psychological, spiritual and social needs is the cornerstone, as is involving family, friends and carers of dying individuals.

The Office for National Statistics (ONS) reported a 5.6% increase in deaths in England and Wales in 2015 - the greatest annual increase for half a century. Whilst these figures are set against a backdrop of a longstanding decrease, January 2017 saw a 21% increase in deaths compared with January 2016 (2). An increasing older and frailer population means more people dying each year, and increasingly complex populations using services.

Of all deaths, three quarters are expected with individuals experiencing an end of life (EOL) phase with a life limiting long term illness (LLLTI) – 530,000 died in 2015 England and Wales, so almost 400,000 could have benefited from EOLC services (3–6). Whilst EOLC is generally well regarded nationally, reports and research frequently identify sub-standard care in the EOLC settings (7–10). The Parliamentary and Health service Ombudsman's report *Dying without dignity (2015)* outlined some key themes related to EOL care shortcomings. These included poor recognition of the dying process, poor symptom control, poor communication and inadequate out of hours services (10).

This JSNA will explore what is known about palliative and end of life care (EOLC), which groups of individuals use these services, and what we know about services in Nottinghamshire. Recommendations will be made based upon the findings the JSNA, and offer an insight into overarching issues that act as barriers to good EOLC.

Unmet need and gaps

Service gaps and needs are discussed in-depth in section 8. The key themes supporting the recommendations are:

- A culture amongst generalist providers that does not always see EOLC as "their business".
- Society also still sees EOL as a taboo subject.
- Clinical staff may fail to recognise dying and/or disease trajectories, and may not always enact good EOLC through ACP and palliative registration (EPaCCS).
- The use of EPaCCS (electronic palliative care co-ordination service) is very variable amongst GPs, with improvements in particular surgeries required to embed its use of as a cultural norm in the community setting.
- There is also a lack of use in hospital settings and other services. Hospitals would benefit greatly from routine access to EPaCCS as many EOLC discussions and plans are made when EOL patients deteriorate and require admission to hospital. EPaCCS in hospital would alleviate some pressure from community EOLC providers, but also encourage a positive culture amongst hospital doctors regarding EOLC.
- Finally, there are many barriers to achieving death in an individual's PPC. Barriers to achieving a death at home include:
    - A lack of understanding amongst family/carers of EOL/dying individuals,
    - Gaps in services e.g. night sitter availability and bed based specialist care.
    - Gaps in EOL education
    - Unequal access to EOL/palliative services which currently see a mismatch in service need and use amongst older patients, and those with non-cancer diagnoses.

Recommendations for consideration by commissioners

Recommendations	
Holistic and effective care	
1	End of Life care is everybody's business and this responsibility is explicit in every contract, especially in relation to older people
2	Encourage a culture among all healthcare professionals to discuss EOL openly, and recognise EOL as their business
3	Improve the ratio of referrals to specialist palliative care for patients with dementia/non-cancer diagnoses through improved inter-disciplinary working and medical education. (see also recommendation 6 below)
4	Each person recognised to be in EOL has a named responsible clinician, and a named care coordinator as a first point of contact
5	Health and Wellbeing board to consider enabling choice, better coordinated care and integrated models of EOLC in making strategic plans
6	Conduct qualitative studies/obtain user feedback/outcomes measures for the bereaved and dying
Better information sharing	
6	EPaCCS is made accessible to health and social care providers involved with patients in EOL (particularly hospital wards, acute services, GPs)
7	Improved data collection through EPaCCS to identify rates of access for older people, people with dementia, BME and LGBT populations, and therefore identify populations requiring intervention.

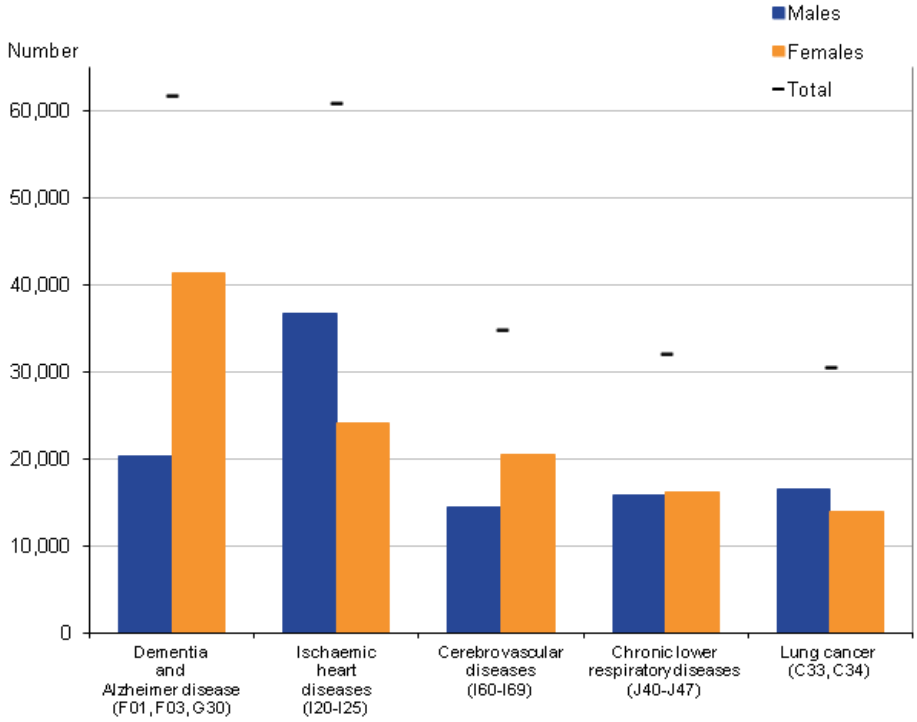
8	Participate in the development of GSF EOLC measures to be used by all localities to improve EOLC benchmarking, and improve EPaCCS data collection and interrogation (e.g. primary life-limiting diagnosis, contributing co-morbidities).
9	Continued improvements of diagnosis rates and use of ACP (through EPaCCS) for dementia patients – using EPaCCS data interrogation as appropriate
10	Adopt the ReSPECT tool in hospitals and the community to improve ACP amongst health care professionals (see also recommendation 13 below)
Education and Training	
11	Improve generalist palliative care quality – further update training is mandatory for healthcare professionals (a) recognising dying, ACPs, (b) meeting needs - understanding of local services). Existing training for foundation doctors continues.
12	Promote care staff training schemes, particularly domiciliary care (such as GSF/LOROS training programme). Consider whether providers could access health funding for this.
13	Promote education/positive EOLC culture through introduction of ReSPECT tool
14	Encourage compassionate communities though strategies as mentioned through understanding public perception, engaging people in commissioning, encourage wider public engagement informing community development and working with health/social care professionals in community development and engagement

Full JSNA report

1) Who is at risk and why?

Roughly 1% of the England and Wales population is expected to die annually, which was 530,000 in 2015 (2, 3). Of these deaths, three quarters might benefit from palliative and/or EOL services as an EOL phase occurs (5). In 2015 therefore, roughly 397,500 people in England and Wales could have benefited from EOL services (2, 10). The people most likely to die are those with life-limiting long term illnesses (LLLTIs). The other quarter makes up those who die unexpectedly (e.g. suicide, acute illness). Figure 1 illustrates the numbers of deaths by the top 5 causes (2).

Figure 1: Number of deaths from top 5 leading causes, 2015, England and Wales (2)



Source: Office for National Statistics, Deaths registered in England and Wales

The latest data (2015) from the Office for National Statistics (ONS) shows that Dementia has overtaken ischaemic heart disease (IHD) as the leading cause of death in England and Wales. Dementia and IHD made up 11.6% and 11.5% of total deaths respectively (2). IHD was the leading cause of death for men (14.3%), and dementia for women (15.2%). It is likely that dementia has been a leading cause of mortality for a long time, however improved reporting rates of it as an underlying (rather than contributory) cause of death have increased its presence in mortality statistics. Population ageing and improved diagnosis rates have also played a major role.

1.1 The Government Response to the Review of Choice in End of Life Care

The key recommendations of "'Our Commitment to you for end of life care' – The Government Response to the Review of Choice in End of Life Care" (11) are outlined below. This report was a response to "A Review of Choice in End of Life Care 2015" (8) which built on other preceding reports over the years including "Ambitions for Palliative and End of Life Care" (12), which laid the framework for national and local health systems to take action to better EOLC.

Key recommendations – The Government response
Holistic and effective care
Each person requiring care in EOL are offered holistic choices to them as soon as possible, based on honest discussions with regular review.
The individual in EOLC should have friends, family and significant persons involved in discussions of EOLC preferences if the individual wishes, and this is appropriate.
Increased working between specialist palliative clinicians and secondary and primary care staff, to identify early those needing EOLC
Commissioners and decision makers at every level (CCGs, Health and Wellbeing boards) ensure universally good EOLC in all relevant settings, with person-centred care in mind
Carers for those in EOL are identified formally, and their eligibility for support (outlined in Care Act 2014) are provided, as well as support during bereavement.
By the end of 2019, every locality should have 24/7 specialist palliative care (SPC) in the community, in line with NICE guidance.
Health and Wellbeing boards consider enabling choice, better coordinated care and integrated models of EOLC in making strategic plans for their locality.
Personal budgets should be explored and provider organisations should consider how they can best use these budgets to enable their choices/preferences to be met
The NHS and social care organisations should work closely with the voluntary sector to support hospices in providing choices to their patients.
Health and social care commissioners make initiatives aimed at improving community resilience and involvement in EOLC in their plans
Improved information sharing
Care choices are recorded in their individual care plan held on Electronic Palliative Care Coordination System (EPaCCS)
Each person receiving EOLC has a named clinician responsible for their care needs and preferences, and a care coordinator as a first point of contact to communicate wishes
Each person wishing to express EOLC choices can do so through accessing their own medical records and and/amend information on these choices
EPaCCS (or equivalent) covers 100% of localities by April 2018, and are fully accessible for all those involved in the provision of EOLC (especially social care)
Education/Training
Health Education England, Local Education and Training Boards and Skills for Care ensure their staff delivering EOLC focus on key elements of their roles to enable early identification of needs, ACP, communication skills, shared decision making and the use of EPaCCS, as well as working with other organisations to deliver person-centred care.
Local areas already with systems and services in place offering choice to individuals share their expertise with others through a central knowledge hub

These recommendations will inform local strategy development and models of care. The implications for specific at-risk groups are discussed below in more detail.

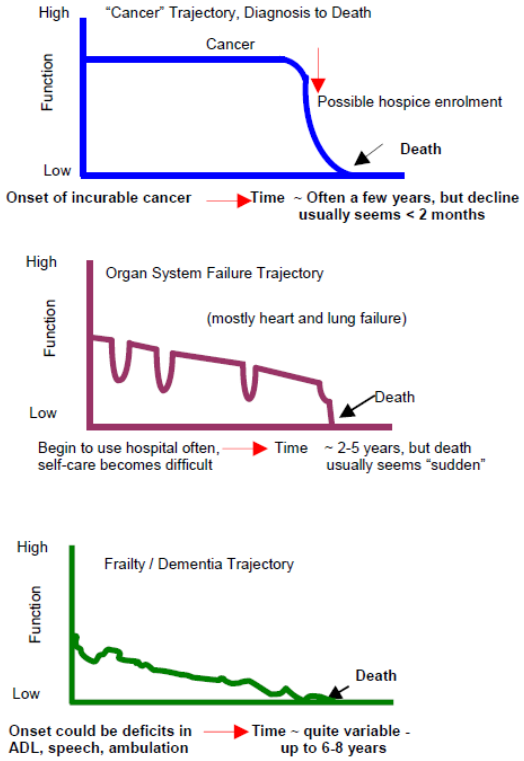
1.2 Older people

In England and Wales, 2015; 85% of deaths were in over 65s, two thirds were over 75. Whilst over 85s made up over a third of deaths (2), the only represent 15% of those accessing specialist palliative care (SPC) (2, 13). The population is ageing, with the number and proportion of older people increasing (14). With this, services need to become better suited to deal with chronic disease, and complex social needs. Many older people live alone driving a need for social care. Whilst 16% of people in the UK live alone, 59% of over 85s and 38% of 75-84 year olds live alone (15). It is evidenced that with age, access to specialist palliative care decreases (16). Data from two hospitals involving 514 older people, the Gold Standards Framework (GSF) prognostic indicator found 36% met the need for palliative care, however only 43% of those meeting the criteria were identified. Qualitative research found medical professionals saw palliative need less in older people as death was “more expected”, and their age made terminal diagnoses more “acceptable” (17).

