LEICESTERSHIRE JOINT STRATEGIC NEEDS ASSESSMENT

End of Life Care and Support

2022

Leicestershire County Council

NHS
East Leicestershire and Rutland
Clinical Commissioning Group

Leicestershire County Council

NHS
West Leicestershire
Clinical Commissioning Group

Public Health Intelligence

Strategic Business Intelligence Team
Strategy and Business Intelligence
Chief Executive's Department
Leicestershire County Council
County Hall, Glenfield
Leicester LE3 8RA

Tel 0116 305 4266
Email phi@leics.gov.uk

FOREWORD

The purpose of the Joint Strategic Needs Assessment (JSNA) is to:

- To improve the health and wellbeing of the local community and reduce inequalities for all ages.
- To determine what actions the local authority, the local NHS and other partners need to take to meet health and social care needs, and to address the wider determinants that impact on health and wellbeing.
- To provide a source of relevant reference to the Local Authority, Clinical Commissioning Groups (CCGs) and NHS England for the commissioning of any future services.

The Local Authority and CCGs have equal and joint statutory responsibility to prepare a Joint Strategic Needs Assessment (JSNA) for Leicestershire, through the Health and Wellbeing Board. The Health and Social Care Act 2012 amended the Local Government and Public Involvement in Health Act 2007 to introduce duties and powers for Health and Wellbeing Boards in relation to JSNAs.

The JSNA has reviewed the population health needs of the people of Leicestershire in relation to End of Life care and support. This has involved looking at the determinants of the End of life, the health needs of the population in Leicestershire, its impact, the policy and guidance supporting End of Life care and support, existing services and the breadth of services that are currently provided. The unmet needs and recommendations that have arisen from this needs assessment are discussed.

The JSNA offers an opportunity for the Local Authority, CCGs and NHS England's plans for commissioning services to be informed by up to date information on the population that use their services. Where commissioning plans are not in line with the JSNA, the Local Authority, CCGs and NHS England must be able to explain why.

EXECUTIVE SUMMARY

Adults are usually considered to be approaching the end of life when they are likely to die within the next 12 months (10). The aim of end of life care is to help people to live as well as possible during this period, and to support them in achieving a dignified death (10). It is the responsibility of all to support the delivery of this, with health and social care staff from all settings and specialties having a role.

For Children and Young People, life-limiting and life-threatening conditions are used to describe the population of children who may benefit from input from paediatric palliative care services. For Children and Young People End of life care is generally considered to be the last few weeks/ days as the condition changes and deteriorates.

The death of a loved one, along with the time both leading up to the event and following it, are significant and traumatic periods in people's lives. It affects not just individuals, but also their family and social networks, and local communities. End of life care therefore also seeks to support the individual's family, carers and those who are important to them.

Most people reaching end of life in Leicestershire are over 75 years of age. Although the majority are older, chapter 2.12 highlights the end of life needs of children and younger people who often require a specific approach to their care. Other population groups highlighted as sometimes requiring adjustment in care or approach to avoid poorer outcomes, experiences and health inequalities include:

- Those living in deprivation
- Homeless people
- Imprisoned people
- LGBT people
- People with learning disabilities
- Ethnic minority groups
- Non cancer diagnosis
- Dementia
- Sudden and unexpected deaths

Identified unmet needs/gaps

Whilst this section has been divided into different components of end of life care and support, many of the themes and issues discussed are common to many if not all aspects.

Advanced care planning

National and local insight tell us that as people become severely ill, they prioritise quality of life over the length of time remaining to them. They also value clear communication, being involved in decisions and being treated as an autonomous individual. The Advanced Care Planning approach provides people with the opportunity to plan their future care and support while they have the capacity to do so. Despite this, as few as 9.7% of adults have an advance care plan in place prior to their final hospital admission (11). For children and young people, advanced care planning is used more frequently.

Evidence also suggests that whilst people report feeling comfortable talking about topics relating to the end of life, there is poor understanding of the options and services available. Indeed, in one survey, as many as 55% of those in the last years of life reported not knowing where to find information on how to plan in advance for care at the end of life (12). Whilst these resources do exist, it seems that there is a gap in terms of connecting people to them. Only with adequate access to high quality information, can people make informed decisions about their end of life care.

Utilisation and delivery of End of Life and Palliative Care Services

End of Life and palliative care often involves receiving input from multiple organisations and services. Whilst the quality of support received from these services once in receipt of care from them is generally rated highly, a common complaint is that they are difficult to access in the first place.

It has also been frequently reported both nationally and locally, that services coordinate poorly with one another. This is particularly a challenge when patients move from primary to secondary care or vice versa and results in staff often working with incomplete information or without a complete overview and understanding of the persons' needs. Finally, we have heard of challenges in accessing support out-of-hours. This is not only a matter of service users being unsure of how to access it, but also includes a lack of available services.

Support for those who are bereaved

Those who are bereaved have rated the level of support that they received poorly, particularly that in relation to their emotional, social, and practical needs. Once again, service users appear to be happy with the quality of care they receive once they are in receipt of it, but often find themselves unsure of what is available, facing uncertain referral routes, and made to join lengthy waiting lists. In addition to formal services provided by healthcare organisations, there is a wide range of local community groups which are also available. It is unclear however, how widely these are known about. More therefore needs to be done to provide residents with complete and accurate information, and to facilitate the process of connecting them to sources of help and support.

Support for informal carers

The support that carers require can be divided into two broad categories. The first of these is support to undertake their caring role, including through adequate training and the provision of sufficient equipment. The second, is support for them as an individual who is experiencing a traumatic life event as their loved one is unwell. Both forms of support are required if they are to help their loved one and remain well themselves. Sadly, local people report being unhappy with the levels of either type of support that they are receiving.

Finally, the burden of coordinating health and social care services for someone approaching the end of life, often falls onto carers. Similarly to the other groups discussed in this section so far, carers report not knowing what services are available and find identifying the various sources of support and navigating their access routes to be challenging. Existing methods of collating and sharing methods of support with carers are therefore in need of review.

Support for staff working in End of Life care

The roles of staff in end of life care are diverse, and as it was drawn from a self-selecting sample, caution must be taken when interpreting the results of the local survey that was undertaken due to the risk of responder bias. Across work areas however, responders were generally happy with the resources and equipment that they received to help them undertake their role. Differences were seen though in terms of the training received, when considering the person's job description. Those whose primary role is not delivering end of life care, reported feeling that they had insufficient training to adequately support people towards the end of life. As we are faced with an ageing and increasingly co-morbid population which interacts with multiple health services and specialities, staff will increasingly work with patients who are approaching the end of life even if that is not the focus of their role. This is therefore likely to be a growing problem, and it is important that those within the health and social care system feel adequately supported in this area.

Recommendations

This JSNA chapter has identified the local needs and current gaps in service provision relating to end of life care and support. The following recommendations have been produced on the basis of these findings, to support improved outcomes for the people in Leicestershire.

Further exploration of the issue

- Undertake a tailored piece of engagement to capture the views, preferences, and experiences of those who are themselves approaching the end of life.
- Produce a health equity audit to further explore inequalities in end of life care and how services can be tailored to better address the needs of disadvantaged groups.
- Further explore the reasons for deaths taking place at hospital / hospice / home / care home, to better understand if this is due to patient choice or factors such as a lack of community services meaning there is insufficient capacity to support people dying at home. To particularly consider those who live elsewhere but die in a care home as discussed in Section 3.5.2.

Facilitating conversations

- Seek to modify social norms by utilising behaviour change theory and social marketing, to improve the acceptability of discussing death and end of life preferences.

- Consider how conversations relating to end of life preferences and planning can be initiated at times surrounding major life events, by incorporating a Making Every Contact Count (MECC) approach.

- Seek to increase the number of people with an advance care plan.

- Encourage healthcare staff to initiate advance care planning discussions during early interactions, particularly for those with degenerative conditions such as dementia who will be less able to contribute meaningfully as their condition progresses.

Increasing public understanding

- Undertake local campaigns aimed at enhancing the public's understanding of what is meant by end of life, the terms frequently used in relation to it, and the role of different services.

- Improve awareness of existing, locally available services.

- Build on work by Dying Matters to provide a central source of information and signposting advice to end of life and bereavement services.

Delivering services

- Develop a more robust community out of hours offer so that support for those approaching the end of life and their carers is available throughout the week.

- Improve the coordination of services working together to deliver end of life care, to reduce the burden currently placed on patients and their loved ones.

- Promote continuity of care within services, particularly with primary and community services, to support the building of trusted relationships between patients and their health or social care provider.

- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.

- Consider the need for a paediatric palliative care consultant and the need for community paediatric and nursing support that responds to the rising numbers of children and young people on end of life pathways with increasing complexity.

Supporting carers and staff

- Improve the advice and support available to informal carers, so that they feel better equipped with the skills and knowledge to support their loved one.

- Consider how regular check-ins with informal carers can take place.

- Support informal carers in taking respite care, so as to ensure their own wellbeing.

- Ensure training is available and accessible for staff who do not regularly deliver end of life care as a core part of their role.

Next Steps

This JSNA chapter will be used to inform a refreshed end of life strategy which is being developed across Leicester, Leicestershire and Rutland by the Integrated Care Board.

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1. Introduction

Adults are usually considered to be approaching the end of life when they are likely to die within the next 12 months (10). This is often difficult to predict and even when someone has a chronic or life-limiting condition, they may not be identified as approaching the end of life until their final weeks or days. The aim of end of life care is to help people to live as well as possible during this period, and to support them in achieving a dignified death (10). It is the responsibility of all to support the delivery of this, with health and social care staff from all settings and specialties having a role.

Palliative care is closely linked to end of life care and relates to the management of symptoms and caring for someone with a terminal illness. In addition to clinical management, it involves providing psychological, social and spiritual support for the individual, their family, and carers (10). Whilst end of life care is usually delivered during someone's last 12 months of life, palliative care is available from when they are first diagnosed with a life-limiting condition. People may therefore receive palliative care for longer than end of life care and may be in receipt of it whilst simultaneously receiving active treatments and therapies for their condition.

For Children and Young People, End of life care is generally considered to be the last few weeks or days as the condition changes and deteriorates. Children and young people can fluctuate in and out of the end of life phase as they can be vulnerable when experiencing infections or other illnesses. Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death.

The death of a loved one, along with the time both leading up to the event and following it, are significant and traumatic periods in people's lives. It affects not just individuals, but also their family and social networks, and local communities. End of life care therefore also seeks to support the individual's family, carers and those who are important to them.

2. Who is at risk?

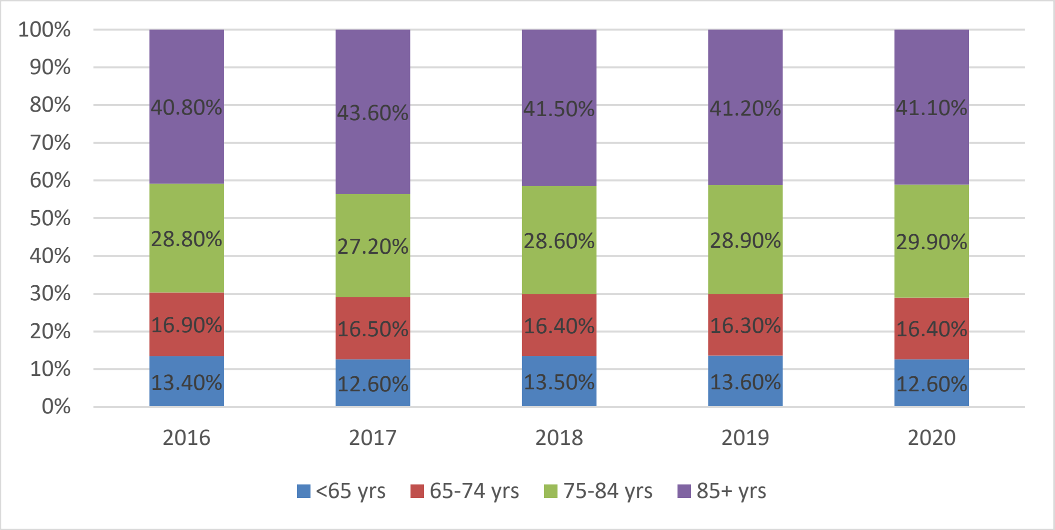
2.1. Groups at risk of negative end of life outcomes

Everybody is affected by death, both directly and indirectly through the loss of loved ones. How someone interacts with this life event varies, however. It depends for example on the age at which a person dies, and whether the death follows a prolonged illness or has taken place suddenly. The experience someone has of end of life and palliative care, and bereavement support, can similarly be affected by a range of demographic and diagnostic characteristics. Here, we discuss those groups at increased risk of negative outcomes and those which are more likely to face challenges.

2.1.1. Increasing Age

In 2020, the life expectancy at birth of people in Leicestershire was significantly greater than the England average. This was 79.9 years for men (78.7 in England), and 83.7 years for women (82.6 in England) (13). Leicestershire has a growing population, with the greatest cumulative change projected to occur in the 65+ age band. There are predicted to be 71,888 additional older people in 2041 compared to 2018 (14). Most deaths occur in these older age groups, with 2,975 deaths in Leicestershire in 2020 attributed to people aged 85+ years, accounting for 41.1% of all deaths in Leicestershire (Figure 1). Apart from the age group of <65 years which accounts for a significantly lower proportion of deaths in Leicestershire than England, the proportion of deaths occurring at each age group in Leicestershire is similar to that in England (Figure 1) (2). Whilst England has experienced a significant increase since 2016 in the percentage of deaths at ages 75-84 and a decrease in those at 65-74 and <65 years, Leicestershire has seen no significant change (2).

Figure 1: Percentage of all deaths in Leicestershire by age group (2)



Source: OHID Fingertips, Palliative and End of Life Care Profiles

Older age and frailty are associated with an increased need for social care which often requires at least partial self-funding. This can serve as a barrier for access to services and result in a heavy reliance on family members as carers (15). There is also evidence that those aged over 85 years are less likely to access palliative care than are those below 85, with those who do access it also on average receiving a shorter duration of palliative care prior to death (15, 16). Despite representing nearly 40% of all deaths nationally, only 16.4% of people aged 85 or older gain access to specialist palliative care services (17). Emerging evidence indicates however, that access to hospice care for this group is improving (18).

Older adults may also receive less adequate pain relief and receive more unwanted treatment decisions, than do people from younger age groups (16). Between 2014 and 2018, 69.6% of people in England who had 3 or more emergency admissions to hospital in the last 3 months of life were aged 70 or older (19).

2.1.2. Children and Young People

The national prevalence of life limiting conditions in children (aged 0-19 years) in England was 63.2 per 10,000 in 2017/18 (20). Based on these figures, there are approximately 1,000 children in Leicestershire living with such conditions. In 2021, the Child Death Overview Panel were notified of 96 child deaths in Leicester, Leicestershire and Rutland, including 42 neonatal deaths.

Nationally, the prevalence of life limiting conditions was highest in the under 1 year age group at 226.5 per 10,000 in 2017/18 (20). Congenital abnormalities were the most common life limiting conditions, followed by neurological disorders. Life limiting conditions were highest amongst children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000). More children with a life limiting condition lived in areas of higher deprivation (13% most deprived versus 8% in least deprived). The future prevalence of children aged 0-19 years with a life limiting condition in England is estimated to be between 67.0 and 84.2 per 10,000. There are increasing numbers of children with a life limiting condition who have a hospital stay of greater than 28 days each year, rising from 2482 in 2001/2 to 3538 in 2017/18.

There are several differences to the end of life and palliative care needs of children compared to adults. Life-limiting and life-threatening conditions are terms which are used to describe the population of children who may benefit from input from paediatric palliative care services. This is something that lasts longer than the 12 months prior to death. For Children and Young People end of life care is generally considered to be the last few weeks or days as the condition changes and deteriorates. Children and young people can fluctuate in and out of the end of life phase as they can be vulnerable when experiencing infections or other illnesses. Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death.

Palliative care for children is often provided over a longer period than for adults, with services often involved from the time of diagnosis (21, 22). During the time children are cared for, they will continue to develop physically, emotionally, and cognitively, and so their individual understanding and needs will also change (21). Local services advise that children would usually be constantly meeting milestones throughout their lives. Hence, a life limiting condition has implications for the family as the child can appear to be improving when a milestone is reached even though the child still has a life limiting condition. This is seen more in non-neurological conditions. Care is needed when advising parents of prognosis as child as gaining milestones can cause confusion for families when they feel that their child appears to be doing better than expected.

A large part of paediatric palliative care is providing support for the affected family, in addition to the child (23). In most cases the direct family are the primary carers for the child, and may also have other children affected by the same condition (21). This can be a particularly difficult time for parents and can result in placing pressure on relationships within the family (23).

Other challenges faced by families of children with a life limiting condition is the feeling that there is a failure to include both parents or other significant family members in discussions about the child's care (24). Furthermore, there has been shown to often be a lack of family privacy, and also a lack of support in managing parental anxiety (24).

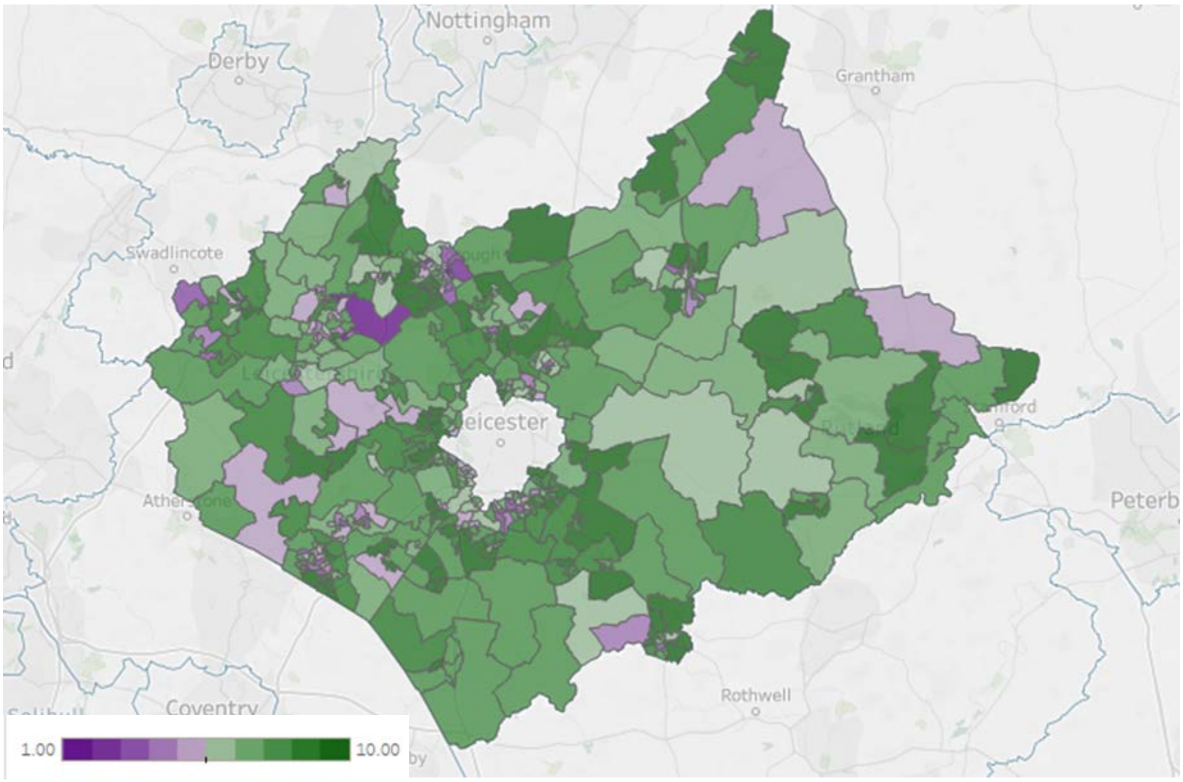
Advance care planning is important with parallel planning often undertaken locally, using advanced care planning and anticipatory care planning approaches. These should consider all possible outcomes and ensure that families are offered choices in care options throughout their journey. In Leicester, Leicestershire and Rutland, Diana staff will advocate for all children and young people with a life limiting condition to have an advanced care plan. Children who are felt to be end of life will also have a ReSPECT form completed. Families are asked where their preferred place of death for their child/ young person is, and this is rechecked regularly.

Finally, children often receive more aggressive treatments than adults, and so are more often in a hospital when receiving palliative care (25). Interaction with palliative care services however, can result in reduced hospital admissions, reduced risk of Intensive Care admission, reduced length of hospital stay, and being more likely to die at home rather than in a medical setting (26).

2.1.3. Deprivation

Leicestershire is overall one of the least deprived upper tier local authorities in England, being in the top decile when ranked using the Index of Multiple Deprivation 2019 (Figure 2) (14). Despite this, pockets of significant deprivation do exist, with four neighbourhoods in the county falling within the most deprived decile. These can be found in Loughborough and the Greenhill area of Coalville (14).

Figure 2 Leicestershire and Rutland LSOA map of Index of Multiple Deprivation 2019



Source: IMD 2019

It is well recognised that people living in more deprived areas have shorter life expectancies than do comparable individuals living in more affluent areas. In Leicestershire, this gap in life expectancy at birth stood at 6.0 years for men and 4.9 years for women in 2018-20. This compares to gaps of 9.7 and 7.9 years for men and women respectively in England (13). There is also a strong association between the incidence of many chronic diseases including frailty and cognitive function, and deprivation (27). Furthermore, people of lower socio-economic status experience a shorter time period between diagnosis of a life-limiting illness and death, and therefore require more complex end of life care needs (27).

Increased social needs associated with deprivation relate to a range of factors including social isolation, increased caring responsibilities, and housing concerns (27). Whilst the majority of people would prefer to die at home over other settings, these concerns and in particular that of substandard housing, can be obstacles for those in poverty to achieve this. Indeed, in England the more deprived an area a person is from, the more likely they are to die in hospital. It is not clear however if this is due to choice or a lack thereof.

Deprivation impacts on multiple end of life related outcomes. Work by Macmillan Cancer Support has shown that patients with cancer in the most deprived areas are more likely to die in hospital, have a higher number of emergency hospital admissions in their last 12 months of life, and to report receiving either poor or fair quality of care (28). The National Survey of Bereaved People (VOICES) has similarly shown that those from the most deprived quintile are more likely to report receiving either fair or poor care in the last 3 months of life than are those in the least deprived quintile (29), whilst work by PHE has shown that they are more likely to have 3 or more emergency hospital admissions in the last 3 months of life (19). It has been suggested this is due to their being able to access fewer information sources to help navigate end of life care, finding it difficult to ask for information, and to be more likely to misunderstand the role of services (30).

People experiencing poverty have higher rates of poor mental health than the general population, and there is emerging evidence that this may translate into increased anxiety and depression amongst people receiving palliative care (27). It is also documented that family caregivers of lower socio-economic status are more likely to experience moderate to severe depression when caring for someone with palliative care needs, and that grief and vulnerability following bereavement is heightened for this population (27).

2.1.4. Homeless People

The term homelessness includes those who are rough sleepers, in temporary accommodation and 'sofa surfing'. In 2018, Charnwood was the district that both had the largest number of households in temporary accommodation [42] and counted the most rough sleepers [3] (31).

People who are homeless are more likely to be exposed to death, especially premature, violent, and traumatic deaths (15). Across England and Wales, the most common cause of death in this group is drug related poisoning (38.5%) (32). This is also the most common cause seen for the general population aged 20-49 but at higher rates, with accidental poisoning at 11.1% (32). In 2020, the mean age at death among men and women who were homeless was just 45.9 and 41.6 years respectively (32), whilst age adjusted death rates are up to four times higher than for the housed population (33). Furthermore, it appears that the crude death rate for this population is increasing, having more than doubled in the East Midlands since 2013, to approximately 14 per million people in 2020 (32).

Factors that contribute to these poor outcomes include barriers to accessing healthcare that are direct (such as requiring an address) or indirect (due to rigid models of care that do not accommodate the uncertainty that homelessness creates) (15). This results in treatment often being crisis-led, and so a greater likelihood of having emergency admissions to hospital than the general population (34). Furthermore, people experiencing homelessness often fear discrimination from, and negative interactions with, health professionals which can reduce the likelihood with which they will seek help (15, 34). Small, but strong social networks amongst individuals of this population allow for negative news to spread quickly which may make institutional trust slow to re-build and quick to break (15).

Once these barriers are overcome and people who are homeless do interact with services, healthcare professionals can then find it difficult to know whether they would benefit from palliative services. This can be due to their having less regular interaction with health professionals, having more complex needs, conditions with uncertain prognosis (such as drug or alcohol related liver disease), and being of a younger age than most who are referred for end of life care (34). People experiencing homelessness are also less likely to receive support from family members and friends in managing their practical, financial, physical, and emotional needs (34). As a result of these multiple complexities, advance care planning rarely happens.

Higher rates of alcohol and drug dependence can also make it difficult for people who are homeless to stay in hospital and hospice settings for prolonged periods, and lead to them self-discharging (especially if services hold zero tolerance policies towards illicit substances) (33, 34). Having a history of addiction and tolerance to certain medications can also complicate the delivery of pain relief, requiring combined input from both palliative care teams and substance misuse teams (34). Providing care in the community is also a challenge, with a potentially high level of responsibility on hostel staff to try and support people with complex health and social care needs with little specialist training (33, 34).

2.1.5. Imprisoned People

In June 2019, HMP Gartree had a prison population of 680 males, against an operational capacity of 708 (14). Across England and Wales, people aged 50 and over made up 16% of the total prisoner population in 2020 with this value predicted to increase further in future years (35). Indeed, over the last 20 years the number of people in prison aged over 60 has more than tripled (15). Furthermore, someone experiencing long-term imprisonment is considered to have the equivalent health status of someone 10 years older in the general population (35). As a result, deaths in prisons across England from natural causes have increased by 77% over the last decade, and the palliative care needs of this population are expected to rise (15).

It is recognised that people in prison should have access to palliative care services equitable to those available outside prison, and in 2018, HMPPS launched the Dying Well in Custody Charter to set out standards and guidelines for palliative and end of life care (36). Whilst prisoners suffering from terminal conditions can apply for early release, not all will be eligible. Some may also choose to remain in prison, particularly if they have served long sentences and no longer have social connections in the community (37). Thus, there is a requirement for prisons to be able to offer quality end of life care and support in-house.

2.1.6. LGBT People

An estimated 2.7% of the UK population aged 16 years and over identified as lesbian, gay or bisexual (LGB) in 2019, with an increasing trend being seen in the recent years up to this point (38). Based on this figure, it would be estimated that there are approximately 19,000 people in Leicestershire who identify as LGB. There is a lack of robust data to indicate what proportion of the population identify as transgender.