Currently, place of death is an area of work that receives much focus and investment. There is a drive to allow people to die at their permanent residence if it is their preference (DiUPR). This is not necessarily the same as dying at home. Whilst achieving DiUPR is important (two thirds of people would like to die at home), around half of people die in hospital (2, 6). One study found deaths more common in hospital over home in London compared to New York, with the authors accounting for confounding factors (e.g. symptoms, family structure) (18). The challenge of achieving DiUPR for older adults can go under appreciated – particularly in the context of disability, cognitive impairment, and lack of social care capacity or quality. Many older people have informal care from their ill or frail spouses, typically facing their own challenges that come with age. Some have no informal care which greatly reduces the likelihood of remaining at home in EOL as their needs may eventually exceed what is available (e.g. lack of night sitters). Another barrier to achieving DiUPR is disease trajectory. With sudden/unexpected death aside, people die following three types of disease trajectories (see Figure 2):

- Cancer: EOL is predictable in cancer patients whose prognosis is informed with imaging and clinical deterioration.
- Organ failure patients (e.g. heart failure, COPD) suffer a steady decline over years with intermitted exacerbations, an unpredictable terminal phase and eventual death.
- Frailty/dementia trajectory: “dwindling”, where patients suffer multiple comorbidities and slowly deteriorate with fluctuations in physical/functional state. Because of these trajectories, predicting when an older person will die is difficult.

Figure 2: Disease Trajectories in EOL (19)



Source: The Gold Standards Framework. Full Guidance on Using QOF to Improve Palliative/End of Life Care in Primary Care

It is anticipated the latter two disease trajectories will dominate over the coming years as the population ages and people live increasingly with morbidity (19). These unpredictable trajectories frequently result in inappropriate admissions in last months of life, and can result in a hospital death.

Quality of care for older patients (particularly EOLC) contributes to achieving DiUPR. Better education amongst doctors and carers regarding disease trajectories and the EOL phase would improve recognition of EOL in older people. A 2013 research review on EOLC by Age UK (20) suggested some key policy issues, with salient ones mentioned below. Whilst most of these issues are not directly related to EOLC, improving on them will improve EOLC. EOLC quality is a useful indicator for health and social care quality, and how our society cares for sick and vulnerable people:

Ageism and access to health care (e.g. older people seen as 'bed blockers')

- Viewing older people's needs as social vs medical, rather than being holistic
- Poor coordination between services (e.g. hospitals and residential homes)
- Abusive practice (inappropriate physical and medical restraint)
- Domiciliary care packages restricted from those with moderate or low level needs
- Service gaps for older people with mental health problems/sensory impairment
- Lack of training in EOL issues and older people's health/social issues
- Poor communication between; users, carers, providers, particularly in EOL
- Little data on palliative and end of life care in older adult
- Poor understanding of trajectory of older people's health

1.2 People with Dementia

Dementia was the leading cause of death in 2015 in England and Wales (2). In recent years, mortality from dementia has increased with population ageing and improved reporting of dementia as a cause of death rather than a contributory cause. Reporting dementia deaths as a contributory causes perpetuates a culture whereby dementia is a "normal" part of ageing

(21). Thirty percent of over 65s will die with dementia (2, 22). There are three well broadly themed barriers to dementia patients receiving optimal EOLC – identification and planning, inequality of access and care quality (21). Lack of timely diagnosis, until recently has been a major barrier.

Historically, dementia patients have had poor access to SPC, with <1% occupying hospice beds in Europe) (21). Likewise, the same study found only 17% of dementia suffers who died as inpatients were referred to palliative medicine (23). Whilst most dementia sufferers do not need SPC input, many who would otherwise benefit from specialist input are not identified. SPC nurses from hospital palliative care teams (HPCT) could effectively support dementia patients. Generalists (including carers) need better training in dealing with EOL in dementia.

Given the nature of dementia, and the concept of advance care planning (ACP), one would expect these individuals to have the best rates of use of ACPs. Unlike most LLLTIs, these individuals can lose capacity over care decisions years before their death. Therefore, ACP is more important. Paradoxically, dementia sufferers in the US and UK are less likely to have their advanced directives recorded compared to other LLLTIs (24, 25). Without ACPs, holistic care for these patients is difficult to achieve

Another major issue relates to inappropriate presentation (and admission) to hospitals. People in care homes with dementia are more likely to be admitted for avoidable conditions than those without (21), and studies have found unplanned admissions increase mortality in half of dementia patients (26). Dementia is known for precipitating “bad days” where a patient can appear to be delirious or unwell. Lack of training and awareness of behavioural and psychiatric symptoms of dementia and EOL, and out of hours services can result in inappropriate admissions at the first sign of deterioration. This hinders EOL experiences of dementia patients who are frequently placed in an alien environment.

Most dementia sufferers are older, and therefore suffer arthritis and other problems which precipitate pain (27). They are less likely to be able to express that they are in pain (28), which in turn is exacerbated by anxiety of being in hospital. Dementia sufferers are frequently subjected to artificial feeding and antibiotics that are shown not to improve outcomes in EOL - palliative intervention is more appropriate. Lastly, it is important to acknowledge family, friends and carers of those suffering dementia. Experiencing bereavement long before the death of the sufferer is a typical occurrence as the sufferer’s “personhood” is argued to be lost. The distinction of this form of bereavement is not frequently made, and services need to appreciate this.

Further information about dementia is available in the Nottinghamshire County Dementia JSNA (2014) and the Nottinghamshire County Dementia Framework for Action (2016) http://www.nottinghamshireinsight.org.uk/

1.3 BME groups

Evidence shows that ethnic and cultural differences in populations play a significant role in disease pattern, disease experiences and use of healthcare services (29). Over decades, England has become more diverse – in 2011, a fifth of England were BME (30). Also, the proportion of people in England who do not have a faith doubled between the 2001-2011 censuses. This is reflected in changes in religious and spiritual needs – spiritual care is an important component in EOL, and does not necessitate religious belief (31).

Population projections see proportional and absolute numbers of BME populations increasing. There is an important correlation between BME groups and age – there have been substantial increases in the number of older BME individuals. In England and Wales (2001) there were 500,000 over 65 BME individuals – compare this to the projected 1.3 million expected in 2026,

half a million of which will be over 70 (32).

A report commissioned by Marie Curie and the Public Health England (PHE) found 45 literature reviews describing unmet needs in palliative and EOL care of BME groups (29). These reviews also accounted for social inequalities that may confound findings. Issues with coding and monitoring ethnicity were noted, and assumptions/stereotypes around care of BME groups were also found amongst healthcare professionals. This report found that BME groups are less likely to be in receipt of palliative/EOLC services relative to White-British people. This was directly related to a lack of referrals, lack of awareness of services and a lack of information in relevant languages or formats and family/religious values conflicting with the idea of hospice care. Poor communication was a salient issue – typically there was a lack of sensitivity to cultural differences, and a lack of interpreters and training regarding these issues.

Nottinghamshire has a higher proportion of White-British persons, and a lower proportion of Black/Afro-Caribbean people as compared to England. Gedling, Broxtowe and Rushcliffe have higher proportions of Asian/Asian British people and CCGs should ensure services meet the needs of this population (e.g. access, language and cultural barriers) (33). Gypsy and Traveller Groups are estimated to make up 2-300,000 persons in the UK and there is a significant population in Newark & Sherwood. They have a higher burden of long term conditions (42% vs 18% general population) and very poor access to healthcare. Low literacy, stigma and poor health-beliefs decrease the likelihood of help-seeking behaviour. The nature of their lifestyle also makes registration with GPs difficult and quality of information sharing poor (34). Evidence suggests there is unmet need of terminally ill (35) Gypsies and Travellers, exacerbated by the law which requires them to travel or be evicted (36). This group access EOLC services late if at all – greater efforts are required to attempt to engage this group, as well as understand them better.

1.4 LGBT Groups

In 2015, 1.7% of UK individuals identified themselves as LGB (37), with no census data yet on those identifying as transgender/non-binary gendered. In England, it has been reported in 2008 that LGBT individuals were the most at risk group of experiencing discrimination when accessing quality palliative and EOL care (38). In 2011, another report found that LGBT groups were concerned that EOLC services were not open to them (39). LGBT individuals access services late, if at all, because of a fear of stigma and discrimination. Stonewall reported 3/5ths of older gay people are unconfident with social services understanding and meeting their needs (40–42). Other evidence suggests EOL/palliative services may not ensure LGBT individuals and their families have the same level of spiritual needs addressed as their non-LGBT counterparts. Healthcare professionals may make assumptions about their gender/sexual identity, and some discriminate based on this (42). LGBT individuals are also more likely to experience barriers to good EOLC as they are three times more likely to be single, they are less likely to have children, and more likely to be estranged from family or suffer mental health problems (43).

1.5 People with Learning Disability/Intellectual Development Disability (IDD)

In the UK, 2.5% of people have an IDD. This population increases around 1.1% annually with improving neonatal survival of those with IDD (44). The number of over 60s in this population are expected to increase 36% between2011-2021. Individuals with IDDs suffer more morbidity compared to the general population. For example, they are twice as likely to suffer mental health problems and specific long term illness or disability, and are more likely to suffer obesity, cardiovascular disease, diabetes and visual disorders. Notably, 40% of the IDD population have hearing impairment, and 22% suffer epilepsy (vs 0.75% of general population) (45–52). Adults with IDD will be more likely to be uninformed on death and dying, including the fundamental understanding of the inevitability and permanent nature of non-consciousness. This is especially true of institutionalised individuals who may be “protected” from such topics.

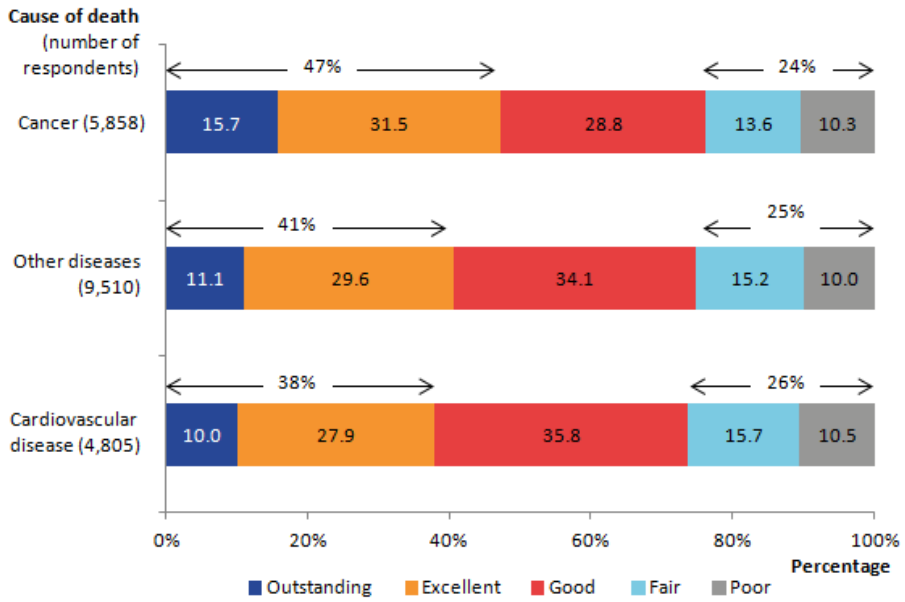
People with IDD are also more likely to have communication difficulty, making EOL discussions and assessing consent/capacity more challenging (51–53). Assessing pain in patients with IDD can be challenging because of communication. There has also been work that has found many individuals have a lower pain threshold – 25% in one study. People with IDD are more likely to express their pain in a behavioural rather than verbal fashion – this can be easily misinterpreted (53). Generalist palliative healthcare professionals need to ensure they are able to communicate with this at-risk population, including working alongside carers and families to properly understand the individual's needs and wishes.

1.6 People with non-cancer diagnoses

Over three-quarters of deaths in Nottinghamshire are due to non-cancer diagnoses (54). The main LLLTIs contributing to this group are chronic respiratory diseases (i.e. COPD), cardiovascular and dementia. Modern palliative medicine has evolved from the hospice movement where the initial focus was for cancer sufferers who now see the best access to palliative and EOL services. It is also much easier to recognise the EOL phase as compared to LLLTIs, as discussed. They have the best perceived overall quality of care (Figure 3 below).