Today’s LGBT older adults belong to a generation that experienced criminalisation and pervasive negative social attitudes, and who’s sexual orientation or gender identity was considered to be deviant (39). Even today, LGBT people face ongoing challenges when interacting with healthcare services. A national survey of LGBT people by the Government in 2017 found that at least 16% who accessed or tried to access public health services had a negative experience because of their sexual orientation, and that at least 38% had a negative experience because of their gender identity (15). Discrimination is not always overt, but can instead exist in more subtle forms such as a heteronormative bias and a lack of LGBT representation in service promotion leaflets or assumptions that patients are heterosexual unless stated otherwise (40). LGBT people have been shown to have grater all-cause mortality than heterosexual people, and to be more likely to present with more advanced disease (39). It has been suggested that this is due to their having higher levels of smoking, drug and alcohol misuse, and mental ill health leading to increased risks of cancer, coronary heart disease, and suicide (41).

With many LGBT people experiencing discrimination in their everyday lives, some delay accessing end of life care or palliative services for fear of further negative experiences, particularly if a service is linked to a church or religion (40, 42). Older adults in particular may be less open to disclosing their sexual orientation than younger LBGT people, especially when in a vulnerable position (39). This can be a particular challenge in care homes, where other older residents may retain negative views towards LGBT people (43). Such concerns extend to worry about how partners may be received with some feeling unable to show each other affection in front of staff, leading to increased loneliness and isolation at the end of life (42, 43).

Delivering care at home for LBGT people can also present challenges, as they are more likely to live alone than are their heterosexual counterparts. This has practical impacts on the levels of informal care and support available to them at home (39). Issues of lack of support and loneliness are further exacerbated as older LGBT people are less likely to have children, and more likely to be estranged from family members than are heterosexual individuals (40).

Barriers also exist for same sex partners of people at the end of life, as they are not always included in care planning and provision in the same way as heterosexual partners (43). This can stem from a failure to recognise those who are important to the patient. It has also been noted that the pain of bereavement of LGBT partners can be exacerbated by a lack of social recognition and validation that they have suffered a significant loss (15, 42).

Bisexual and Trans people face different kinds of prejudice and discrimination from gay men and lesbian women (15). As many as 2 in 5 trans people have reported that healthcare staff lack understanding of specific trans health needs (15). Concerns include areas such as what will happen after they die such as not being buried as their correct gender (40, 42).

It is important to recognise that the LGBT community represents a diverse population, and whilst some experiences will be common to the majority, others will not. There is emerging evidence to show that people of different sexualities approach end of life care planning differently. One study for example showed that gay men are more likely to have considered advance care planning than bisexual men, and that lesbian women were more likely to have done so than bisexual women (39).

2.1.7. People with learning disabilities

As many as 1 in 50 people in the UK have a learning disability (44), and this population are three times as likely to die early than are the general population (45). Based on 2018-19 data, life expectancy for a man with a learning disability is 14 years lower than for males in the general population at 66 years. The life expectancy for women with a learning disability is 17 years lower than for women in the general population at 67 years (46). The median age of death of this population is increasing however, and so aspects of ageing common to the general population such as frailty are likely to become more apparent, adding a further level of complexity to end of life care provision (45). This group are also at increased risk of developing dementia as they age. People with learning disabilities are more likely to have high levels of unmet physical and mental health needs, and were found by the CQC in 2016 to generally receive poorer quality end of life care due to a failure to understand or fully consider their needs (45). This included being less likely to have access to specialist palliative care services and opioid analgesia, at least in part because of difficulty in reporting and describing pain (45, 47).

One barrier to accessing end of life care is that people with learning disabilities are more likely than the general population to have an unidentified health issue, which often results in late identification of those nearing the end of life (47). In the absence of advance care planning, this can lead to problems in coordinating end of life care for the individual and their family. Indeed, people with learning disabilities are sometimes excluded from advance care planning conversations, through the belief that they need to be protected from such topics, but it is vital that they are empowered to contribute to these discussions (15, 44, 45, 47). Even if they do not have the mental capacity to fully participate or have difficulty in communicating their wishes, it is important that they are supported to identify and share their choices about care (44, 45).

Transferring to a hospital or hospice can be a source of anxiety for many, but being in unfamiliar environments can be particularly distressing for those with a learning disability and thus negatively impact on their end of life care experience. Having honest and open conversations to help prepare individuals for what to expect can help to ease this (45). This is particularly important given that rates of poor mental health are already higher in this population than for the general population (45).

People with learning disabilities may also need additional support in processing a bereavement of a loved one, with grief responses possibly delayed or expressed in unconventional ways (45). This may include the need for multiple open and honest conversations to help individuals to fully understand and accept what has happened (44, 45).

2.1.8. Ethnic minority groups

The majority of the Leicestershire population (91%) belong to White ethnic groups, including White British and White Irish (14). This equates to almost 600,000 people and is slightly higher than the figure for the East Midlands (89%) and England (85%). The next largest ethnic group is Asian (6.3%), followed by the Mixed or Multiple Ethnic Group (1.7%) and Black ethnic groups (0.6%) (14).

People from Black and minority ethnic (BME) groups have been shown to be less likely to rate overall care as outstanding or excellent, particularly if they spent time in a care home or hospice (48). This may be because some groups report being unaware of the aims and role of palliative and end of life care, including what roles care homes and hospices have in delivering this (48, 49). Historically there has been reduced uptake of palliative and end of life care services by people in BME groups (49).

It has been reported that there is often a lack of sensitivity to cultural and religious issues in health and social care delivery, contributing to a poor understanding of people's needs (49). During the COVID-19 pandemic for example, restrictions have been in place limiting the number of visitors allowed to patients in health and social care settings. Evidence indicates that this has had a disproportionate negative impact on ethnic groups that would traditionally have large numbers of family members involved in providing care and support near the end of life (50). Services in England have also reported difficulty in fulfilling religious and culturally prescribed responsibilities under these circumstances (50). Such needs may include the need for access to female members of staff, and the timely release of the deceased person's body and death certificate to enable funeral arrangements to be made within required timeframes (48).

Members of ethnic minority groups are also more likely to experience communication challenges when English is not their first language (48, 50). The absence of a professional translator can result in a reliance on family members and friends to help communicate wishes. In such situations, it can be difficult to be confident that the dying person has been able to make genuine and independent choices about their care (48, 49). Even when organisations have systems in place for accessing professional translators, it may be difficult to do so in a timely manner and particularly out of hours. It is important to remember however that in some cultures, patients want to be protected from hearing about diagnoses and prognoses and that these conversations are actually expected to be had with family members (49). This underlines the importance of early conversations to explore the wishes of individuals.

Overall, people from BME groups are less likely to undertake advance care planning and are more likely to advocate for life-sustaining and aggressive treatments such as artificial nutrition and cardiopulmonary resuscitation (49). Contributing to this are higher levels of mistrust towards healthcare services, particularly when discussing ceilings of treatment with such planning potentially being seen as 'an excuse to limit treatment' (48-50).

2.1.9. Non-cancer diagnoses

In 2019, 71.5% of all deaths in England and Wales were from conditions other than cancer and yet these only accounted for 15.3% of deaths occurring in hospices (18) despite having comparable symptom burdens and palliative care needs (51). This issue of reduced access is also generally true for generalist care, including being in receipt of district nursing and care from a GP (51). There is evidence however that access to hospices is increasing for people with non-malignant conditions (18).

Studies have shown that people with non-cancer diagnoses benefit from palliative care interventions, including through fewer emergency hospital attendances, and lower symptom burden (52). Despite this, people with a non-cancer diagnosis tend to have less access to supportive and palliative care, and also to have a poorer experience of care towards the end of life than people with cancer (53). It is often reported that it is more difficult to identify when someone without cancer is approaching the end of life. With clinical courses often less predictable (51), clinicians often report a fear of 'getting it wrong' (53). Failure to have these conversations can result in patients and their loved ones feeling uninformed and unsure of what to expect in the last months of life (53). It is therefore important to normalise and encourage having discussions relating to advance care plans early, to ensure that they are not left until more terminal and less beneficial time points.

Some of the difference in quality of end of life care for patients appears to be linked to where they are looked after. The National Survey of Bereaved People in England found that people with cancer who die at home are more likely to experience 'outstanding' or 'excellent' care in their last 3 months of life (62.8%), than are those with cardiovascular disease (46.2%) and other diagnoses (36.9%) (51). These differences were not replicated in other settings, including hospital and care homes.

Healthcare professionals have also described documents, guidelines and services relating to end of life care to be developed with cancer patients in mind, and to be less applicable to people with other diagnoses (51).

2.1.10. Dementia

In 2019/20 there were 6,579 patients recorded on GP practice disease registers with dementia in Leicestershire (54). Affecting an estimated 1 in 14 people aged over 65 and 1 in 6 people aged over 80, it is a condition which increases in prevalence with age (54). With a predicted increase of 43.2% in over 65 year olds and an 84.7% increase in over 85 year olds in Leicestershire from 2020 to 2040, the burden from this condition is expected to increase over the coming years (54). It is also important to acknowledge that dementia is not only associated with older ages but is itself life-shortening (55, 56). It has consistently been reported as the leading cause of death in England and Wales by the Office for National Statistics (57).

Dementia is a progressive condition and is likely to impact a person's abilities including memory, communication, and ability to undertake everyday activities as they approach the end of life (58). As such, people with dementia are likely to have additional care and support needs as they near the end of life, compared to the general population including higher levels of emotional distress that require management (59). Transferring people with dementia to unfamiliar environments such as hospitals and hospices, away from people they are used to, can exacerbate this (58). Admission to hospital for example can result in rapid physical deconditioning, distress, and delirium (56).

People with dementia require high levels of carer support, to help manage common symptoms such as incontinence and wandering (56). Despite this, compared to those without dementia, they are less likely to be referred to specialist end of life care services, are prescribed fewer palliative care medications and are less frequently referred or considered for hospice care (15). They are also more likely to experience invasive interventions such as blood tests, intravenous treatments, and feeding tubes.

Part of the reason for this is the person’s reduced capacity to communicate verbally as the condition progresses, which can make it particularly difficult for them to relay to carers when they are in pain. They may instead cry out or become restless, which can sometimes be dismissed by staff as an element of the dementia or purely as ‘challenging behaviour’, leading to poor quality care and inadequate symptom relief (55, 56, 58). A further challenge with communication is that people whose first language is not English may revert to their mother tongue, thus introducing an additional language barrier (45)

Advance care planning is an important step in ensuring that people are able to receive the care and support that they would like. For people with dementia it is important that these conversations are initiated early, while it is possible for them to contribute and make shared decisions (59, 60). This is particularly important as it can be difficult to know when a person with dementia is coming to the end of their life due to often unpredictable clinical courses (55, 56, 58). The Leicestershire JSNA chapter on dementia identified that having early conversations with those affected by this condition was a ‘gap’ in services (54).

2.1.11. Sudden and Unexpected Deaths

The causes of a sudden or unexpected death range from medical (including stroke, myocardial infarction, acute aortic aneurysm), trauma (arising from road traffic accidents, natural disasters, or violent attacks), and taking one’s own life (61). When a death occurs suddenly, loved ones have no opportunity to prepare and feelings of grief, shock and confusion can be intensified (61). Furthermore, if they are not present when their loved one dies suddenly, they may experience guilt or anger. Alternatively, if they are present, they may find themselves affected by additional trauma if they were responsible for calling for help or delivering first aid (61). The unexpected death of a loved one is associated with depression and anxiety, substance misuse, and a heightened risk for prolonged grief reactions (62).

2.2. Informal Carers

It is estimated that informal carers provide as much as 75-90% of homebased care for people who are near the end of life (63) and it is predicted that the reliance on carers is likely to increase over the coming years. During the course of the COVID-19 pandemic, the number of deaths in private homes increased placing an additional burden on carers (64). The caring role does not end when the cared for person is admitted to a place of care though, with loved ones often visiting frequently and being responsible for bringing in their personal effects (65). It can however be difficult to identify and clearly define this group, as many who are caring do not recognise themselves as a carer but instead consider themselves to be doing what needs doing for their loved one (66).

In addition to a sense of fulfilment and wish to provide for a loved one, there are multiple negative impacts that may arise from doing so, with one of these being a high financial burden. Costs that are faced may be direct (such as transport, food, medication) and indirect (including changes to employment status through taking unpaid leave, reducing working hours, or changing to a lower paid but more flexible job) (63, 67). Such financial costs often impact those from lower socio-economic groups the most (63). Informal carers also face non-monetary costs such as time cost and potential negative health impacts. Indeed, as time is dedicated towards caring for a loved one, major life changes may be needed including moving house, delaying education, and taking time off work which may impact on future job opportunities and earning potential (63).

Informal carers are more likely to experience higher levels of anxiety, depression, and social isolation than are formal carers or non-caregivers (67). Studies from other countries have shown that they often experience sleep deprivation and fatigue as a result of caregiving, which can exacerbate poor mental health. The needs of carers can be divided into those which support the carer in looking after their loved one, and the distinct needs of the carer themselves (65). With a common theme among informal caregivers being that they often put the needs of their loved ones first whilst neglecting their own, there is sometimes a risk that this latter is overlooked (65, 67).