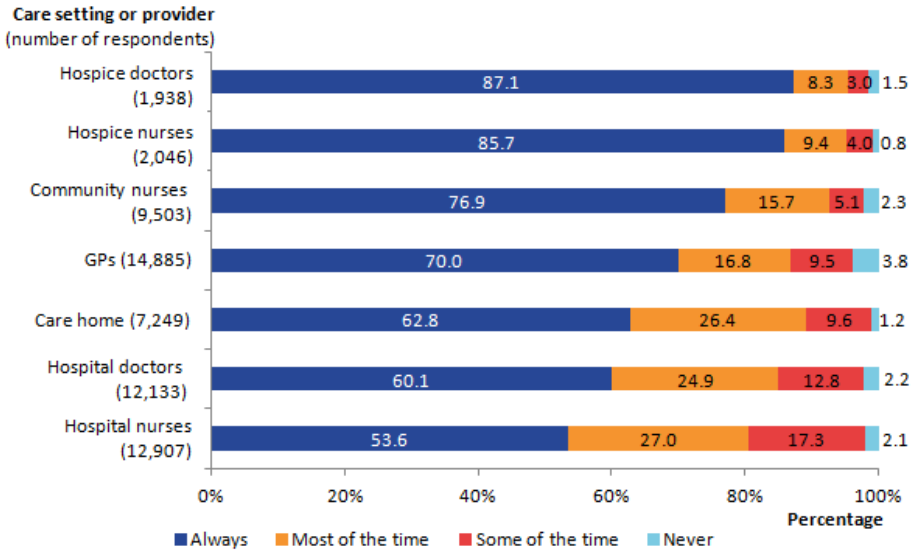
There is a large evidence base describing comparative symptom burden and palliative needs amongst non-cancer patients (16). People dying with non-cancer diagnoses typically carry a higher co-morbidity burden than their cancer suffering counterparts – this also increases the likelihood of a hospital death (16, 19). Non-cancer diagnoses make it more difficult to predict deterioration for and therefore their EOL phase. A culture shift is required to improve recognition, as doctors in particular can be anchored on an intent to preserve life (55). Those with non-cancer diagnoses will be using hospital services more frequently and heavily, and therefore overall experience a poorer level of dignity, respect and care during their last months of life (see Figure 3,4 below) (56).

Figure 3 - Overall quality of care by cause of death in the last 3 months of life, England, 2015 (56)



Source: Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015

Figure 4 - Dignity and respect by care setting or provider in the last 3 months of life, England 2015 (56)



Source: Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015

1.7 The Bereaved

Bereavement can cause physical and mental problems in otherwise well people – 47% of people in the last 5 years alone have been bereaved. It increases the risk of mortality and poor health, and perceived isolation (57). Three quarters of the bereaved say they didn't get the support they required (58).

The National Bereavement Alliance have recommended 6 steps to improve services: a named government minister responsible for bereavement, a national review on the financial/economic impact of bereavement, clarity about who is responsible locally for commissioning and providing support with better coordination and information about services, training in bereavement for all those coming into contact with the bereaved, better support at work and finally compassionate communities where everyone knows enough about grief to help support the bereaved (59).

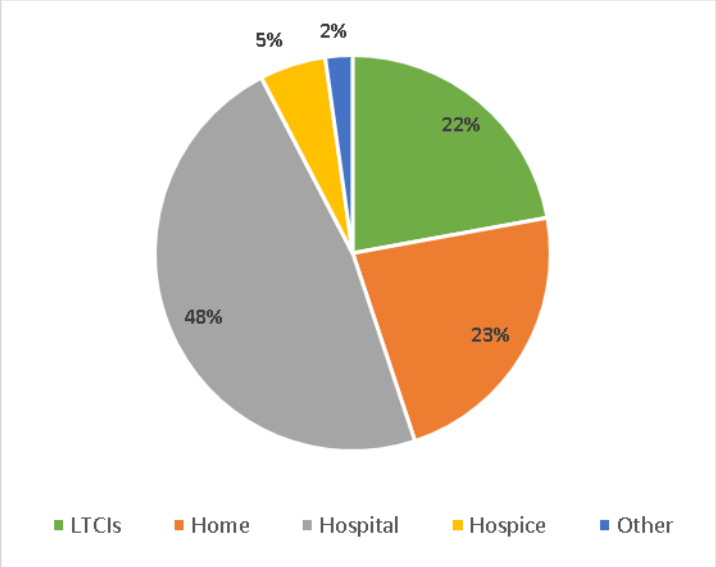
Bereavement assessment tools are available which can help healthcare professionals. Use of these would help the bereaved have good access to services (e.g. Macmillan, Notts hospice) and identify those who are higher risk for depression, adjustment disorder and/or other consequences of bereavement are identified.

1.8 Long term care Numbers of those aged between 45-64 who live alone has increased by one third between 2001-2010 (60). There are 198 care homes within Nottinghamshire registered for older people/dementia. Discussions have suggested that there is a lack of domiciliary care capacity for EOL patients and that people with a LLLTI are eventually likely to require social care. This can be in their home (domiciliary – formal or informal care), or in a care homes), depending on their care needs and the availability of informal support.

People with no family or friends willing and/or able to act as informal carers will require admission to a care home towards their EOL as their needs exceed what can be offered in a domiciliary setting. This is true for most dementia sufferers – as their disease progresses, without 24/7 informal care, home is not safe (e.g. wandering, leaving the stove on). Whilst all CCG areas offer night sitter services for EOL patients through various providers (e.g. Notts hospice), there is a lack of capacity – increased commissioning for these services could prevent inappropriate admission, as well as improving the overall EOL experience for the dying and their loved ones.

22% of all deaths in England and Wales occur in care homes, whilst 23% occur at home. Hospital deaths make up almost half (2) (see Figure 5). The vast majority of people admitted to a care home will die there (61). Care home and domiciliary care providers are generally well regarded, but a 2016 CQC survey saw 16,000 respondents reply, of whom 26% stated their care required improvement, and 2% stated it was inadequate (62). In this survey, domiciliary providers faired the best, and nursing providers the worst. EOLC in care homes and domiciliary care remains an area for improvement, particularly dementia care. Efforts by these care providers can be made to improve EOLC through various training programmes, including the GSF which improves EOL outcomes (including DiUPR). However, uptake of this scheme has been quite low (9 care homes in Nottinghamshire have achieved the standard). To combat this, a shorter GSF programme was offered for which 50-60 Care homes achieved this accreditation. Training domiciliary providers is more challenging however - barriers include a lack of funding and a time/staff to carry out such training. Quality domiciliary care is key to ensuring people can have a “good” death in their own homes.

Figure 5 - Proportion of deaths by care setting (2015, England and Wales) (2)



Source: Office for National Statistics, Deaths registered in England and Wales

A qualitative study from Nursing Times (61) found that although many staff in care homes were not trained in EOLC, they would be open to training to develop their confidence and practice. Respondents that had received training in EOLC said it helped them engage more sensitively, respectfully and creatively with dying individuals. Allowance of meaningful EOLC interventions can only occur with sufficient staffing and time to attend dying residents. Lack of confidence or understanding in certain scenarios (e.g. EOL events such as aspiration, stroke) are major causes for carers (domiciliary or institutional) to call an ambulance. The only safety net to prevent this is the clinical assessment desk that take the emergency phone call. This team in themselves face barriers: they are not medical professionals, nor have knowledge of the patient’s long term health status besides data on EPaCCS (if used).

1.9 Carers

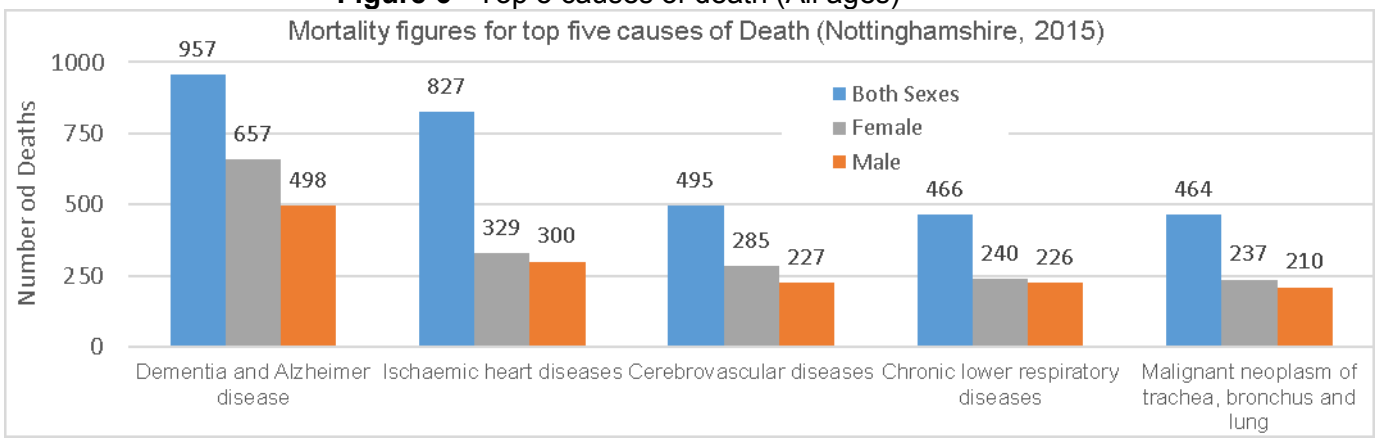
Whilst not an at-risk group themselves, it is important to acknowledge the role of informal carers. In 2011, 5.4 million people (10.2%) in England were acting as informal carers. This was an 11% increase over the preceding decade. Two thirds of us will be carers in our lives (63). Caring impacts on physical and mental health and finances and consequently people’s ability to care for those in EOL. The contribution of informal caring (including money saved) is significant.

Further information about carers can be found in the Nottinghamshire Carers JSNA (2014)
http://www.nottinghamshireinsight.org.uk/

2) Size of the issue locally

The Nottinghamshire population (excluding Nottingham city) has 805,848 residents as of 2015, Nottinghamshire has a population of 805,848. Whilst the proportion of persons aged 75-84 has remained stable in comparison to England, the proportion of those over 85 and those aged 65-74 have increased at a rate slightly greater than that of England. Directly age standardised mortality rates (DASMR) for all ages in Nottinghamshire match that of England over 2014-2015, however the overall rate is 4.8% higher at 1049/100,000 as opposed to 1001 of England. The age group with the greatest increase in DASMR relative to England was those aged over 85 (64). Causes of death are similar to England. Figure 6 shows the top causes of death in Nottinghamshire - dementia (13%) and ischemic heart disease (11%). Cerebrovascular disease (stroke), chronic respiratory disease and respiratory cancers each made up roughly 6%. Other causes made up 58%. It is estimated that about three quarters of deaths are anticipated and therefore there is opportunity to introduce palliative care during their EOL phase (10).

Figure 6 - Top 5 causes of death (All ages)



Source: Primary Care Mortality Database

The Office for Primary Care Mortality Database shows in 2015 (54), 7615 people died in Nottinghamshire (excluding the City). This is 0.94% of the whole Nottinghamshire population which roughly matches the figure of 1% of the population dying nationally each year. Applying the proportion of three quarters expected to die with an EOL phase, this equates to around 5711 persons annually who could benefit from EOL services.
Rates of DiUPR and deaths in other care settings in Nottinghamshire are similar to that of the England average, with no obvious outliers to mention. There is a range of results by CCG given differences in demographics and intrinsic differences, but no specific outcomes that require specific discussion.

3) Targets and performance

The End of Life Care Intelligence Network (link below) presents performance data for England organised thematically under six domains: place of death, death in usual place of residence (DiUPR), underlying causes of death, mortality, dementia and other contextual indicators. It includes over 80 indicators encompassing data from 2004-2014, this section comments on key data sets comparing CCG performance.
http://www.endoflifecare-intelligence.org.uk/home

There are limitations with the existing data sets, for example, a lack of qualitative data. This chapter therefore also uses local data sources, however these are not necessarily available

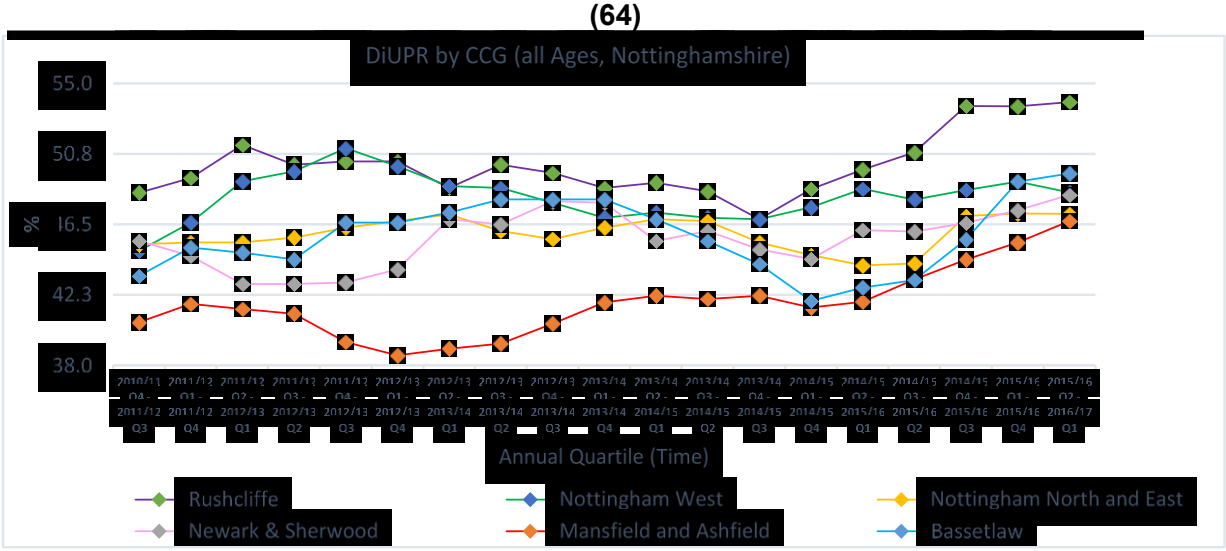
for other CCGs or individual hospital trusts and cannot always be benchmarked. For example, feedback from SFHT from the bereaved can be useful in identifying areas for improvement in generalist palliative care, however, a lack of comparable data from NUH, and/or nationally, means it is difficult to rate the Trust's performance. Data from CityCare for EPaCCS is also difficult to use as it is limited by sample size, particularly for CCGs where uptake of EPaCCS has been less widespread.

The Royal College of General Practitioners have suggested metrics for EOLC in recent guidance for commissioners. This included: numbers with non-cancer diagnoses, numbers of carers offered assessment and care in bereavement, numbers offered ACP, hospitalisation metrics including percentage of deaths with 3+ admissions in final 3 months of life, length of stay and more. These metrics could potentially provide a better understanding of EOLC performance across CCGs and regionally.

3.1 Deaths in Usual Place of Residence (DiUPR)

Deaths in Usual place of residence (DIUPR) is a proxy measure for good EOLC - the higher the rate, the less inappropriate admissions have occurred, and the greater the fulfilment of patient preference in place of death (although not always sensitive to patient preference). DiUPR have seen a general improvement since 2014/15 Q1- 2015/15 Q4 across all Nottinghamshire CCGs and that was co-incides with the local introduction of EPaCCS. The England average for 2015 was 46% (64). The graph below (Figure 7) shows DiUPR by CCG.

Figure 7 Proportion of Deaths in Usual Place of Residence (DiUPR), all ages by CCG (64)



Source: Public Health England. End of Life Care Profiles

The best performing CCG is Rushcliffe, whilst Mansfield and Ashfield are performing the worst (although their rate has seen marked improvement and is still better than the England average). Mansfield and Ashfield has low rates of DiUPR for over 85 year olds at 49.9% (other Nottinghamshire CCGs average 56.8%). Rushcliffe has strong EOLC leadership supported by the GP federation group particularly regarding EPaCCS use.

Whilst DiUPR rates are generally improving, barriers remain – for example, access to social care services, both in a domiciliary and care home setting. If a patient is in hospital and requires a discharge into care for their PPC/PPD, a delay in receiving a care package or choosing a home (choice made by patient/family/IMCA) may result in their death before achieving PPC. Delays can be attributed to:

- delays in fast track continuing care funding approval

- lack of district nursing care and/or out of hours services and night sitters
- though not specifically evidenced, anecdotally it is noted that there is a lack of capacity for EOL beds amongst care homes and hospices in Nottinghamshire.
- patients/carers experiencing difficulties in care, may be reluctant to choose their home as their PPD. Access to services are paramount to ensuring DiUPR is desirable (110).
- Circumstances around dying can mean that whilst someone wishes to die at home, their deterioration can be too great a burden on their care-giver.
- Quality of pain control at home – only 18.6% of respondents in the National VOICES survey reported that pain was treated "completely, all the time" (56).

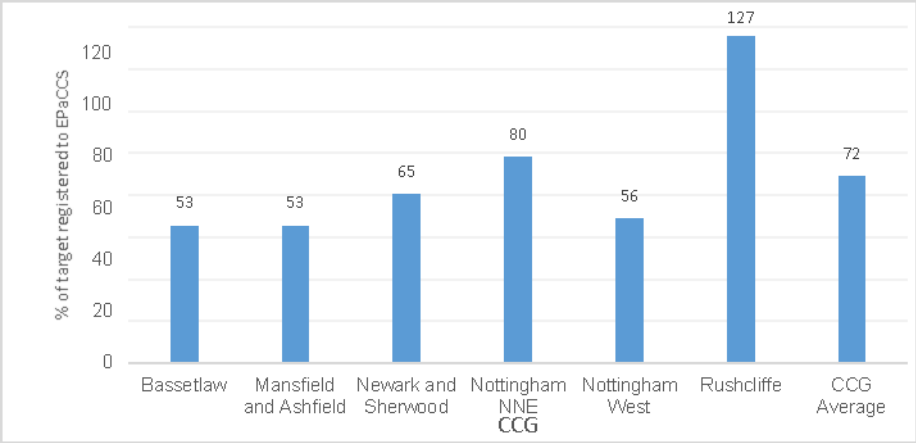
However, it is also noted that hospital deaths are the worst rated of all care settings to die in, or spend time in within the last 3 month of life (49).

Most people do not want to die in hospital, however a death at home may not be as comfortable (49). As stated in a Marie Curie commissioned report (16), *"Where people are cared for and die is influenced by the care options available locally, with good quality, community-based palliative care increasing the chance of DiUPR"*. Ambulance service studies (71), show breathlessness is the most common cause (by far) of emergency presentations for EOL patients – most of these patients suffered COPD. This makes achieving DiUPR for patients with respiratory LLLTIs more difficult, and that improved palliative input may help.

Lastly, whilst DiUPR is a useful indicator to benchmark EOLC and/or ACP performance, it is not as desirable as using preferred place of death (PPD). Whilst most people prefer to die at home, a proportion still choose to die in hospital and/or hospices and DiUPR assumes this is a negative outcome. At the same time, it assigns a positive outcome to deaths in care homes even though this may have occurred because death at home could simply not be achieved.

3.2 Electronic Palliative Care Coordination Systems (EPaCCS)

Figure 8 % of expected patients registered on EPaCCS in 2016, by CCG (100 represents 0.75% target) (65)



Source: Citycare EPaCCS data 2016

If all EOL patients were registered on EPaCCs, at least 5711 patients (as discussed above) would have been added in 2015 within Nottinghamshire (excluding city). This figure is based on the proportion expected to die with a LLLTI for a given year (2015 mortality data). The figure could be higher since more than those in their last year of life may be identified, or lower, since those who are in their last year may not be appropriately recognised as dying.

Nottinghamshire has 3918 active EPaCCS patients in total (65). This accounts for roughly 0.54% of the total population (NB: based on figures used by CityCare, refer to Figure 8). Ideally this number would be closer to 0.75%. Therefore, Nottinghamshire is two thirds of the way to registering the number of persons expected to benefit on EPaCCS. This number is cumulative, so it is difficult to ascertain how many were registered in this year alone – however, over three months roughly 500 patients were added to the register which equates to roughly 2000 per year i.e. about 32% of the expected number of nearly registered patients. Also, 31.9% of referrals are non-GP (these are usually done by district or specialist nurses). A detailed breakdown of EPaCCS use amongst GPs, shows that it is certain GP surgeries rather than specific CCG areas that are not using EPaCCS as much as desired.

3.3 Other EOL data obtained from EPaCCS

3.3.1 CPR status (Figure 9)

The average percentage of patients with a recorded resuscitation status is currently well below the expectation that all 100% registered patients have this recorded (see figure 9). There are few circumstances where resuscitation discussions are inappropriate, if a patient is identified on an EOL register (EPaCCS). There will always be a small number of patients waiting to have their EPaCCS updated, or have these discussions following a recent life-limiting diagnosis, however this is not accounted for by the these rates.

3.3.2 PPC/PPD (Figure 10)

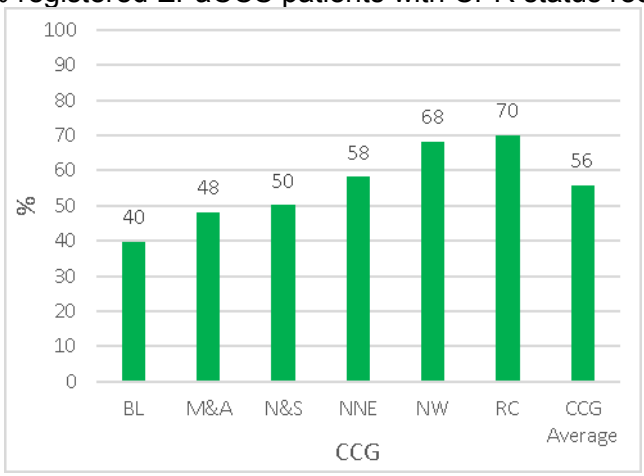
EPaCCS is useful also for data collection on EOLC targets such as those with a recorded preference for resuscitation, place of care (PPC) and death (PPD), and the average number of weeks to death from the date registered to the programme. Data is limited by the sample size of patients registered by CCG (66). It is also confounded by the fact that GPs who use EPaCCS may have better behaviours and practices around effective, holistic EOLC and therefore components of ACP such as DNACPR. Rates of recorded PPC/PPD are higher than CPR status, although there is still a need for improvement.

Similar to resuscitation status, recorded PPC and PPD are significant importance in EOLC. PPC/PPD preference are particularly important for emergency healthcare staff (both GPs, hospital doctors and ambulance crew) when considering acute deteriorations for EOL patients.

3.3.3 Cancer/Non-cancer

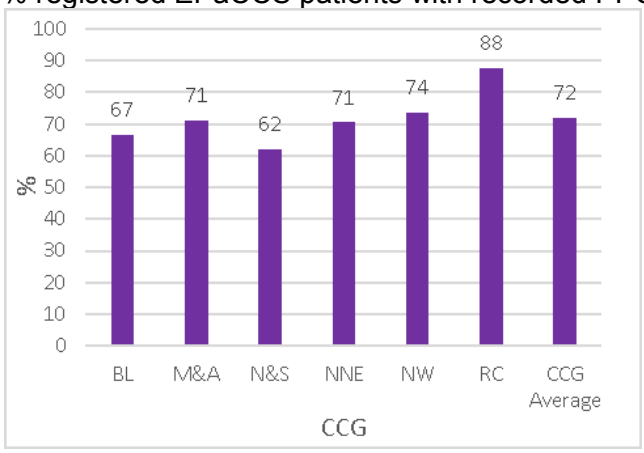
It is suggested anecdotally by clinicians that non-cancer diagnosis rates on EPaCCS (and therefore ACPs) are greatly improving, however, it is difficult to show how cancer and non-cancer registered patients compare. Non-cancer diagnosis patients made up 69.5%, cancer patients 55.1% and patients with both made up 24.6%. but it is difficult to ascertain from national mortality statistics what proportions of deaths by cause were avoidable or unexpected, and what the life-limiting diagnosis is in patients with “both” (e.g. patient dying of advanced lung disease, with a low grade prostate cancer).

Figure 9 % registered EPaCCS patients with CPR status recorded (68)



Source: Citycare EPaCCS data 2016

Figure 10 % registered EPaCCS patients with recorded PPC/PPD (68)



Source: Citycare EPaCCS data 2016

BL= Bassetlaw CCG M&A=Mansfield and Ashfield CCG N&S=Newark and Sherwood CCG NNE=Nottingham North and East CCG NW=Nottingham West CCG RC=Rushcliffe CCG

3.4 Dementia

The Nottinghamshire dementia diagnosis rate is above the national target - the mean diagnosis rate at October 2015 was 69.5% (67). DiUPR for dementia patients (all ages) in Nottinghamshire decreased between 2012-2014, however has greatly improved back to the % expected with the progressive trend as seen with England for 2015. The latest data for dementia patients aged over 65's (2014) shows "significantly" poorer rates of DiUPR (3.1% lower) and "significantly" higher rates (4.2% higher) of hospital deaths – this may improve with the inclusion of 2015 data. If not, one could elude that the anecdotally noted lack of EOL beds in care homes may cause delays to discharge causing higher hospital deaths.

Regarding equity in access and quality of care, there is no hard data to benchmark this. DASMR of over 65s with dementia is also "significantly" higher than England (13% higher) for latest data (2014). This is difficult to comment on – this may simply be due to improved registering of dementia deaths as main cause of death rather than inadequacies in care. Until dementia diagnosis rates and registering of dementia deaths becomes roughly consistent, DASMRs for dementia cannot be benchmarked (64).