Carers also face challenges in undertaking their role, with a lack of information and knowledge about the end of life shown to be one key issue (68). Studies have shown that carers often feel that they have either received insufficient information about their loved one’s illness or their care needs and how to seek help, have received information at too late a timepoint, or failed to receive it in a written format (69). A lack of information can be a particular challenge given that end of life care is often delivered in a multidisciplinary manner, with input from multiple services. Carers have reported that there is at times a lack of a clear action plan, with poor understanding amongst organisations regarding who is responsible for delivering aspects of care. In these cases it often falls on the carer to navigate and coordinate services which can place additional pressure and stress on them (70).

Upon the death of their loved one, carers may feel a mix of emotions in addition to bereavement. This may include a sense of relief, which can in turn cause guilt (65). These feelings are not distinct from the caring role, but may also be experienced whilst the loved one is still alive, with many experiencing an ‘anticipation of loss’ (66). Carers can also experience a secondary loss which compounds the bereavement, through the abrupt withdrawal of professional support from health and social care services. It has been reported that this can leave carers feeling abandoned and invisible (66).

Informal carers comprise a diverse population, and experiences are not uniform across this group. There is considerable evidence that women are more likely to be caregivers to family members than are men (63, 67), and so are more likely to be affected by the challenges associated with this role. The relationship between health impacts and other carer demographics is complex though. For example, younger carers have been shown to mainly suffer greater psychological impacts whilst older carers have worse physical health, and spouses appear to suffer greater overall health impacts than other carers (64). A certain level of physical fitness is needed to be able to deliver some practical aspects of care, which can be increasingly challenging with an increasingly ageing population taking up caring responsibilities (65).

2.3. Staff working in end of life and palliative care roles

Whilst a large amount of research has been undertaken to investigate the challenges faced by informal carers in providing end of life care, there is little in the literature considering the impacts on staff in this area. Those who work in end of life and palliative care roles face numerous emotional demands which may negatively impact their mental health and psychological wellbeing, including recurrent exposure to death and patient suffering, breaking bad news, and the absorption of negative emotional responses (71). Practical considerations including limited time and resources have also been cited as further sources of stress in this area (72).

Persistent work-related stress can lead to burnout, which consists of emotional exhaustion, depersonalisation, and feelings of reduced personal accomplishment (73, 74). Due to differences in how it is measured, prevalence estimates vary and range from 3% to 66% (73). In addition to directly affecting the wellbeing of staff, burnout can result in reduced quality of patient care, increased risk of mistakes being made, and impact healthcare organisations through time off work and staff leaving (73).

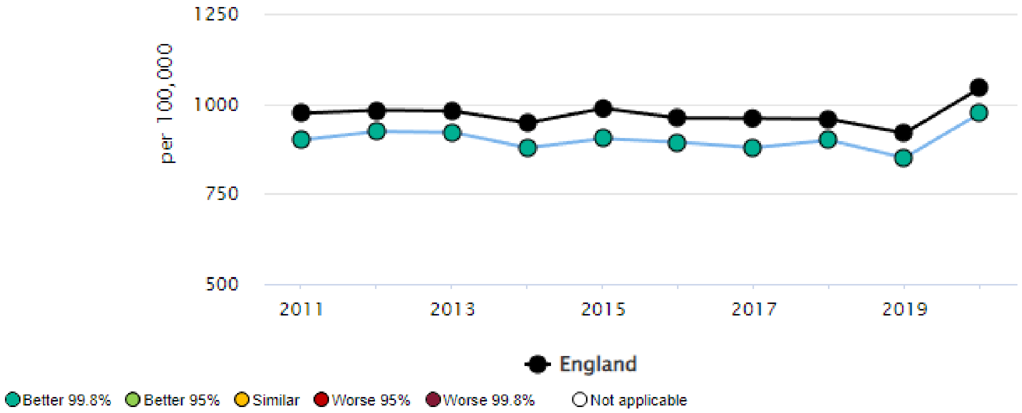
Work undertaken by the British Medical Association has shown that significant numbers of junior doctors have also highlighted a lack of confidence when managing end of life situations stemming at least in part from a lack of exposure, with complex conversations often left to more senior colleagues (75). Even doctors at more senior levels of training felt that they had received little training in discussing sensitive issues with patients. Areas of particular difficulty included the administration of pain relief, and challenges in predicting how long a patient has to live.

3. Level of need in Leicestershire

3.1. Mortality Rate

The mortality rate for all ages in Leicestershire of 973 per 100,000 population in 2020, with no significant change in trend over the preceding 5 years. This is significantly better than the rate for England, which in 2020 was 1,042 per 100,000 (Figure 3) (2).

Figure 3: Mortality in England and Leicestershire (all ages) (2)



Source: OHID Fingertips, Palliative and End of Life Care Profiles

When considering mortality rates in Leicestershire by age, those aged 85+ years have a similar rate to that of England. All other age groups for which data is available have a significantly better mortality rate in Leicestershire (Table 1) (2).

Table 1: Mortality rates per 100,000 population in England and Leicestershire by age group (2020) (2)

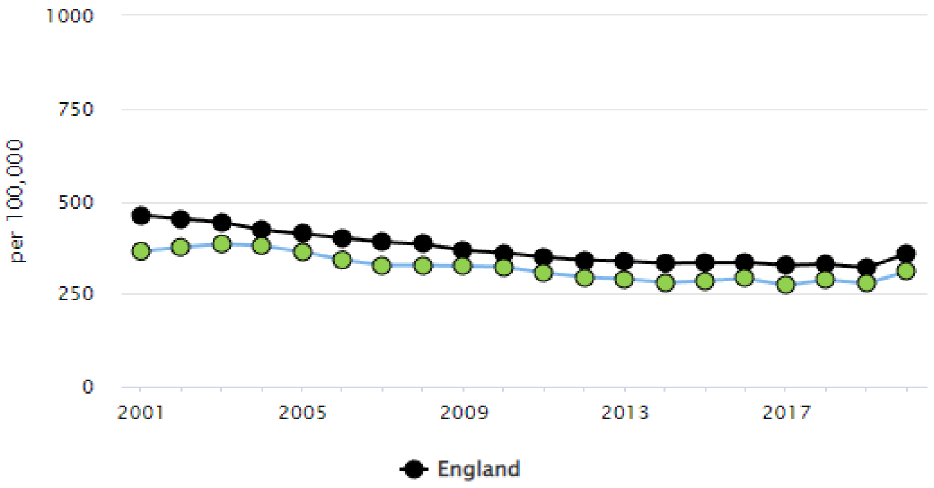
	<65 yrs	65-74 yrs	75-84 yrs	85+ yrs
Leicestershire	*158	*1,480	*4,384	16,192
England	193	1,630	4,649	16,558

*Significantly different (lower) to England value

Source: OHID Fingertips, Palliative and End of Life Care Profile

Premature mortality is defined as deaths under age 75 for all causes. In Leicestershire, the under 75 mortality rate was 310.8 per 100,000 in 2020 (Figure 4). This is significantly lower than both the East Midlands (362.5 per 100,000) and England (358.5 per 100,000) (3).

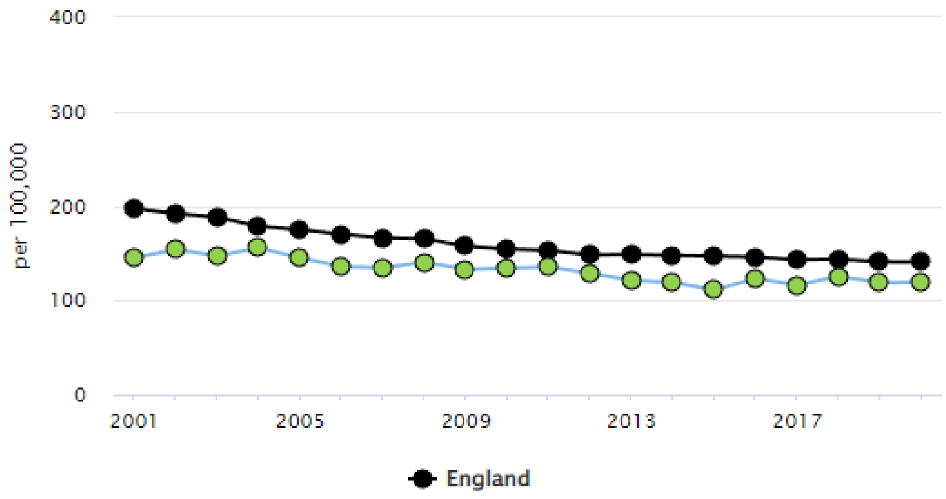
Figure 4: Under 75 mortality rate from all causes in Leicestershire and England (3)



Source: OHID Fingertips, Mortality Profile

Some causes of death are considered preventable. These are causes where all or most deaths could potentially be prevented by public health interventions. In Leicestershire, the under 75 mortality rate from causes considered preventable was 118.8 per 100,000 in 2020 (Figure 5). This is significantly lower than both the East Midlands (142.1 per 100,000) and England (140.5 per 100,000) (4).

Figure 5: Under 75 mortality rate from all causes considered preventable in Leicestershire and England (4)



Source: OHID Fingertips, Mortality Profile

3.2. End of Life Preferences

National Data

If severely ill, the majority of people would prioritise their quality of life over the length of time remaining to them. In one survey commissioned by Marie Curie, 77% of people either agreed or strongly with the statement “If I was severely ill with no hope of recovery, my quality of life would be more important than the length of my life”, whilst only 6.7% either disagreed or strongly disagreed (12). This proportion is similar for those identified as being in their last years of life (79%), carers of people with terminal illness (76%) and bereaved carers (81%).

This same survey also asked members of the general population to select the three priorities that would be most important to them in their final days of life (12). The highest ranked priority was being free of pain and other symptoms, selected by 46.5% of respondents. This was followed by being in the company of loved ones (43%) and being able to maintain personal dignity and self-respect (35%). Being at home was the fourth ranked priority, selected by 26% of respondents. Being at home was a greater priority for those who self-identified as being at the end of life, than for members of the general population. For these individuals, being at home became the second highest ranked priority, replacing being in the company of loved ones (Table 1).

Table 2: Most selected personal priorities for individuals during the last years of life (12)

	Top priority	Second Priority	Third Priority
General Population	Being free of pain & other symptoms	The company of loved ones	Being able to maintain personal dignity & self-respect
Individuals in the last years of life	Being free of pain & other symptoms	Being at home	Being able to maintain personal dignity & self-respect

Source: Public attitudes to death and dying in the UK, Marie Curie, 2021

Other research has shown that key themes important to the general public when considering good end of life care include being treated as a person, the timely provision of medical services, the location of services, and provision of information (75). The concept of being seen as a person, encompasses the recognition that they remain an individual with particular needs, wishes and goals. It was recognised as being important to have care tailored to the person themselves, rather than being placed on a generic plan which could be applicable to anyone with their condition (75). This includes having choice with regards to what treatments they do or do not receive and being able to change one's mind. This reinforces the importance of robust and timely advance care planning, to support the delivery of tailored care.

Local Insights

UHL collate feedback collected through their bereavement service (see section 6.2) to create 'End of Life' themes. Both positive and negative feedback is received, and so these themes can give an indication of what is considered important to the loved ones of those receiving end of life care in hospital. The theme of 'communication' is by far the largest of these, with subthemes including communication around the topics of imminence of death, DNACPR, prognosis, results, management, and care planning. This links with national the national findings discussed previously that people value being included in decision making and being treated as an autonomous individual.

3.3. Advance Care Planning

National Data for adults

Advance care planning provides people with the opportunity to plan their future care and support, whilst they have capacity to do so (76). It should be personalised to the individual and emphasises personal reflection and choice (76). Whilst not everyone may wish to make an advance care plan, it may be particularly relevant to those who are at risk of losing mental capacity through a progressive illness such as dementia. Such plans can take place either through informal conversations with loved ones, or through formal routes such as the completion of advance statements, lasting power of attorney, and advance decisions (76). Although these are not legally enforcing, planning in this way does make it more likely that a person's wishes will be understood and followed (77). Evidence indicates that timely advance care planning is strongly associated with lower rates of hospital deaths, and greater odds of being cared for and dying at home (78, 79). It allows for a more proactive approach to delivering care and support, in place of a reactive one. This also has the benefit of supporting friends and family in being better prepared (12).

Despite the important role of advance care planning, only 15% of those participating in a national survey by Marie Curie reported having already talked to someone about their end of life care wishes (12). Slightly more (20%) had made financial arrangements for their funeral. These figures remain low, even amongst those who are in their last years of life (13% reported having made advance plans). This is in line with results from other studies, such as The National Audit of Care at the End of Life which found that only 9.7% of people had an advance care plan before their final hospital admission in 2019 (though this was an increase from 4.5% in 2015) (11). With approximately half of all participating adults reporting that they intend to have these conversations, there appears to be an intention-action gap in this area (12). Some topics appear to be easier to discuss however, with 40% saying that they had talked to someone about whether they want their body to be buried, cremated, or donated. It also appears that there is a reluctance by individuals to discuss their own preferences about end of life care, but also to discuss those of others. As little as 16% of respondents reported asking a family member/friend whether they had made a living will, and 15% had asked what type of care support they would want at the end of their lives.

Barriers to initiating these conversations from a carer's perspective include a fear of causing further pain or upset. Furthermore, acknowledging the need to discuss these topics can be seen as 'giving in' and abandoning hope of recovery by the individual (80). One way to build effective communication and create trust is through having one-to-one relationships with a health or care professional (1). This is particularly important for those who may have negative past experiences of healthcare services, such as those who are homeless or Gypsies and Travellers.