3.5 Hospital inpatient end of life care 2015

In England hospitals, every two years a national audit of care of patients dying in hospital takes place. These reports enable hospitals to benchmark themselves with each other, and the England average. The sample is based on up to 80 records of people dying in each hospital 1-31 May (link below). End of Life Care Audit

3.5.1 Sherwood Forest and NUH

Below are some relevant findings from SFHT and NUH from their local reports. (66, 68).

Figure 11 Audit results of EOLC in SFH and NUH trusts (66, 68)

Clinical Audit questions	England (9302)	SFH (81)	NUH (80)
For the last episode of care, was there documentation of recognition of the patient being in their last hours-days?	**83%**	**85%**	**88%**
For those recognised as dying – was this discussed with a nominated person(s) important to the patient?	**79%**	**84%**	**84%**
Is there documentation the patient was given opportunity to have their concerns listened to? %YES or NO BUT	**84%**	**91%**	**91%**
Is there documentation the needs of the person(s) important to the patient were asked about? %YES or NO BUT	**56%**	**69%**	**78%**
Is there documentation in the last 24 hours of life of a holistic assessment of their needs regarding an individual plan of care?	**66%**	**95%**	**84%**

Sources: Nottingham University Hospitals NHS Foundation Trust. End of Life Care Audit - Dying in Hospital Site Report. 2016.
Sherwood Forest Hospitals NHS Foundation Trust. End of Life Care Audit - Dying in Hospital Site Report. 2016.

Both trusts were performing above average regarding the clinical aspects of inpatient palliative care. There are no areas for major improvement – 100% scores are always desirable however, and further efforts into documentation of the individual's important needs could be improved upon in particular. Rates for these are relatively low to other indicators, although NUH/SFH perform well overall. Other indicators have been collected – some are more useful than others due to the sample sizes, so only the relatively significant differences will be discussed. The mean age was found to be 79 in England, and similar at 80 in SFH and 78 in NUH. Only 8% were under 60 years old in England – 7% in SFH, and 6% in NUH. Under 60's make up a very small proportion of hospital deaths for these samples – this reinforces the view that quality care for older patients is essential to ensure equity in care provision for dying patients.

Both Trusts performed better than the England average in relation to:

- Recognising that the patient was in the last days of life
- Regular review once recognised as dying,
- Proportion of senior doctors (consultants and GPs) who took part in discussions around the recognition of dying.
- Percentage of patients dying with ACPs made before admission
- Family supported immediately after death,

3.5.2 Doncaster & Bassetlaw Hospitals

Doncaster & Bassetlaw Hospitals also scored higher than the national average in 10 of 13 categories for clinical and organisational care, which included recognising that the patient was in the last days of life, providing an around-the-clock palliative care service and involving those close to the dying person in decisions about the care provided.

Equity in Access at NUH (Hospital and SPC Inpatient Units)
Data from NUH between 1st April 2015-31st March 2016 offers an insight into the types of patients referred to hospital palliative care services (HPCT) and the SPC inpatient unit (Hayward House) (69) This data reflects the issues identified in Section 1 *Who is at risk and why*? The overall findings are:

- Age - younger groups were more likely to be referred to SPC services. The 75-84 age group saw the most equitable levels of referrals to services, whilst the under 65 group received the most referrals relative to "actual" numbers. The over 85 group saw the lowest overall proportion of referrals relative to the "actual" proportion
- Cancer/non-cancer diagnoses – the audit shows that cancer patients were the main users of SPC services
- Dementia - the patients seeing the greatest apparent inequity in care are patients with dementia – only 1.5% of all referrals to HPCT (NUH) had dementia, and 0.65% of NUH SPC Inpatients. Considering the actual numbers of those dying with dementia, and the repeated inappropriate admissions they encounter, it would be appropriate for these patients to receive more referrals for optimisation of their EOLC.
- Ethnicity -it is difficult to identify the proportions of patients by ethnicity expected to be seen using services. Numbers by ethnicity vary greatly between the city and the county (e.g. 71.5% white in the city, 95.5% are white in the county) (33). Nonetheless, the audit suggests there a deficit in the numbers of non-white persons accessing services for HPCT. It is difficult to comment on whether this is a problem in access to SPC or access to healthcare services in the first place.

The details of this audit can be found at Appendix A

4) Current activity, service provision and assets

4.1 Specialist palliative care services

John Eastwood Hospice (JEH) comprises **–**

- 12 bed SPC unit covers mainly the north of the county - Mansfield, Ashfield, Newark and Sherwood (part funded by these CCGs). The unit provides a multidisciplinary approach with special focus on the patient's physical, psychological, social and spiritual needs, as well as the needs of their carers/families (holistic care).
- a day therapy service 4days a week.
- a specialist palliative 24/7 advice line a
- Bereavement support is also offered to patients registered to John Eastwood

Hayward House – based in Nottingham City hospital comprises,

- an inpatient ward
- a day hospice service, l
- Bereavement support is also offered. Rushcliffe, NNE and Nottingham West CCGs fund the service partially, and they provide their services mainly for the south of the county.

4.2 Palliative care services

Hospital Based Palliative care - NUH, SFHT and Doncaster and Bassetlaw Hospitals provide inpatient care for people with palliative care needs.
Community Based Palliative care - Notts Healthcare Trust provides local Integrated Teams and in Bassetlaw, Integrated Neighbourhood Teams consisting of district nurses, occupational therapists, physiotherapists and community matrons. The Teams work closely with GPs, hospitals and other health and social care colleagues.

Nottinghamshire Hospice mainly provides a service to Nottingham city but also provides a hospice at home, bereavement support and day therapy for the County

Beaumond House – a community hospice, funded charitably which offers services to patients within a 15 mile radius of Newark. It offers four in-patient beds, however there is no specialist palliative consultant – a consultant from John Eastwood does visit on a needs basis, however this is not commissioned. It is staffed with specialist nurses and out of hour GPs. Care in the community is also offered.

Treetops – this hospice serves patients from Southern Derbyshire and Nottinghamshire (mainly Nottingham West CCG). It has a day-hospice service and a hospice at home service. This service is particularly useful for those requiring care at night, however capacity is limited. Treetops also commissions a specialist palliative consultant providing an outpatient service.

Bassetlaw Hospice has a 6-bed inpatient unit, a day therapy unit. The unit is led by a team of experienced and qualified nursing staff with daily clinical support from a Palliative Care Consultant, local GPs and an Occupational Therapist.

Fast Track Continuing Care (FTCC) - Nationally, the Fast Track Pathway offers expedited continuing care (paid for by the NHS) for those identified to be rapidly deteriorating and their life-limiting illness may be entering the terminal phase, helping them to die at home by providing e.g. night sitters, or pay for care in a care home or hospice.

Rapid Discharge - From hospitals, the pathway allows patients who will die imminently (within days) to be transported home in hope of them passing away in their home, as they wish.

Bereavement services - Local hospitals do not have the capacity to offer formal bereavement services unless provided by the hospice (for those who have been in contact with the service only). The bereaved can access bereavement services through referral from their GP. Organisations such as Cruse Bereavement Care, MacMillan and Nottinghamshire hospice also offer bereavement support.

Voluntary sector support services - Charities such as Macmillan, Marie Curie and Age UK offer various services and care for dying/cancer patients as well as bereavement support. Depending on availability they can also deliver overnight nursing/caring (limited capacity).

Interdependencies

East Midlands Ambulance Service (EMAS) - EMAS plays a crucial role in the delivery of quality EOLC through patient transport (e.g. hospice discharge), appropriate emergency care and supporting patient choice regarding EOLC and death. Ambulances are frequently called when there is a sudden deterioration or end of life event and are often the first or only healthcare professionals present at the scene, or soon after a death. Their clinical assessment desk has access to EPaCCS however there is no data or evidence looking at how widely it is used, and outcomes of its use before and after implementation. The first (recent) national report on the Ambulance service's role in EOLC has been released which recommended the development of evidence based EOLC decision support tools to help ambulance crews identify EOL patients, and enable safe and appropriate care decisions (71)

5) Evidence of what works

5.1 Education and Culture (Carers and Communities)

5.1.1 Carers

Some care homes offer Gold Standard Framework (GSF) training. These care homes are usually recognised by CQC, NHS Choices and commissioners for their higher quality care. The

training results in better care, proactive planning, improved working with GPs, better staff morale, more ACP and reduced (usually halved) hospital deaths (72). These schemes are also offered to domiciliary care providers however uptake is low due to workforce and financial barriers.

The LOROS care provider pilot (2015-2017) is an example scheme aimed similarly at improving EOLC outcomes for individuals in an institutional and domiciliary setting, through training of staff (managers and senior carers). Unlike GSF accreditation, many staff trained on the programme decide to continue their training to a higher tier level (three levels of accreditation). It was funded by various organisations including local authorities, CCGs, EMAS, Skills for Care and the GP EOL lead. It was shown to improve numbers of unplanned hospital presentations, and improved DiUPR and ACP rates. The project is hoped to be sustainable as provider staff implement EOL forums for staff to meet and discuss current and future practices, negotiate engagement with Gold Standards Framework, have forged positive working relations with LOROS (the hospice service), and the involved staff championing EOLC. Further information is available at: LOROS EOLC PILOT

5.1.2 Communities

Regarding the general attitudes and culture around death and dying, it is still largely a taboo subject in England. The avoidance of these sometimes difficult discussions has adverse consequences – people become unnecessarily frightened about dying, whilst others may feel ill-equipped to make decisions about their care or place of death (6, 73). This is not least because of family members, friends, and even healthcare professionals who too often avoid the subject – sometimes because they wish not to have such morbid discussions, or lack the confidence and/or vocabulary to initiate such discussions. After death, the bereaved can find themselves isolated following an avoidance of discussion regarding grief and loss (73–75).

Within older age groups, since 2009 we have seen a general improvement in attitudes however there is still much to be desired – only 11% of over 75s have an ACP, and only 1 in 10 people have a funeral plan (6). The End of Life Care Strategy (38) recommended that services should promote awareness and conversations around EOLC and dying through local strategies. These should be centred on three levels; individual, societal and infrastructural.

Community based strategies are needed to overcome the taboo – there are many potential parties that can be involved in these – from GPs, to bereavement groups, funeral directors, social services, schools, trade unions, faith groups, older people and their carers, families and friends. There have been various strategies local to Nottinghamshire – for example, there is a monthly death café, and a social media page called "Die-alogue". NHS Devon and Devon County Council used a joint approach to engage patients and services involved in EOLC, to create a "compassionate community". Some of their strategies included (76);

- **Understanding public perception -** Surveys and consultations with various groups (disease reference groups, pensioner forums, care and voluntary sectors).
- **Engaging people in commissioning** – "big conversations" with local stakeholders and further events asking specific questions about where services should focus. The outcomes informed local EOLC strategy and a "good death charter" outlining principles by which people wished to be treated (e.g. privacy, dignity, respect).
- **Wider public engagement informing community development –** to name a few strategies; three "dying matters" themed conferences, collaboration with local solicitors and funeral advisers to raise awareness, teaching in school curriculum for teens, working with various groups for various projects including the Church clergy, disability groups, Age UK, Macmillan, Citizens advice bureau.
- **Working with health/social care professionals in community development and engagement –** local governance to encourage local health/social professionals to de-

liver high quality care. Some initiatives included: 24/7 community nursing and domiciliary care, and 24/7 access to SPC advice, universal ACP, DNACPR and anticipatory medication guidelines, clinical champions in EOLC, introduction of dying matters care home training, and development of a dementia and carers strategy

5.2 Education and Culture (healthcare professionals)
It is appreciated that overall good EOLC relies upon generalist healthcare professionals particularly doctors, who will be responsible for recognising EOL and determining management. The majority of dying people will be cared for by generalists. Recognising individuals to be reaching their EOL is pivotal for prioritising management. Late recognition, exercising life-prolonging intent and a culture that discourages these difficult discussions results in individuals dying in hospital (55, 77).

These barriers derive in part from a culture amongst some doctors that does not recognise disease trajectories in the EOL (mainly non-cancer diagnoses) (54), and a culture that views death as a failure. Too often EOL discussions are reserved for the last days once doctors realise their life-prolonging attempts are futile. Speaking generally, there is a lack of EOL as a theme in medical education. In five years of medical school, teaching of EOLC can vary from a single day to a week in a hospice, with no EOLC teaching delivered with a generalist focus rather than EOLC in the hospice setting. In a report by the RCP (2012), physicians reported being less confidence with ACP and dementia patients, and two-thirds had attended no EOLC training events in the preceding 5 years. Audit data has also showed self-reported confidence In EOLC is sometimes misplaced, and early recognition of EOL and ACP use is lacking (77).