It is also important to consider when conversations take place. Although it may feel easier to have these discussions when either yourself or a loved one are nearing the end of life, cognitive capacity can be compromised in the later stages of some terminal conditions (such as dementia) and so make these conversations less meaningful (1, 15, 80). Beginning these conversations earlier suggests better control, making it easier to plan for the practicalities of death such as wills and finances. The CQC acknowledge that there ought to be a shift towards having conversations about wishes and preferences at an earlier stage in the care pathway, even if diagnoses and prognoses are less clear (1).

Multiple factors may explain these low figures. Being able to talk about death is vital to facilitating advance care planning, and yet the majority of people feel we do not talk enough about death and dying (12). Some feel that the COVID-19 pandemic has highlighted the importance of talking about death and dying, and that the amount we now discuss this subject as a society has increased as a result. Despite the belief that death and dying are not discussed enough, 65% of people responding to a survey by Marie curie reported feeling either comfortable or very comfortable discussing these topics (12). This was even higher for people in the last years of life, carers and bereaved carers, of whom 80% reported feeling comfortable discussing these topics with family and friends. An exception to this, was seen in relation to discussing the arrangement of virtual possessions such as social medial accounts with only 45% reporting feeling comfortable.

A further barrier to advance care planning appears to be a lack of knowledge and understanding of the types of services available, and of terms commonly used in end of life care. Amongst the general population, as many as 78% are unaware of the term "Advance Care Plan", whilst 88% are unaware of the term "Advance Directive" (12). The most recognised terms in this survey were "Palliative Care" and "Hospice Care", although 31.3% and 31.6% were respectively unaware of these. Furthermore, 55% of those in the last years of life reported not knowing where to find information on how to plan in advance for care at the end of life.

There also appears to be a low level of understanding as to who can access end of life care. This same survey found that 45% of respondents either did not agree, or did not know, that people thought to be approaching the end of life are themselves able to access end of life care facilities. Those who have actively made advance plans around their end of life preferences however, appear to have a far greater understanding on this issue. This same survey found that between 55% and 76% of those who had made advance plans agreed that those approaching the end of life are able to access end of life care facilities.

Local Insights

One challenge with ensuring advance care plans are followed locally, is in initially identifying that the person actually has one. Known as Integrated Care Plans in the community, these are completed by GPs and recorded electronically on SystemOne whilst the patient is provided with a paper copy. Hospital teams, however, do not have access to SystemOne and so are reliant on the patient bringing their physical copy with them, should they be admitted. Similarly, GPs do not have access to hospital records and if an advance care plan is completed during an inpatient stay, they are reliant either on this being clearly documented in the discharge letter or on the patient bringing them a physical copy. This failure of systems to communicate results in confusion, duplication of work, and the risk of going against a patients' clearly identified wishes.

An audit of 36 patients in the Leicester Royal Infirmary over the space of 2 weeks in April and 2 weeks in May 2021 who died in hospital identified 85% had a ReSPECT form completed in hospital, identifying their clinical care and treatment recommendations for an emergency (this includes forms that were re-written during their stay) (81).

Where plans are in place and held by the patient at the time of admission, the quality can sometimes cause problems when patients wishes aren't clear or use statements that are ambiguous.

Children and Young People

Advanced Care planning is used more frequently with children and young people than with adults in Leicester, Leicestershire and Rutland. Local teams advocate for a combined CYPACP (Child and Young Person's Advanced Care Plan) with ReSPECT embedded and ensure that families are offered choices in care options throughout their journey. A much higher percentage of children and young people die with this combined document in place wherever death has been anticipated due to the child having a life limiting and/or life threatening condition. Figures from the Diana service for 2021 identify over 57% of children that died in this period having a CYPACP and/or ReSPECT in place. The majority of those without plans were due to the unexpected or rapid death of the child.

3.4. Delivery of End of Life Care and Support

National Data

There is evidence that end of life care is often not well coordinated, and that having multiple people involved in delivering care can be confusing and result in inconsistent quality of care (1). This can have a particular impact on carers, who must subsequently spend time coordinating services. This can also be challenging for staff working in the sector, with a lack of clarity over whose responsibility aspects of care falls under. Evidence suggests that poor coordination of care is particularly an issue for hospital services attempting to coordinate with services outside the hospital such as General Practice, compared to community based services working together (11).

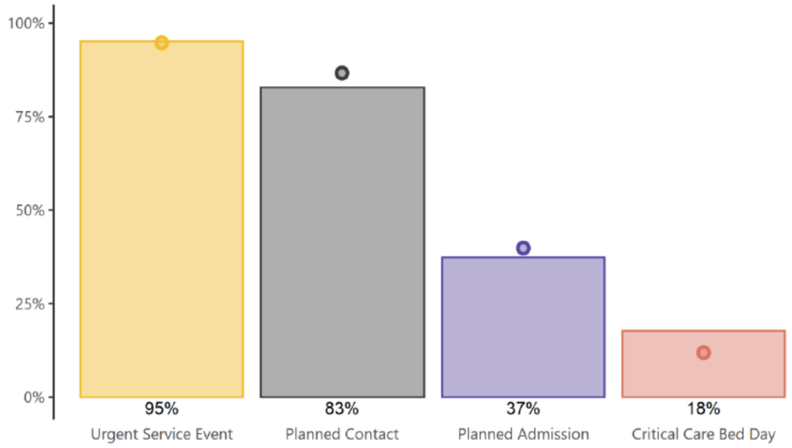
It has been identified nationally that many inappropriate hospital admissions amongst end of life patients occur because the patient and/or family are concerned over a sudden deterioration in health and do not know who to contact. They therefore call an ambulance, whose staff do not know the patient's full medical history and so transfer to hospital where the emergency team similarly lack information about decisions that have previously been made about the patient's care. This leads to admission to a ward. It is important to have timely discussions with patients and families, and to signpost who to contact in such situations (75).

Local Insights

In the two years before they die, most people access some form of healthcare (6), but it is the nature of the services with which they interact which is important. Compared to the Midlands as a whole, a lower proportion of people in Leicester, Leicestershire and Rutland access planned admissions whilst a greater proportion access critical care beds (Figure 6). Data shows that those dying from cancer are likely to have more planned contacts and planned bed days than people from other groups (6). Part of this is due to their undergoing cancer treatment regimens.

A review undertaken of deaths that took place in UHL or LPT, or within 30 days of discharge from UHL, found that elderly patients in particular are often admitted to hospital out of necessity due to deterioration in their condition. They felt however, that this necessity could be mitigated by placing a greater emphasis on preventative measures in the community. These may include providing greater clinical solutions in community hospitals and nursing homes, and providing more focussed support for informal carers (82).

Figure 6: Proportion of people who in the last two years of life accessed healthcare services. Leicester, Leicestershire and Rutland indicated by bars (with percentages) and Midlands region indicated by dots (6)



Source: Health Service use in the last two years of life. Leicester, Leicestershire and Rutland STP, Midlands and Lancashire Commissioning Support Unit, 2020

To enhance our understanding of the needs and experiences of local people, an online survey was conducted by Leicestershire County Council. Of those who responded, 26 people had both undergone a bereavement within the last 3 years following the expected death of a loved one, and identified Leicestershire County as the primary location to which their experiences related. These individuals were asked to reflect on the care that their loved ones received as they approached the end of life, with the results outlined below and in Figures 7-13 (note that this was a self-selected sample, and so may not be representative of experiences across the county).

Figure 7: There was a sufficient range of services to meet my loved one's physical needs

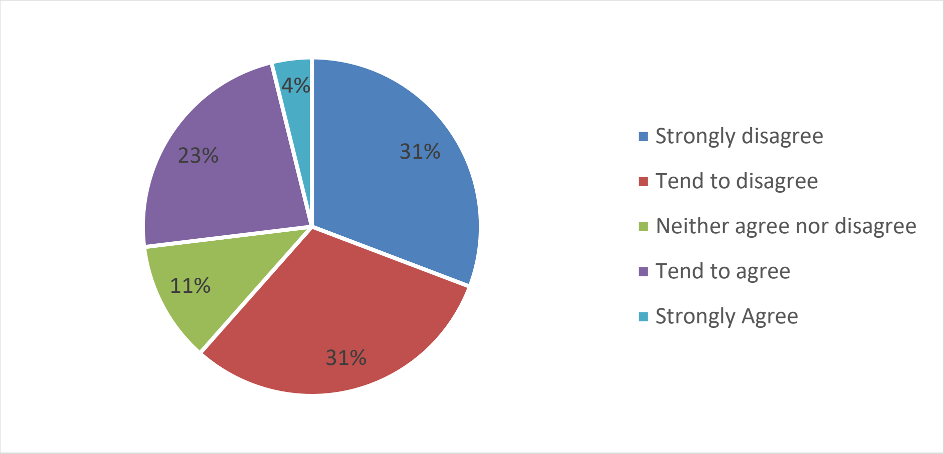


Figure 8: There was a sufficient range of services to meet my loved one's mental health needs.

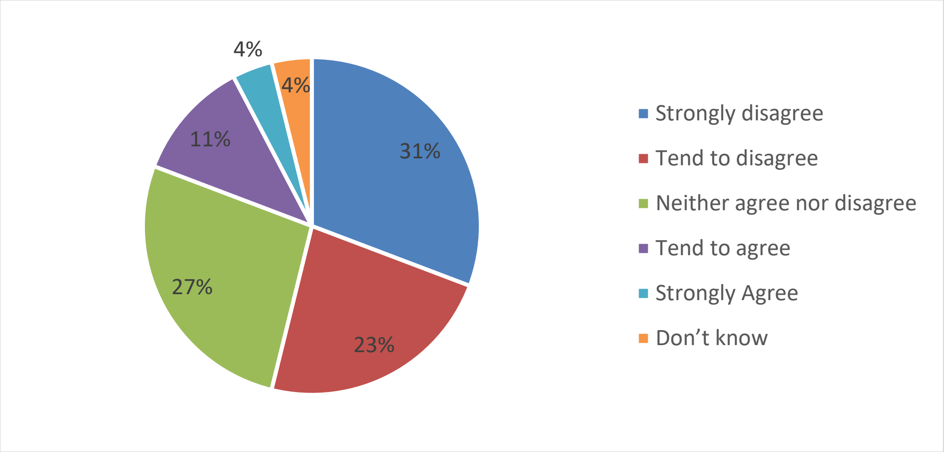


Figure 9: There was a sufficient range of services to meet my loved one's financial needs.

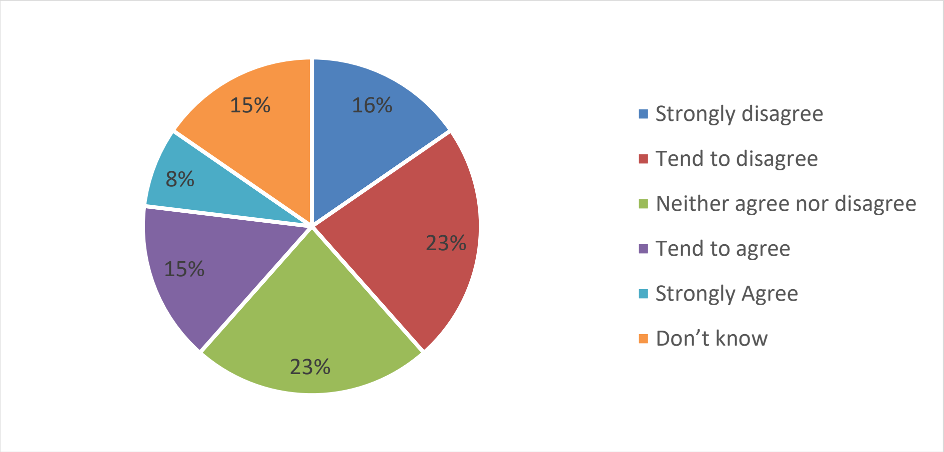


Figure 10: There was a sufficient range of services to meet my loved one's cultural needs.

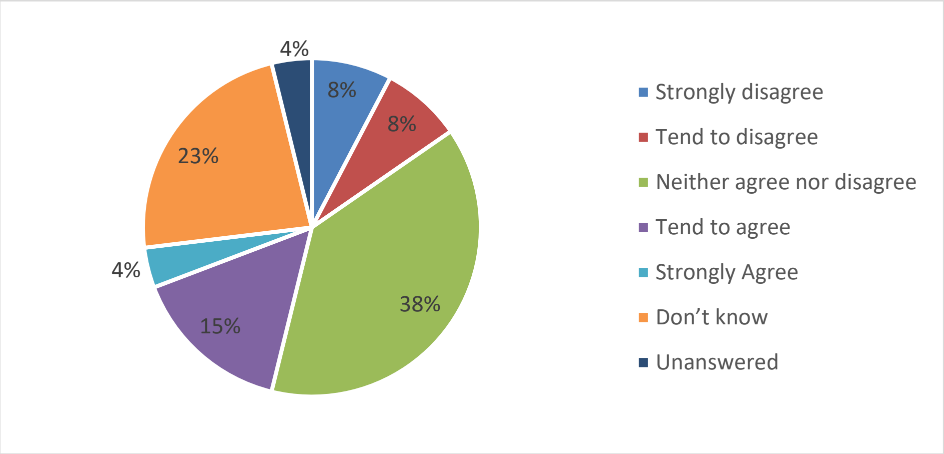


Figure 11: It was easy to access support services for my loved one.

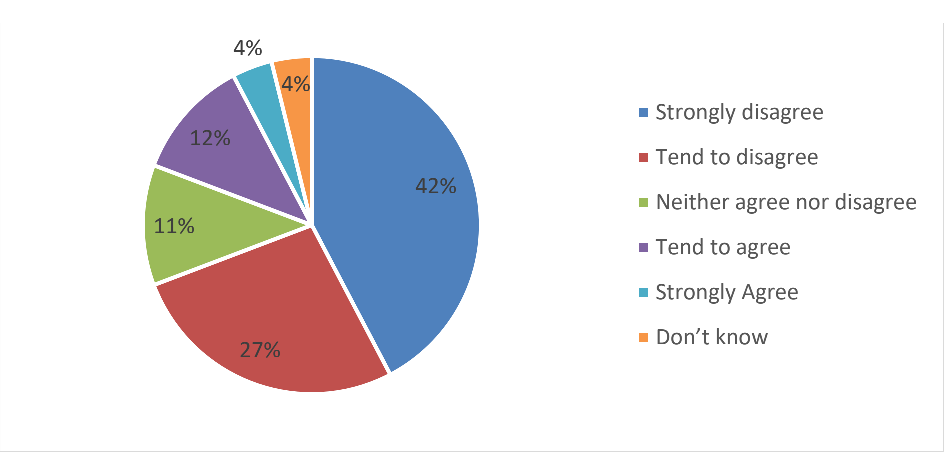


Figure 12: My loved one received the equipment (such as medical devices and mobility aids) that they needed in a timely manner)

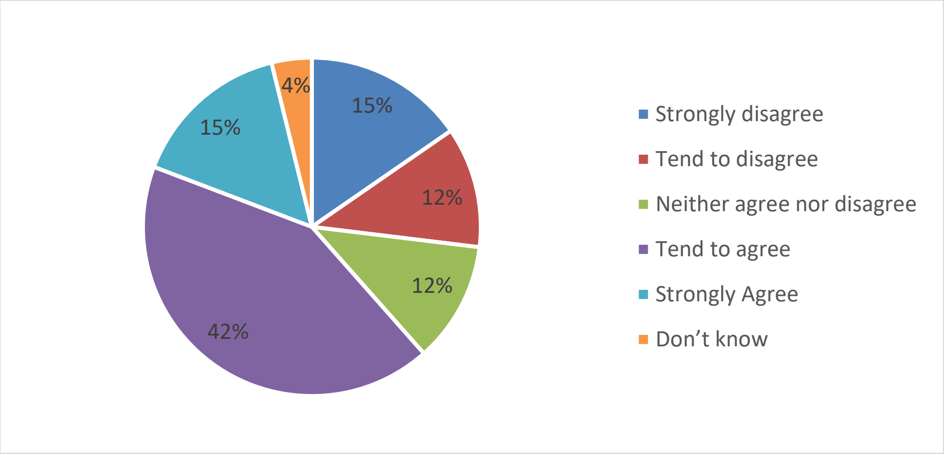
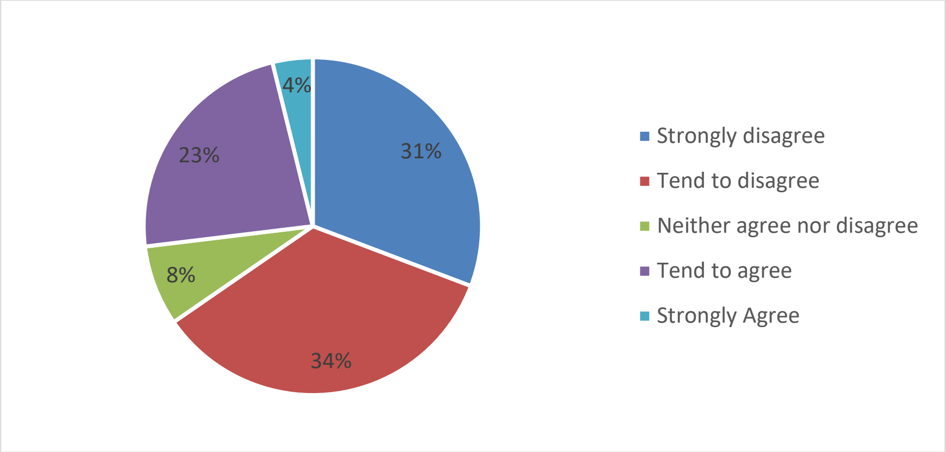


Figure 13: Overall, I was happy with the care and support that my loved one received.



Respondents were also asked which aspects of care and support they felt currently worked well, and which need to be strengthened and developed further. In line with responses highlighted in Figure 12, receiving equipment in a timely manner was commented on positively overall. This was not universal however, with one respondent informing us that they were advised to buy their own equipment to ensure it arrived in time. The other main positive theme to emerge was that staff delivering services (including GP, district nurses, occupational therapists, and hospice staff) were generally found to be empathetic, kind, caring, and supportive. This was particularly true when continuity of care was able to be maintained, and relationships created and maintained. Misunderstandings and inappropriate advice were more likely to be experienced when interacting with new healthcare professionals who do not know the patient well.

Some also felt that their loved ones were referred into services too late, and so the input received from these individuals and teams was often too brief and at a stage where there was little that they could realistically do to help. It was also felt that there often isn't sufficient capacity within services to provide the required level of support, particularly with regards to district nursing. Many respondents believe that there is instead an over-reliance by services on the support provided by informal carers and loved ones. This is combined with a lack of sufficient training or advice on how loved ones should undertake this role, making them feel under increased pressure during an already distressing time.

A further weakness in the current system identified by multiple respondents is a lack of obvious coordination between services, particularly between primary care or community care services and secondary care. This left loved ones being unsure of who they should contact to seek advice and support from, with it commented on that this then led to a reliance on generic services such as 111. This was particularly an issue for out of hours support, with comments received that improved access on evenings and weekends is needed.

Quotes provided by respondents:

“I thought the UHL Consultant was excellent, compassionate, responsive and available to answer questions. The palliative care team in last few weeks of life were also excellent and supportive.”

“[Their] GP was brilliant but their input was limited but did all they could to try to help get services in place.”

“They couldn't find capacity for a nurse to visit [them] regularly at home so [they] had to stay in - we need more specialist district nurses”

“Some aspects of [their] care and support in the last couple of weeks especially were hard to deal with and we could have done with more support from the district nursing and palliative team (and easier access to them) at this stage.”

“We had to purchase aids for [them], we were bluntly told if we didn't they wouldn't come in time because [they] needed to be assessed first and they knew that wouldn't happen for ages”

“We were left to our own devices to deliver the care regardless of the fact not one of us are medically trained or even had any idea how to safely help move and transport our family member! None of us knew what to expect or what was coming and found the lack of support very distressing!”

“How you access support i.e. ring GP for this, district nursing will cover this, carers are able to do this, we ended up going through the only channel that would respond even though it was clear they could not provide the solution.”

“The surgery sent different doctors, one suggested my [parent] read a good book, to take [their] mind off things, [they were] registered blind”.

“District nursing falls short now in providing pallative support,intergrated palliative care only accept refferal if your relative is symptomatic. There is a gap in the care once you are palliative ie the bit where treatment has stopped but the person not quite dying.”

“I had no support, to the point that my [parent] was left completely without ANY care for 4 days when one care company ended before another one started. There was not even enough time to get [them] into a care home for those few days as there was not availablity.”

“Care in the community falls short and as patients are not supported until they meet crisis point for them or there carer. They end up being addmitted to the acute sector and this is of no use to them or the hospital. There is a lack of training for residential and nursing homes thus patients are moved at a time they need support and comfort in a familiar enviroment.”

3.5. Place of Death

3.5.1. Preferred Place of Death

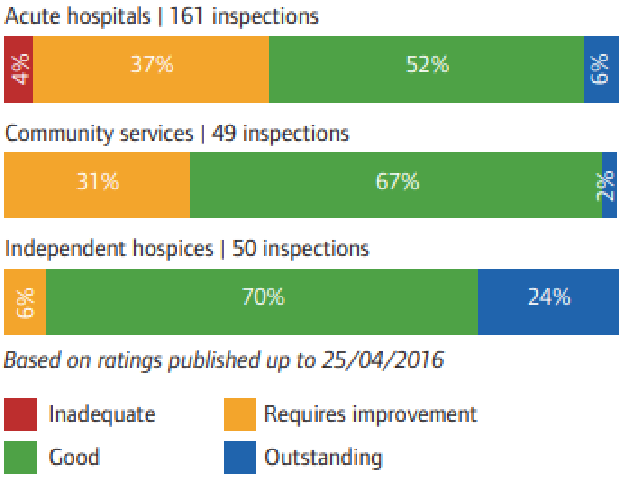
It is estimated that for 81% of people in England, home is the preferred place of death (29). This is followed by hospice (8%), care home (7%), hospital (3%) and other (1%). Caution ought to be taken however when considering these figures. Indeed, in many studies a large proportion of respondents indicate that they have no preference, and there is also often a shift in preferences away from home and towards hospital as age increases or illness progresses (83). Furthermore, the term 'home' can be poorly defined and conflated with concepts of comfort, familiarity and the presence of loved ones which can exist in other settings (83). Practical considerations also need to be thought of when reflecting on preferred place of death, and yet many surveys do not ask respondents to consider aspects such as access to clinical support when considering their preferred end-of-life location (83). Given that being free of pain and other symptoms is often a top priority for people in their final days (12), it is possible that this may influence decision making.

There are also personal reasons why although dying at home may be the aspiration, it may not be a practical option for a given individual. In deprived areas for example, housing is often of poorer quality, and those in temporary and rented accommodation may also experience housing insecurity (15). In such situations, home may not represent the ideals of comfort and familiarity in the same way it does for others. Additionally, as outlined in Section 2.1, a considerable workload is taken on by families and loved ones when caring for someone nearing the end of life at home. Those with low socioeconomic status may also be less able to take time off work to care for loved ones, whilst those from other groups such as older LGBT adults are more likely to live alone and so not have as robust a support network. Thus, dying at home may not mean the same to everyone and dying well at home may not be possible for all, thus driving inequalities in end of life care.

Whilst hospitals are often considered the least preferred place of death, some suggest that they might be the most appropriate place for some, particularly for those with pain, which can potentially be better managed in hospital settings (75). Evidence suggests however that this isn't the case, with the National Survey of Bereaved People (VOICES) finding that complete pain relief was achieved all of the time during the last 3 months of life in only 39.7% of those in hospital (29). This compares to 63.5% of those in a hospice, and 42.7% in care homes. These results also reflect overall end of life CQC inspection ratings, with hospices being the sector to receive the highest proportion of good or outstanding ratings (Figure 14) (1).

Finally, although large gaps exist between preferred and actual place of death, the majority of bereaved people believe that their loved one died in the right place (29). Based on results from the latest National Survey of Bereaved People (VOICES) survey, 94% of those who died in a hospice were believed to have died in the right place for them, 93% of those at home, and 74% of those in hospital.

Figure 14: Overall End of Life CQC inspection ratings by sector (1)



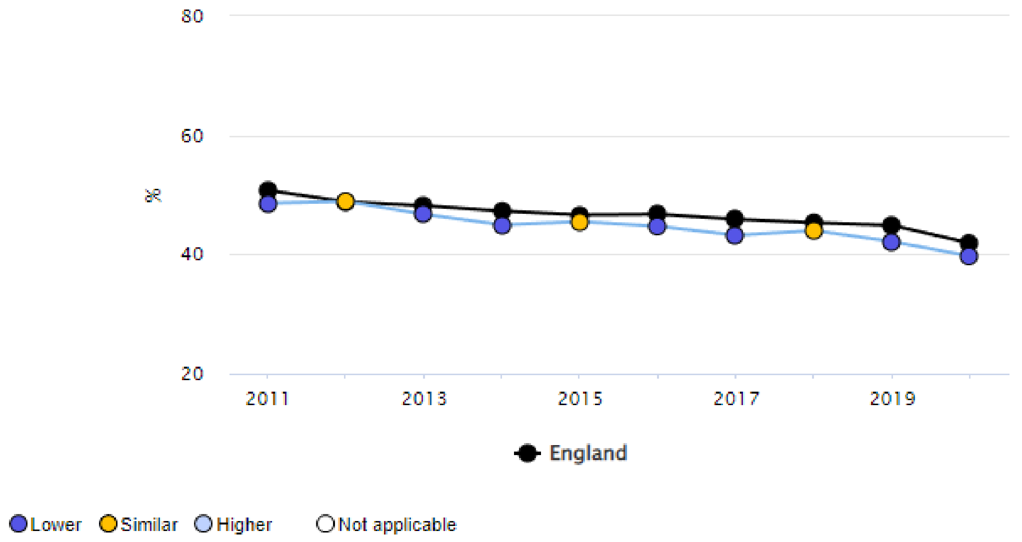
Source: A different ending. Addressing inequalities in end of life care. Overview Report, CQC, 2016

3.5.2. Actual Places of Death in Leicestershire

Hospital

There has been a decreasing trend in the percentage of people in England dying in hospitals from 2016 onwards, and this has been reflected in Leicestershire. In 2020, 39.7% of all deaths in Leicestershire occurred in hospitals. This is significantly lower than the England value of 41.9% (Figure 15) (7).