The NHS requires a system wide approach to deliver EOLC training. Universities need to increase EOL education for doctors (and other healthcare professionals) both at undergraduate and postgraduate levels. There have been small improvements in this recently – for example, a compulsory EOLC training day for foundation doctors. This training is excellent, offering guidance on ACP, EOLC and difficult discussions, although it would be helpful to also include a focus on local service provision. Universities need to increase EOLC teaching and change the culture to see EOLC as a priority in an ageing population. New cohorts of doctors need to be able to recognise disease trajectories, the pattern of “dwindling” and the importance of ACP for these recognised patients (particularly dementia patients). The 2012 RCP report (77) provides for further reading around recommendations regarding medical education in EOLC. Key areas to explore include:

- **Multi-professional collaboration–** encouragement of multi-professional collaboration can modify negative attitudes and perceptions as well as remedy failures in trust and communication between professions and disciplines.
- **Clinical practice** – EOL training currently is mostly gained though clinical practice. Supportive educational approaches such as bedside teaching can further develop existing knowledge, and provide new insights and develop problem solving and reflective skills.
- **Learning from Patients and Carers** – structured interactions with caregivers have proved a powerful approach to challenging EOL misconceptions, as well as to understand the practical and psychological support needs of carers and patients.
- **Promoting cultural change** – Organisational change is more likely to succeed when; the change is clearly identified, the criteria for successes are identified, there is leadership at all levels, the message is clearly communicated, when there is positive gain for all stakeholders, and when the change is supported by respected champions (77).

5.3 Advance Care Planning (ACP)

A survey for *Dying Matters* found only 4% of the adult population (all ages) had an ACP (78). ACP is central to quality EOLC based on patient preference. It offers a holistic approach to care which allows patients a death as close to their wishes as is feasible. It can be undertaken by any health professional involved in EOLC, and should be recorded appropriately (e.g. EPaCCS) (73). GPs and specialist nurses play big roles in this – however, it is commonly undertaken in the secondary setting also. Unfortunately, discussions are not always effectively recorded – provisional audit results from SFH reveal 35% of 110 discharge summaries for FTCC patients were rated "poor" – and it should be noted that (this is an issue nationally. ACP includes discussions around resuscitation (DNACPR), PPC/PPD, lasting power of attorney (LPA) and advanced directives to refuse/accept treatments (ADRTs) (79). ACPs are important for those with LLLTIs, those in their EOL phase, and especially dementia sufferers whose capacity will be lost.

ACP is well evidenced to improve EOL outcomes. For example, one randomised controlled trial found ACP improved patient and family satisfaction in EOL, and reduces family stress, anxiety and depression (80).

ACPs are recommended to be recorded on EPaCCS as well as in possession of the patient/family. EPaCCS is a nationwide initiative currently being rolled out, which has been of particular focus in the recent government response *Our Commitment to you for end of life care* (11). It is a programme that essentially prompts EOL ACP and keeps records up-to-date. It should be accessible to GPs, emergency ambulance services, acute and secondary care settings, community nurses, SPC services, emergency phone services (999, 111), hospices, social care and long term care institutions. In short, everyone involved in EOL phase individual's health and social care should have ease of access to EPaCCS (81). It is hoped this should improve communication between services and focus EOL patient's preferences in care settings.

The use of the palliative care register (EPaCCS) is widely appreciated (and evidenced) to improve outcomes for EOLC, in particular by improving the likelihood of individuals dying where they wish (81). Most people wish to die at home as their PPC/PPD, and the bereaved of individuals who die in hospital tend to state that they died in the wrong setting (56). The average time spent in hospital in the last year of life is 46% longer for those without an ACP (80).

There remain some barriers to the implementation and use of ACPs and EPaCCS – healthcare professionals' unwillingness to discuss such difficult topics, reporting and auditing difficulties (information governance issues), limited research and evaluation into its efficacy, the broader context of initiative fatigue, time and financial constraints, and stretched GP services (82). Incentivising GP's to reach a desired % of the population identified on EPaCCS is one way of improving ACP rates, and in turn, rates of DiUPR. For example, a rate of 0.75-1% of the GP list population with an ACP on EPaCCS would be desirable. The introduction of the ReSPECT tool is hoped to be improve practice in secondary care.

5.4 Dementia

Nottinghamshire's dementia diagnosis services are provided by Nottinghamshire Healthcare NHS Trust Memory Clinics although GPs have also been mandated and encouraged to diagnose and treat where appropriate, particularly where someone is in a care home.

Consideration of how the diagnosis is given is important, and culturally appropriate assessment tools are more widely needed. ACP (via EPaCCS) should be encouraged since people with dementia may need to make their plans earlier. It is appreciated that dementia patients are more likely to be admitted to hospital than the general population, and they also receive poorer care overall. Having a plan reduces inappropriate hospital admissions and improves EOLC outcomes.

5.5 Cost effectiveness of palliative based EOL interventions

PHE (2017) undertook a review of 44 studies exploring cost-effective commissioning in EOLC (83). It reviewed the data with the use of the NICE economic evaluation appraisal checklist. The main review question regarded our current knowledge and identified gaps in economic evidence of palliative/EOLC, and its findings are outlined below:

- The mismatch between PPC and actual place of care in EOL is well established – one study found 90% of people in EOL spend time in hospital in their last year, and there is excessive inappropriate hospital admissions that could have been avoided with high quality community support (84). This discrepancy offers opportunity to reshape community care to better align with individual preferences (PPC/PPD as home), and in turn avoid unnecessary hospital admissions. The cost implications of shifting the focus of care to the community setting is not fully understood – saved costs in secondary care may be offset by community (primary care, social and informal care) costs (83).
- A recent review on equity of provision of palliative care in the UK has evidenced some costs and cost-effectiveness of EOLC despite a lack of data on the differences of costs between generalist and SPC, across care settings (16). This data is largely international however – for example, a Cochrane review of the topic found only 1 of 6 relevant studies to be from the UK. In this study, a fast-tracked group received a multidisciplinary palliative team follow up versus a control group (85, 86). This study, and the others identified cost-savings, however sample sizes disallowed statistical significance. An earlier evidence review using Cochrane methods (with one UK and one US study) identified seven randomised controlled trials comparing specialist and generalist palliative care. Significant cost savings were found (83, 87).
- One review of hospital SPC (mainly US studies) found that costs of their delivered care was less than that of generalist palliative care – this is backed by another review (also mainly US literature) (88,89). One review of four UK studies found an estimated 30% reduction in costs in the last year of life of those receiving specialist palliative input as compared to others (90). Marie Curie, a major provider of community based specialist palliative nursing found costs saved relative to control groups through reduced hospital admissions (91).

The report also answers some sub-questions regarding outcomes/benefits to patients and their families around differing models of care, the value for money and return of these models, and discussions around the optimal approach to EOL care pathways. Further information is found in the PHE report (83)

Regarding the cost-effectiveness of EPaCCS, an economic evaluation was conducted by NHS Improving Quality (92) who created some various scenarios to estimate potential savings. It concluded:

> *"The economic case for EPaCCS has been considered and there is sufficient evidence, with appropriate context taken into account, for recurrent savings after four years to be over £100k pa and cumulative net benefit over 4 years of c. £270k for a population of 200,000 people. Alternative approaches to implementation as well as different starting points will have an impact on these figures as the variation in outputs within the evaluation group clearly demonstrates." – NHS Improving Quality*

6) What is on the horizon?

Pressures from population ageing and dementia incidence

Demand for quality EOLC will grow over the coming decades as the population continues to age, and the proportion and number of older adults continue to grow. With an ageing population comes an increase in disease burden and disability, and therefore a need for equitable health and social care particularly regarding EOLC. For example, the number of people with dementia is expected to more than double by 2050 (93). It is expected that there will be 11,565 dementia sufferers in Nottinghamshire by 2020 (67). This is a struggle even today – for these systems to deliver quality care in the future, we must concentrate on reshaping our services to better suit older adults who are currently using a system that was built for a demographically younger population with less chronic disease.

Sustainability and Transformation Plan (STP)

The Nottinghamshire STP 2016-21 has set out five high impact areas to strengthen primary, community and social care services. It commits to improving EOLC through the strategies set out in this JSNA, including: identifying more people in their EOL, offering more people ACPs, increasing EPaCCS use and providing 24/7 SPC services.

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

The ReSPECT document will supersede DNACPR forms, as it will hold both resuscitation status as well as an overview of some of the individual's advance care decisions. Implementation is being planned on an East Midlands –wide basis and will require consistent training across providers. The document will not only improve the visibility of patient's escalation and care plans, but also prompt doctors to better appreciate and become involved in aspects of ACP. The document is transferable across all care settings. This should play a huge role in changing the culture around EOL through improved practice of aspects of ACP and EOL discussions amongst generalists (particularly hospital doctors) (94).

7) Local Views

Discussions were held to gain some local feedback regarding barriers to effective EOLC, including interviews with a specialist palliative consultant, a specialist nurse (lead for cancer, EOL), GPs, junior doctors (hospital based), a paramedic, several providers and EOL leads. The major themes which emerged from these discussions are summarised below.

7.1 Accessibility to EPaCCS and ACP

All clinicians raised accessibility to EPaCCS as a major barrier. Without access to EPaCCS, unless the patient or ambulance crew find and present a paper documented ACP, there is no way for hospital services to be aware of such a plan. Until EPaCCS is made mainstream, a universal "red wallet" is used by many care homes to carry a patient's DNACPR, ACP and hospital information pack. Without such provision, most patients will have their ACPs unused when most appropriate. The junior doctors interviewed were unaware of EPaCCS, however all knew what ACP was (although did not commonly practice ACP). Whilst accessibility to EPaCCS is improving, use of it is low in some GP practices, and within some areas of secondary care. For example, SFHT has an emergency department with read-only access to EPaCCS, however this is not well-used.

This is probably related to a culture amongst acute medical services that does not place EOLC as a priority for action and clinical staff who historically received little or no EOLC education. This is the same for paramedics leading to a lack of confidence amongst some paramedics to make decisions around appropriate presentations to emergency departments.

Furthermore, once a patient is admitted, EPaCCS is not accessible to ward staff. Most if not all patients in hospital who have a limited prognosis or EOLC discussed, will have topics such as resuscitation status and PPC discussed. This is rarely mentioned in discharge summaries, and the lack of access to EPaCCS on the ward deters clinicians from considering their important role in ACP and communication with primary care services. A reliance is placed on GPs to complete ACPs through EPaCCS – it is common practice to mention in a patient's discharge summary that the GP complete the GSF tool – it would be more appropriate for palliative registration and ACP completion (via EPaCCS) to be done in hospital when discussions are made. GP's have a limited capacity, and introducing EPaCCS to hospital wards would help alleviate some of this pressure. It would also encourage EOL discussions amongst medical clinicians, as well as reinforce the culture of EOLC being "everybody's business".

Lastly, it is appreciated amongst all the clinicians interviewed that IT problems are a major barrier to EPaCCS implementation. This is hoped to be alleviated somewhat with Medical Intraoperative Gateway (MIG). MIG searches relevant ACP programmes to allow automatic collection of ACPs (through EPaCCS for example) and centralising these in one programme. This will also allow better interdisciplinary working as currently differing IT systems is the major reason there is poor communication between different care settings and providers.

7.2 Education and Culture in EOLC

Education and culture in EOLC amongst both non-healthcare professionals and healthcare-professionals was felt to be an important area for improvement. Whilst palliative care doctors, and many geriatricians and specialist nurses are very well versed in effective, holistic EOLC and the use of ACP, amongst non-specialist palliative clinicians there can be a shortfall in quality. Discussions with local clinicians suggested that healthcare professionals (particularly doctors) did not always see palliative care as "their business".

As stated above, there is often a reliance on GPs to complete ACPs, and discuss EOL and resuscitation. Whilst these subjects are discussed in hospitals to varying degrees, there is often poor communication of ACP and EOL discussions on discharge. There is also a lack of referrals to SPC, mainly amongst EOL non-cancer patients. Many speciality doctors and surgeons do not consider specialist palliative referrals for their patients, which may sometimes be appropriate, early enough. This is especially true for dementia and older patients who can be aggressively resuscitated limiting their EOL quality. Another topic that emerged from discussions with the GP was that some clinicians may view ACP as a "do not treat" order, therefore some procedures or therapies might not be offered which could have some benefit. In summary it is important to avoid delivering unnecessary treatment whilst at the same time, deciding what therapies could benefit the patient at EOL.