Figure 15: Proportion of deaths that occur in hospital in England and Leicestershire (all ages) (7)



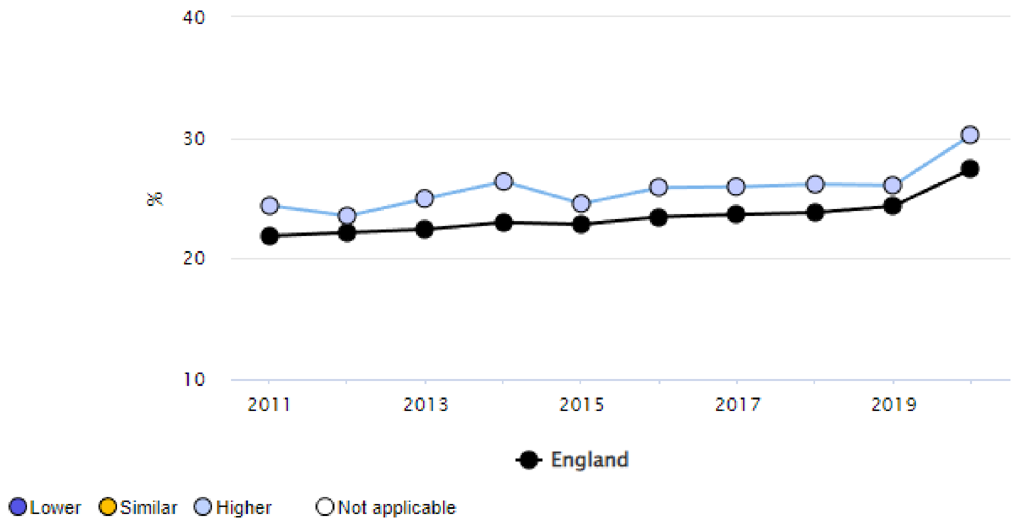
Source: OHID Fingertips, Palliative and End of Life Care Profiles

Based on data collected by the UHL Bereavement Support Service (see section 6.2), 63% of contacted bereaved family members who were willing to provide feedback in Quarter 4 of 2021/22 rated the quality of End of Life care received by their loved one in hospital as good or excellent. This compares to 32% who felt it was satisfactory, and 6% who felt it was poor or very poor.

Home

There has been an increasing trend in the percentage of deaths in England occurring at home over the past decade, and this has been reflected in Leicestershire. In 2020, 30.2% of deaths in Leicestershire were at home. This is significantly higher than the England value of 27.4%. As shown by Figure 16, a significantly higher percentage of people have died at home in Leicestershire compared to England in each year since 2011 (7).

Figure 16: Percentage of deaths that occur at home in England and Leicestershire (all ages) (7)

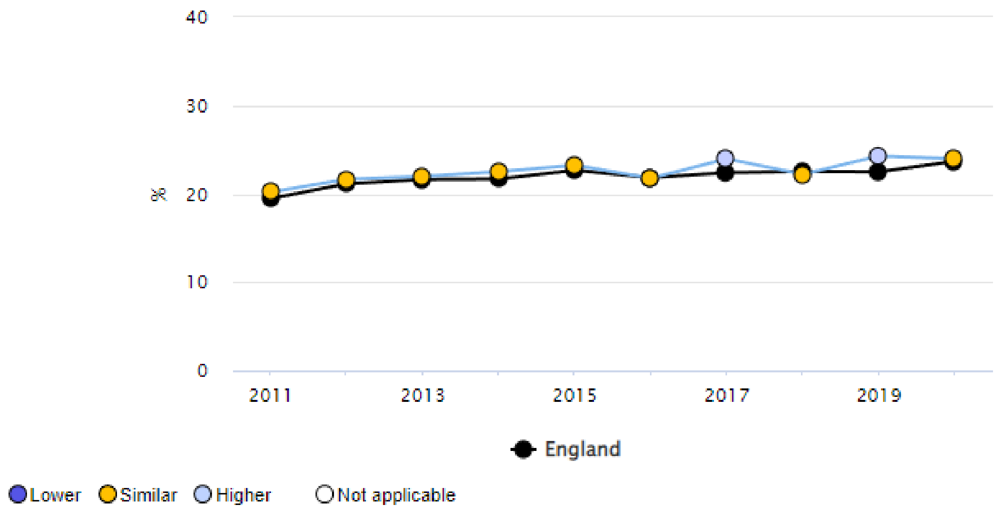


Source: OHID Fingertips, Palliative and End of Life Care Profiles

Care Home

There has been an increasing trend in England for the percentage of deaths to occur in care homes from 2016 onwards, but there has been no significant change in Leicestershire. In 2020, 24.0% of deaths in Leicestershire were in care homes. This is similar to the England value of 23.7% (Figure 17) (7).

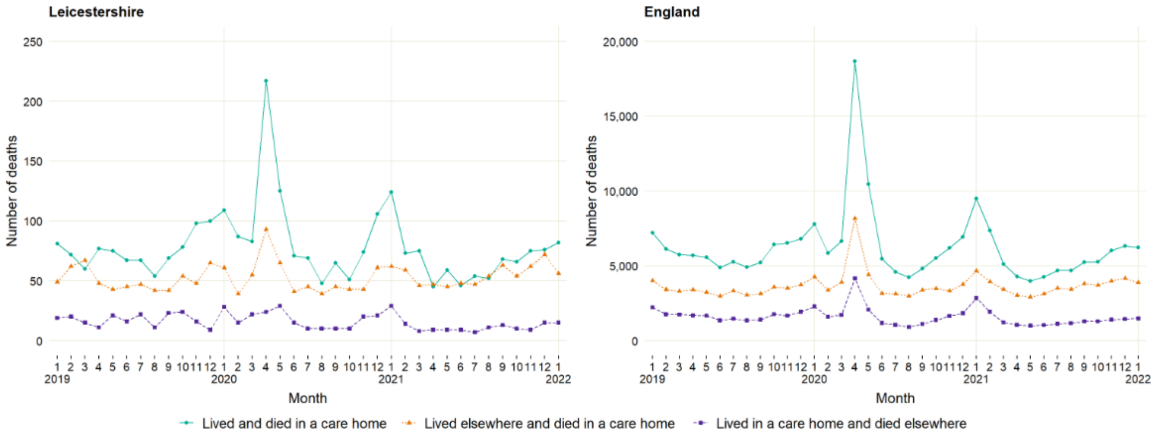
Figure 17: Percentage of deaths that occur in care homes in England and Leicestershire (all ages) (7)



Source: OHID Fingertips, Palliative and End of Life Care Profiles

One difficulty when considering care homes as place of death, is that for many older adults in particular this will represent their place of normal residence. A breakdown of the number of deaths occurring in care homes in those who lived in a care home and those who lived elsewhere, is shown in Figure 18 (8). This shows that the proportion dying in care homes in Leicestershire who previously lived elsewhere, is higher than that for England.

Figure 18: Number of deaths by care home-related place of death (all ages): Leicestershire and England (2019 to 2022) (8)

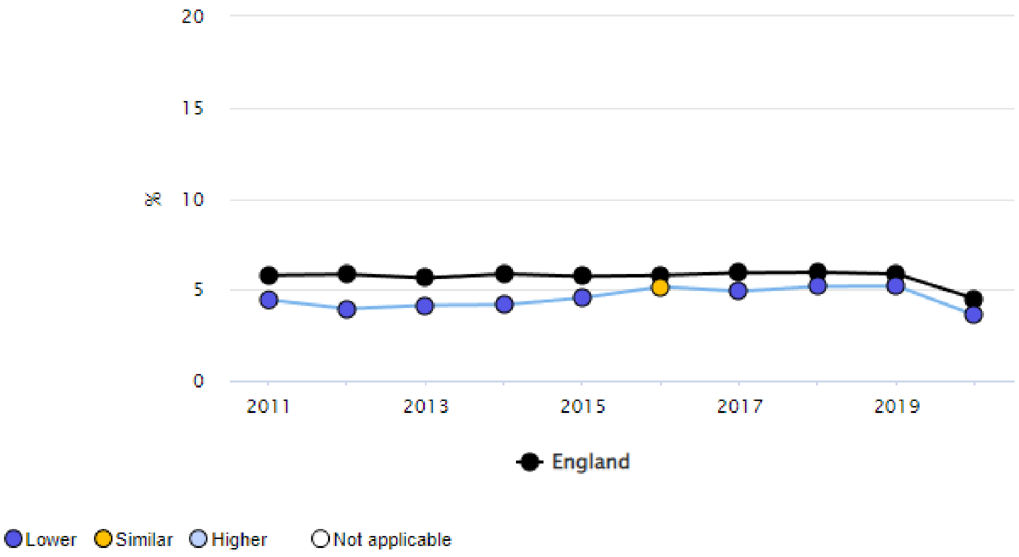


Source: OHID Fingertips, Palliative and End of Life Care Profiles

Hospice

There has been no significant change in the percentage of deaths in England or Leicestershire occurring in a hospice, from 2016 onwards. In 2020, 3.6% of deaths in Leicestershire occurred in a hospice. This is significantly lower than the England value of 4.5%. As shown by Figure 19, a significantly lower percentage of people have died in a hospice in Leicestershire compared to England in each year since 2011 except for 2016 (7).

Figure 19: Percentage of deaths that occur in hospice in England and Leicestershire (all ages) (7)



Source: OHID Fingertips, Palliative and End of Life Care Profiles

3.5.3. Factors influencing place of death

Age

The proportion of deaths in Leicestershire occurring at different locations varies by age. As age increases, the percentage who die in hospital or at home decreases, whilst the percentage dying in a care home increases (Figure 20) (7).

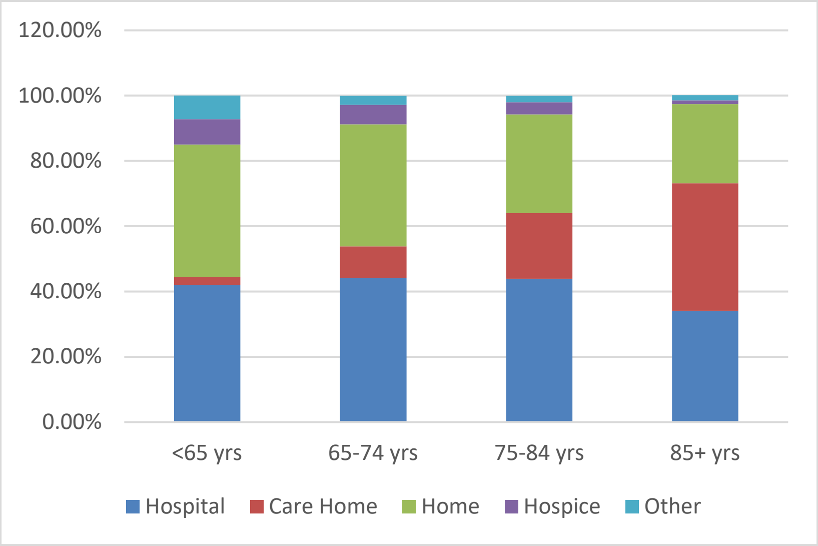
These figures differ to those for England in the following ways:

- Significantly fewer deaths of those aged <65 occur in hospital in Leicestershire compared to England (42.10% vs 43.80%).

- Significantly more deaths of those aged 65-74 (37.40% vs 34.10%), 75-84 (30.20% vs 27.50%) and 85+ (24.20% vs 20.80%) occur at home in Leicestershire compared to England.

- Significantly fewer deaths occur of those aged 85+ occur in a hospice in Leicestershire compared to England (1.20% vs 2.00%).

Figure 20: Percentage of deaths by age group in Leicestershire that occur in different locations (2022)

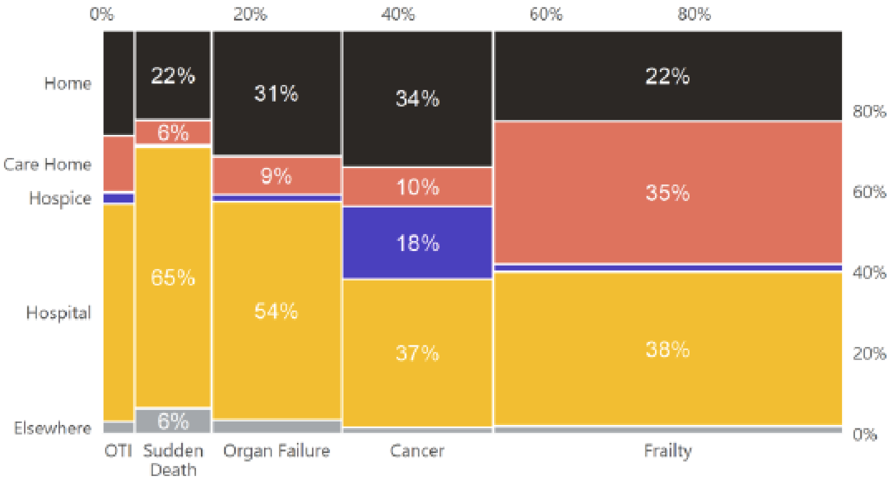


Source: OHID Fingertips, Palliative and End of Life Care Profiles

Diagnosis

Cause of death also influences someone's likely place of death. In keeping with what is seen nationally for example, those diagnosed with cancer in Leicester, Leicestershire and Rutland are far more likely to die in a hospice than are people with other diagnoses (Figure 12). Meanwhile, those whose cause of death is classed as frailty are far more likely to die in care homes.