Research also shows that older people's quality of life is not viewed the same as younger people; they have poorer access to services and screening, and receive poorer care overall. Qualitative and sociological work has also found older people are not valued like younger people, and older people's needs are poorly understood (95–105). Thirty seven percent of English over 65 year olds have perceived age discrimination in healthcare (106). Although this culture is decreasing, it is not uncommon for certain to be viewed as less needing of a costly or time-consuming therapy. This is a problem in culture and education, and clinicians must challenge behaviour such as this. See the box below for an example:

A junior doctor referred an otherwise well, older patient for an intervention to improve their quality of life and mortality. Unfortunately the patient was refused this even with no contraindications. It was thought their new label of 'dementia' guided the decision.

Junior doctors questioned were keen to enact good EOLC through earlier recognition and appropriate discharge but felt that sometimes it was their seniors who were less receptive preventing this by either disregarding palliative intent or simply not taking on responsibility for the role. This can (anecdotally) be more common on surgical wards.

The last emergent theme, particularly from the GP and paramedic, was around education amongst carers (informal and formal). LLLTIs usually have a “dwindling” pattern of disease progression in the EOL phase as previously mentioned. During this time, there are can be “bad” days where EOL individuals can appear to be medically unwell e.g. where pain or breathlessness may peak, massive bleeding or falls. Carers if not educated or confident can have a relatively low threshold to call for an ambulance. Improved communication with patients and their carers/families is required to improve such occurrences – much of these are related to a lack of understanding of what the dying phase entails, or what services are available to them in the community. Regarding dementia sufferers, this is a huge problem in that marked deteriorations on a day-to-day basis is a normal pattern for the disease. This results in frequent inappropriate admissions. This can be alleviated amongst formal carers with specific training programmes as mentioned (e.g. LOROS training, GSF training).

7.3 Barriers to achieving a DiUPR

A major theme emerging from the interviews was around barriers to achieving DiUPR (particularly at home). Family dynamics and living alone can frequently result in a patient requiring residential home placement. Unfortunately, four calls a day and assisted living cannot protect a patient at night for example. Dementia patients who live alone are guaranteed to require LTCI placement as their disease progresses as it is impossible to achieve one to one care for an individual with no informal carer.

Barriers include:

- a lack of a management plan for deterioration (which would be improved by EPaCCS/ACP)
- inexperienced or new care staff in care homes/domiciliary care setting, or informal carers who panic at the first sign of deterioration of symptom problems.
- A lack of continuity amongst staff, where an individual’s carer changes frequently can result in inappropriate emergency presentations.
- lack of a designated care-coordinator, this can improve overall DiUPR rates through better ACP and is one of the key recommendations from *The Government Response to the Review of Choice in End of Life Care.*
- A lack of services resulting in patients requiring permanent admission to care homes masking a true PPC/PPD. Various clinicians suggested that a dedicated care-coordination team with access to EPaCCS and services would help alleviate many barriers through improving access, and reducing inappropriate admissions with specialist advice and/or virtual hospice beds/hospice at home services, as offered by Nott’s hospice. This is already in place in City (24/7 service) and was thought desirable in the County.

Two of the clinicians and a hospice care provider suggested there is sometimes a lack of integrated working of services and a lack of accountability for some community based EOL patients, for whom community SPC capacity may be lacking. They reported poor access to EOL care home beds, domiciliary care and hospice beds in the community. This is difficult to quantify or show without specific evidence, however it is anecdotally reported amongst many clinicians. This may contribute to the number of deaths in hospital, along with a lack of joined up, effective services allowing care and death in the community (e.g. night sitter capacity, GP/nursing capacity, delays in receiving anticipatory medications). Hospice capacity could also be improved with better access to fast track funding. Junior doctors were unaware of what

EOLC services look like in the community, what is available and the real operational and technical issues of allowing a death in home.

7.4 Users – Nationally

There is minimal research enquiring public experiences and perceptions around EOLC. The invaluable 2015 National Survey of Bereaved People (VOICES) by the ONS, offers quantitative data (56). Some key issues are outlined below (see report for full details):

- 75% rated overall EOLC as outstanding/excellent/good, whilst 10% rated it as poor.
- Fair/poor quality of care were higher for those living in the most deprived areas
- A third reported hospital services not working well with GPs/external services
- Only 3% stated their loved one wanted to die in hospital
- Overall quality of care in the last 3 months of life was rated poorest in hospitals
- Dignity in last 3 months was poorest for hospital nurses (never showed dignity or respect - 17.3%), hospital doctors (12.8%) and then care home staff (9.6%).
- Acute care (poor - 16.4%) and GPs (12.5%) faired worst for care quality by setting
- Pain relief was worst at home (partially relief 43.6%) and then hospital (27.6%)

There is a distinct lack of qualitative work in EOLC, however in 2016 however PHE commissioned a qualitative study (107). Whilst more work is needed, this study has laid the foundations of qualitative work in community EOLC. Some key findings are outlined below:

- Carers and the dying have differing needs which may not be recognised
- For dementia carers, there is a gulf that can exist in current care provision
- For some, a substantial gap remains between dementia diagnosis and ongoing support required until EOL.
- EOLC approaches that merge communities and providers were welcomed – however the concept can sound idealistic, and there are some issues and challenges around its concept, delivery and implementation.
- Community approaches were popular in matching areas of unmet needs: emotional support for people and their carers, practical life-planning for people and their carers, logistical and practical support
- Dementia is considered different to LLLTIs (e.g. not terminal during early phases)
- The most impactful insights on community service use include; the nature of the disease and its effects on carers/family, the variability of the condition making it difficult to plan consistent care, the emotional/psychological impact on carers' lives whose needs are rarely addressed, less clear or quality pathways for dementia services, a lack of understanding of the condition and therefore access to services, and the impact advanced dementia on the carer/family
- Language and terminology used to describe EOLC initiatives can be challenging

7.5 Users – Local

SFHT undertake a quarterly bereavement survey which produces many comments, a summary is given below, some negative i.e.

- A small number of relatives commented that they were not listened to
- Relatives felt there was a lack of emotional support and compassion, particularly regarding their support, spiritual and religious needs

- Some relatives felt they did not receive enough information about what to expect in the last days of life
- Staff did not have discussions about specific procedures e.g. giving fluids

Below are some examples of common positive themes that emerged:

- A number of relatives commented that staff were kind, sensitive, and supportive to both patients and relatives – particularly nursing staff
- EOLC could not have been any better. 'Always happy to leave her, knowing she was in 'good hands'' They had confidence in both doctors and nurse.
- Care was either excellent or good and delivered in a compassionate, dignified way.
- Patients felt well informed and involved in decision-making about treatment and care

8) <u>What does this tell us?</u>

8.1 Unmet needs and service gaps

There are a number of service gaps requiring attention, and general needs that could be better met with changes in culture and improved provision. First, many of the shortcomings in EOLC are related to a culture that does not see EOLC as a priority. This is not a problem amongst EOL specific services, however, it is a problem in generalist palliative care where clinicians do not always see EOLC as "their business". This can result in individuals not receiving prompt recognition of their dying, but also a lack of quality EOLC regarding ACP, palliative care registration, EOL discussions, access to services (especially non-cancer/dementia patients) and holistic, patient centric care.

This requires a shift in culture focusing on training, at undergraduate, postgraduate and through ongoing CPD to deliver training that considers an older, frailer, complex population with differing needs and EOL trajectories. Training would refocus the role of the clinician as a facilitator to patient centred goals rather than an intent to simply prolong life. Society as a whole needs to see death as a normal part of life, rather than a taboo subject (and this would help drive an improved culture amongst healthcare professionals). A culture shift in communities could be sough with some community projects aimed at bringing the subject to light. Our population is ageing; LLLTIs, dementia and death have become increasingly visible in society. Now is as good a time as any to embrace our changing society, and reconsider how we talk and feel about death.

Improved communication between primary and secondary care, will improve quality of care. The last year of life commonly results in multiple admissions, some of which are avoidable. These moments are the points of contact whereby good EOLC provision and preparation can be made.

Access to EPaCCS and the introduction of the ReSPECT tool universally in hospitals and GP practices will contribute to change the culture of hospital doctors without directly involving themselves in EOL registration and ACP communication. This would relieve much pressure of primary care in planning EOLC. Likewise, emergency services require improved access, and/or improved use of such software. Improved rates of patient referrals on EPaCCS are associated with improved EOL outcomes and improved DiUPR – improving rates could be sought with incentivisation of a specific target for registered EPaCCS patients of the population (e.g. 0.75%). This should without a doubt be incentivised for dementia patients who have

been evidenced to have the lowest receipt of ACP. Over several years, EPaCCS is evidenced (in the correct context) to save costs through non-hospital deaths and reduced admissions. Embracing EPaCCS could directly and indirectly improve EOLC.

Achieving a death at home can be challenging for many reasons, including

- more integrated, accountable, and accessible services
- More beds in care homes and hospice care. There is a suggestion that there is scope to improve use of fast track funding to fund hospice care, and therefore improve access to SPC.
- A care-coordination helpline which can be accessed 24/7 for advice and service referral – as exists via Notts Hospice in the City.
- Training for patients/carers/families who may not be properly informed about the disease pattern and what to expect.
- Training for domiciliary and care home staff – there are effective training programmes that can be used to improve EOL outcomes e.g. LOROS piloted training scheme

Finally it is important to ensure equity in access to services for all the at risk groups: older adults, people with non-cancer diagnoses dementia patients, and other groups discussed in section1. More in-depth data collection from hospital trusts regarding their population demographics will allow better benchmarking, particularly regarding ethnicity and age.

9) Knowledge gaps

There is a lack of consistent, widespread use of EOL measures, particularly in the community. There are also limitations around some of the popular metrics e.g. DiUPR since it may mask patients being permanently admitted to a care home as an alternative to a home death which may be mainly due to a lack of services. It also takes no account of patients who want to die in hospital (lower rates of DiUPR may be misinterpreted as inappropriate hospital deaths, rather than appropriate ones). Whilst EPaCCS is a useful tool to gain information on patients in EOLC, there are other indicators it does not provide e.g. an option of recording the primary life-limiting diagnosis and contributing co-morbidities,

The RCGP Right Care EOLC Commissioning guide has produced six key broad measures for EOLC. These metrics include: numbers of registered patients, numbers with non-cancer diagnoses, numbers of carers offered assessment and bereavement care, numbers with ACP, hospitalisation rates, length of stay and some other measures. Nottinghamshire is taking part in the pilot in 2017.Some further useful measures would include % achieving PPD, time spent in PPC in last 3 months of life and number of admissions in last year of life and finally, qualitative work on community based services.

What should we do next?

Recommendations for consideration by commissioners

Recommendations		Responsibility
Holistic and effective care		
1	End of Life care is everybody's business and this responsibility is explicit in every contract, especially in relation to older people	CCGs/Providers
2	Encourage a culture among all healthcare professionals to discuss EOL openly, and recognise EOL as their business	CCGs/Providers
3	Improve the ratio of referrals to specialist palliative care for patients with dementia/non-cancer diagnoses through improved inter-disciplinary working and medical education. (see also recommendation 6 below)	CCGs/Providers
4	Each person recognised to be in EOL has a named responsible clinician, and a named care coordinator as a first point of contact	CCGs/Providers
5	Health and Wellbeing board to consider enabling choice, better coordinated care and integrated models of EOLC in making strategic plans	Health & Wellbeing Board
6	Conduct qualitative studies/obtain user feedback/outcomes measures for the bereaved and dying	CCGs/Providers
Better information sharing		
6	EPaCCS is made accessible to health and social care providers involved with patients in EOL (particularly hospital wards, acute services, GPs)	CCGs/Providers
7	Improved data collection through EPaCCS to identify rates of access for older people, people with dementia, BME and LGBT populations, and therefore identify populations requiring intervention.	CCGs/Providers
8	Participate in the development of GSF EOLC measures to be used by all localities to improve EOLC benchmarking, and improve EPaCCS data collection and interrogation (e.g. primary life-limiting diagnosis, contributing co-morbidities).	CCGs/Providers
9	Continued improvements of diagnosis rates and use of ACP (through EPaCCS) for dementia patients – using EPaCCS data interrogation as appropriate	CCGs/Providers
10*	Adopt the ReSPECT tool in hospitals and the community to improve ACP amongst health care professionals (see also recommendation 13 below)	ReSPECT Planning Group
Education and Training		

11	Improve generalist palliative care quality – further update training is mandatory for healthcare professionals (a) recognising dying, ACPs, (b) meeting needs - understanding of local services). Existing training for foundation doctors continues.	CCGs/Providers
12	Promote care staff training schemes, particularly domiciliary care (such as GSF/LOROS training programme). Consider whether providers could access health funding for this.	LA/ CCGs/Providers
13	Promote education/positive EOLC culture through introduction of ReSPECT tool	ReSPECT Planning Group
14*	Encourage compassionate communities though strategies to promote public understanding and encourage wider public engagement working with health/social care professionals in community development	Health & Wellbeing Board

*The EOL Strategic Advisory Group has prioritised adopting the ReSPECT tool (10) and formed a sub-group to progress this
*The Health & wellbeing Board has prioritized Compassionate Communities (14) in its2018-2022

Key contacts

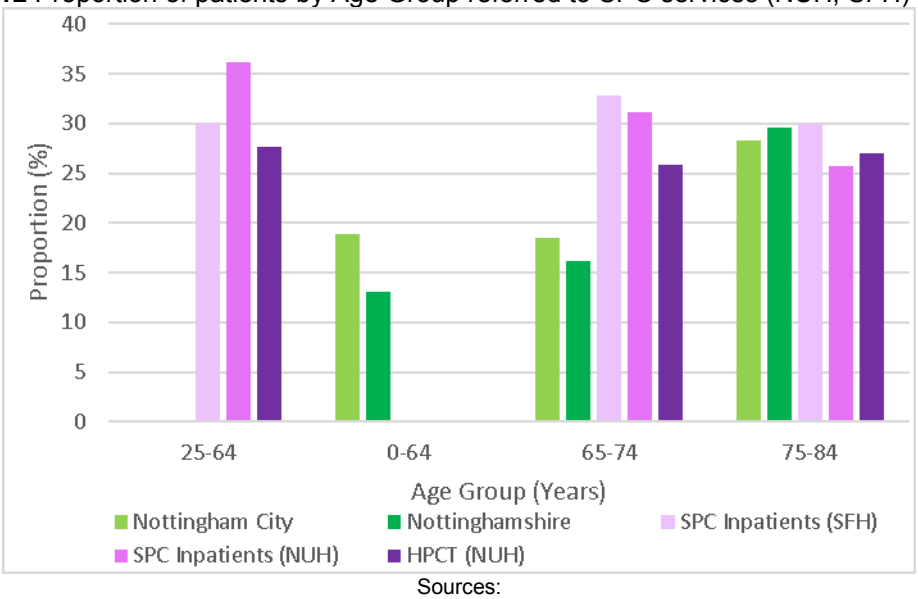
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Appendix A

Equity in Access at NUH (Hospital and SPC Inpatient Units)
Data from NUH between 1st April 2015-31st March 2016 offers an insight into the types of patients referred to hospital palliative care services (HPCT) and the SPC inpatient unit (Hayward House) (72) HPCT refers to ward based hospital patients being seen by a specialist outreach palliative team (this data only accounts for referrals met by specialist nurses which makes up the vast majority). See figure 12, 13, 14 for data on patient referrals by age, diagnosis and ethnicity. For data regarding SFH palliative services, only SPC inpatient (John Eastwood Hospice) by age group was available. The data for this was between Apr '16 - Nov '16, and are included in figure 12 (73).

NUH mainly serves the city of Nottingham, Nottingham West, Nottingham North & East and Rushcliffe CCGs areas making estimating the true demographics of the served population difficult to estimate. SFH serves CCG areas in the north of Nottinghamshire. Overall mortality by age group (or "actual") is also offered for Nottinghamshire and Nottingham, as based on data collated by the End of Life Care Intelligence Network and PHE. Data from EOLC audits from SFH and NUH respectively saw mean age of 80 and 78, and ages of under 60 making up only 7% and 6% (68, 71).

Figure 12 Proportion of patients by Age Group referred to SPC services (NUH, SFH) (72, 73)



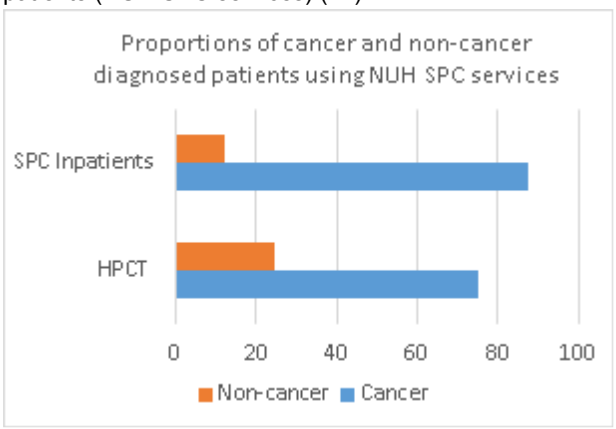
Sources:

The two SPC inpatient units served very similar proportions of patients by age group, and almost identical proportions of over 85s. Younger groups were more likely to be referred to services. The 75-84 age group saw the most equitable levels of referrals to services, whilst the under 65 group received the most referrals relative to "actual" numbers. The over 85 group saw the lowest overall proportion of referrals relative to the "actual" proportion. HPCT (NUH) however were two and half times more likely to offer over 85s services, relative to SPC inpatient services (NUH and SFH).

Whilst there is a substantial mismatch for over 85's receiving SPC referrals, we must consider the differing disease trajectories of older adults, particularly over 85s. Also, looking at referrals by diagnosis (Figure 13), there is a large proportion of cancer to non-cancer patients noted. Whilst this is less pronounced for HPCT referrals, it is still clear that cancer patients are the main users of SPC services. It is difficult without more qualitative work to ascertain why these patients with non-cancer diagnoses are less likely to be referred.

This could be a problem if healthcare teams overestimate their confidence in enacting good palliative care for patients who may otherwise benefit from SPC services, or a problem in an enduring tradition to offer services for cancer patients, given the hospice movement's foundation in cancer EOLC. As previously discussed, older adults and those with non-cancer diagnoses are just as likely to suffer complex palliative needs. This mismatch is likely to endure without some improved education around the role of SPC for older and non-cancer patients. Healthcare teams could benefit from education in the role of HPCT.and what they can offer to improve palliative and EOLC.

Figure 13 Proportion of cancer vs non-cancer diagnosed patients (NUH SPC services) (72)



The patients seeing the greatest inequity in care are patients with dementia – only 1.5% of all referrals to HPCT (NUH) had dementia, and 0.65% of NUH SPC Inpatients. Considering the actual numbers of those dying with dementia, and the repeated inappropriate admissions they encounter, it would be appropriate for these patients to receive more referrals for optimisation of their EOLC. This may include education and discussions with family, carers and/or Care homes as to appropriateness of readmission or symptom management, for example. Dementia patients also suffer a lot of distressing behavioural and psychiatric, and assess their pain can be difficult to manage, for example. This is something that could be aided with SPC input. Dementia may not be a disease for which SPC staff are specifically well trained in. This is something for which there is scope for improvement. With ever increasing numbers of dementia patients presenting to hospital in their last year of life, SPC input could play an important role in assisting healthcare professionals in understanding this disease trajectory, and how to minimise readmission and improve overall EOLC. HPCT could also play an important role in ACP with dementia patients identified to be "dwindling" who still have capacity to make such decisions.

Figure 14 Proportions of NUH SPC service users by broad ethnicity (72)

Ethnicity (by %)	SPC Inpatient	HPCT	Nottingham City	Nottinghamshire County	City/County Average
White British/ White	91.08	96.46	71.50	95.50	88.8
Asian British/Asian	1.93	0.95	13.10	2.18	5.2

British Afro-Caribbean/Afro-Caribbean or Other Black	3.13	1.90	10.14	0.68	2.5
Mixed Race	0.96	0.43	6.63	1.36	2.8
Other	2.89	0.26	1.47	0.26	0.6

As mentioned above, there is no data available looking specifically at the demographics of users of NUH. Therefore, it is difficult to elucidate the correct proportions of patients by ethnicity expected to be seen using services. Numbers by ethnicity vary greatly between the city and the county (e.g. 71.5% white in the city, 95.5% are white in the county) (34). As seen in figure 14, there a probably deficit in the numbers of non-white persons accessing services for HPCT. It is difficult to comment on whether this is a problem in access to SPC or access to healthcare services in the first place as data on the actual demographics of the served population is not available. Future work should use data from hospital visits by CCG postcode, and compare accordingly for a more reliable benchmark of equity in access.

Appendix B

Glossary

Advanced Care Planning (ACP) – a voluntary process whereby a person with a LLLTI can record choices about their care and treatment (or refusal of treatment) under specific circumstances that may arise over their inevitable deterioration from the limiting nature of their illness. ACP usually includes discussions around Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR), preferred place of care and death (PPC, PPD), a chosen lasting power of attorney (LPA) and advanced statements around treatments that may be offered in the future (when they may not have capacity to decide on) (79). ACPs are important for those with LLLTIs, but particularly those in their EOL phase, and those with dementia. ACP's are not legal documents, however should heavily inform care provision.

"Anticipatories"/Anticipatory medications – medicines that are prescribed and used in EOL patients for common symptoms that can be "anticipated" to occur (e.g. pain, vomiting, agitation, respiratory secretions)

Death in Usual Place of Residence (DiUPR) – a measure of EOLC performance. It regards the achievement of someone dying in their usual place of residence (home, LTCI)

Do not attempt cardio-pulmonary resuscitate (DNACPR) - refers to the act of not performing CPR on someone thought to have too poor organ reserve to survive a cardiac arrest, or survive with positive outcomes. DNACPR also refers to the document that carries the patient's resuscitation (CPR) status. CPR has poor outcomes for those without a reversible cause of cardiac arrest (e.g. death, hypoxic brain injury, broken ribs, loss of dignity in death, distress to medical team and family)

Domiciliary care – care provided within someone's dwelling. Offered by informal and formal carers

Dying – Dying usually suggests death is relatively imminent, and represents the last part of EOL (usually recognised days to hours before death). Dying can be difficult to recognise, but patients usually refuse feeding, have fluctuating and reducing consciousness, deterioration in functional status and sometimes have audible upper airway secretions and/or terminal agitation (87).

Electronic Palliative Care Coordination Systems (EPaCCS) – an IT programme that acts as a template for advance care planning (discussed in depth in this report) (92)

End of Life (EOL) - a broad term used to describe the last phase of life leading up to death. It can refer to the last year or months, as well as the last hours to days of life. The last days are however generally described as "dying" (108).

End of Life Care (EOLC) – care provided at the end of life. It should be holistic (social, medical, psychological, spiritual) (108).

Fast Track Continuing Care (FTCC)

IMCA – Independent mental capacity advocate, called upon to act in a patient's best wishes if there is no next of kin (e.g. choosing a care home)
Informal care/carers – informal care is care delivered by informal carers (family and/or

friends of those requiring care) for instrumental and/or activities of daily living. They are unpaid, and usually have no formal training or education in caring

Life Limiting Long Term Illness (LLLTI) – this is a broad term to describe chronic disease that impacts on life expectancy (e.g. cardiovascular disease, dementia, COPD)

LTCI – Long term care institution is a term describing any nursing or residential home (care homes). Long term care is delivered in people's homes, as well as care homes – the term LTCI refers to the care home sector.

Older Adults – For ease of reading, "older adults" generally refers to those over the age of 65, although adults may be "older" for bio-social reasons (e.g. the needs of a 60 year old with multiple comorbidities and no informal support for care would not be viewed the same as a fit, well, independent 75 year old with a well spouse at home).

Palliative care (Generalist) – a multidisciplinary approach to individuals with symptomatic or disabling LLLTIs, which delivers holistic care hoping to improve the quality of life of sufferers and their families. It specialises in treating their symptoms, pain, social problems and improving their general mental wellbeing. Whilst most of the patients receiving palliative care are in their EOL, it is aimed at anyone with chronic or life-limiting disease that causes complex or difficult symptoms and disability. Palliative care is delivered by **all** health and social care providers who work with patients with LLLTIs. Palliative care should support the individuals in their preferred place of care, and aim to keep them there as long as is feasible. It also supports them to have a comfortable death in their preferred place. Psychological, emotional and spiritual needs should be addressed. An example of palliative care would be a respiratory team managing an advanced COPD patient. They may organise long term oxygen, a care package and mobility aid to someone becoming progressively disabled by breathlessness from COPD. Offering drugs for breathlessness, and making a DNACPR, discussing dying and care preferences, and completing the EPaCCS template would be an example of good palliative care.

Specialist Palliative care (SPC) – Specialist palliative care is given to those with life limiting long term illnesses (LLLTIs) whose symptoms are too complex or difficult to manage by their usual responsible clinician and/or multidisciplinary team. Specialist palliative care can be delivered both in hospices, hospitals and the community. For example, a COPD patient already managed by their respiratory team who now suffers intractable breathlessness would benefit from specialist palliative care both through a review from a specialist consultant, but also from specialist nurse reviews in the community and/or a day-hospice service where they may receive complementary therapy or physiotherapy to aid their breathlessness (108,109).

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