Figure 21: Proportion of deaths by cause and place - Leicester, Leicestershire and Rutland STP (6)

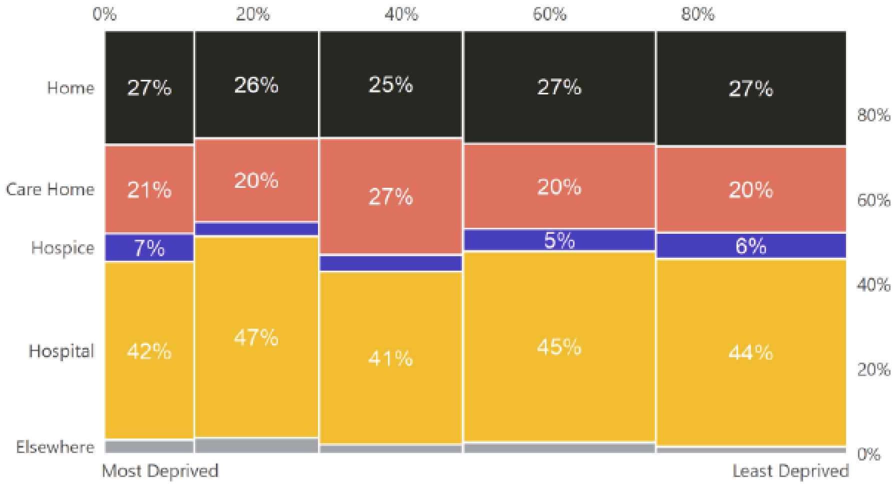


Source: Health Service use in the last two years of life. Leicester, Leicestershire and Rutland STP, Midlands and Lancashire Commissioning Support Unit, 2020

Deprivation

In Leicester, Leicestershire and Rutland, there is a mixed picture for place of death by deprivation level (Figure 22) (6). This is in contrast to the Midlands, which saw the highest proportion of deaths in hospital for those in the most deprived areas.

Figure 22: Proportion of deaths by deprivation quintile and place - Leicester, Leicestershire and Rutland STP (6)



Source: Health Service use in the last two years of life. Leicester, Leicestershire and Rutland STP, Midlands and Lancashire Commissioning Support Unit, 2020

3.6. Cause of Death

The leading causes of death in the UK differs by sex (9). For men, whilst the number of deaths from ischaemic heart diseases have decreased over time, this remains the leading cause of death (Figure 23). For women, the number of deaths caused by dementia and Alzheimer disease has increased since 2001 and has been the leading cause of death since 2011 (Figure 24).

Leading cause of death also varies based on age (9). In 2018 (the most recent year for which ONS data is available), the leading causes of death for different age groups in the UK were as follows:

- <u>20-34 Years</u> - suicide and injury or poisoning of undetermined intent for both males and females (27.1% and 16.7% respectively).
- <u>35-49 Years</u> – accidental poisoning for both males and females

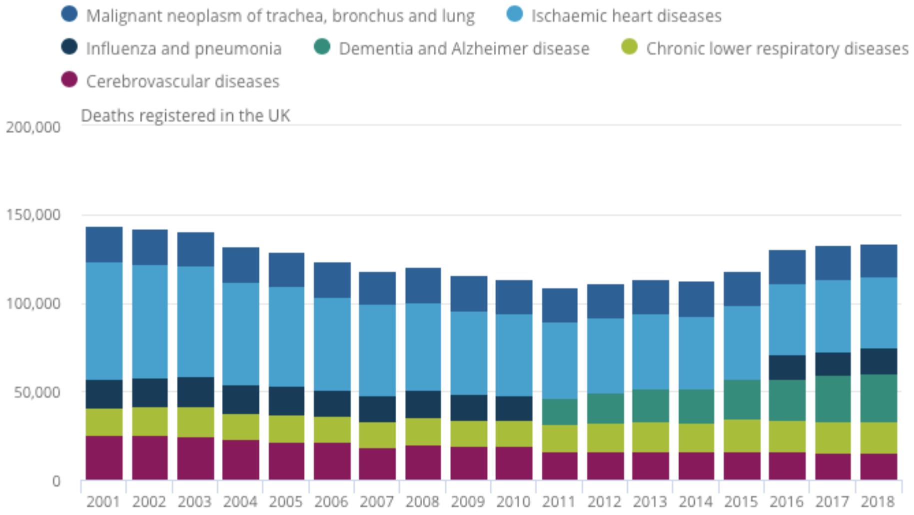
- 50-64 Years – for males, the leading cause of death was ischaemic heart disease (17.2%). For females, the leading cause was cancer of the trachea, bronchus and lung (10.1%).

- 65-79 Years – for males, the leading cause of death was ischaemic heart disease (14.8%) despite a decrease since 2001. For females, the leading cause was cancer of the trachea, bronchus and lung (10.4%).

- 80+ Years – dementia and Alzheimer disease for both males and females

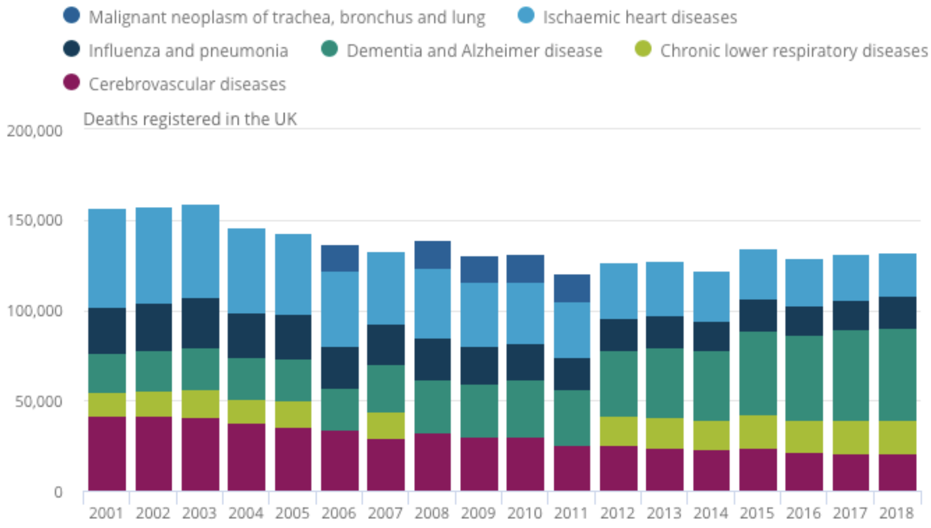
Local data is only available for the conditions of cancer, respiratory disease, and cardiovascular disease, as discussed in the following sections.

Figure 23: Deaths registered in the UK by leading causes of death, males, all ages, 2001 to 2018 (9)



Source: Leading causes of death UK: 2001 to 2018, ONS, 2020

Figure 24: Deaths registered in the UK by leading causes of death, females, all ages, 2001 to 2018 (9)

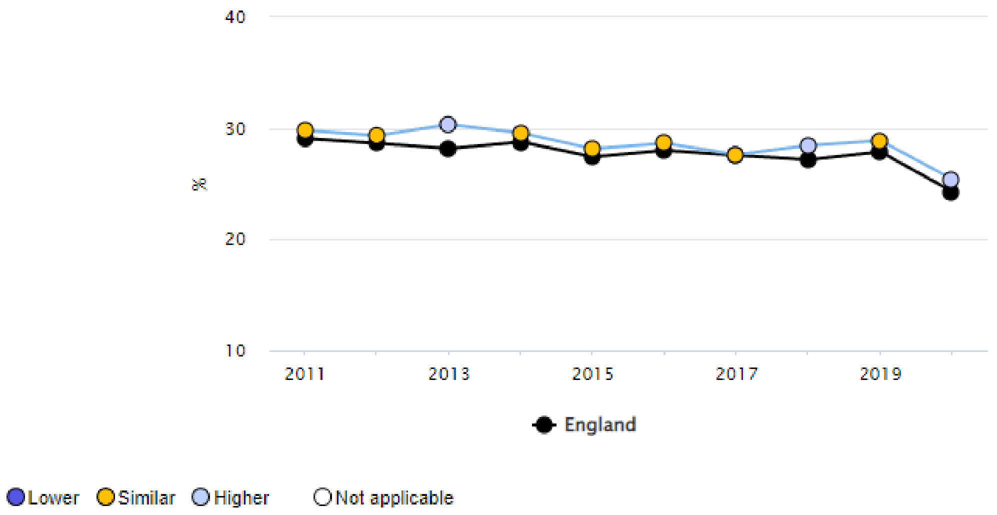


Source: Leading causes of death UK: 2001 to 2018, ONS, 2020

3.6.1. Cancer

In 2020, 25.4% of deaths across all ages in Leicestershire occurred with cancer as the underlying cause (5). This is significantly higher than the England value of 24.3% as shown by Figure 25. There has been no significant change in this figure in Leicestershire since 2016, whilst a decreasing trend has been experienced in England.

Figure 25: Percentage of deaths with underlying cause cancer (all ages) (5)

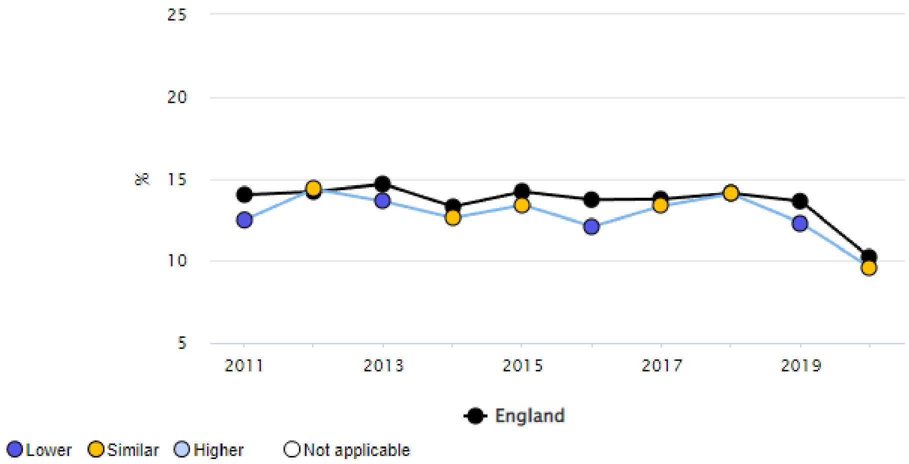


Source: OHID Fingertips, Palliative and End of Life Care Profiles

3.6.2. *Respiratory Disease*

In 2020, 9.6% of deaths in Leicestershire occurred with respiratory disease as the underlying cause (5). This is similar to the England value of 10.2% as shown by Figure 26. There has been no significant change in trend in either England or Leicestershire for the percentage of deaths with respiratory disease as the underlying cause from 2016 onwards.

Figure 26: Percentage of deaths with underlying cause respiratory disease (all ages) (5)

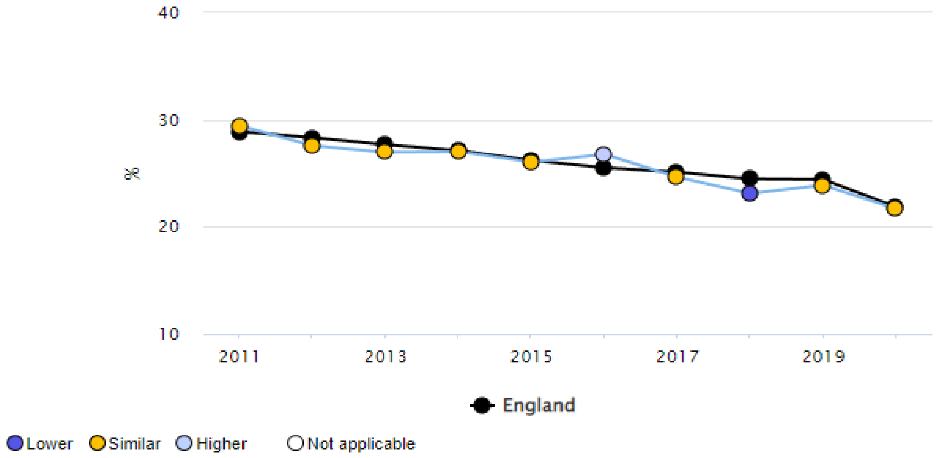


Source: OHID Fingertips, Palliative and End of Life Care Profiles

3.6.3. *Circulatory Disease*

In 2020, 20.7% of deaths in Leicestershire occurred with circulatory disease as the underlying cause (5). This is similar to the England value of 21.8% as shown by Figure 27. Both Leicestershire and England have shown a decreasing trend in the percentage of deaths with underlying cause circulatory disease from 2016 onwards.

Figure 27: Percentage of deaths with underlying cause circulatory disease (all ages) (5)



Source: OHID Fingertips, Palliative and End of Life Care Profiles

3.7. Bereavement support

To enhance our understanding of the needs and experiences of local people, an online survey was conducted by Leicestershire County Council. Of those who responded, 34 people had both undergone a bereavement within the last 3 years and identified Leicestershire County as the primary location to which their experiences related. These individuals were asked to reflect on the bereavement support that they had received, with the results outlined below in figures 28-35 (note that this was a self-selected sample, and so may not be representative of experiences across the county).

Figure 28: To what extent are you satisfied with the formal emotional support that you may have received?

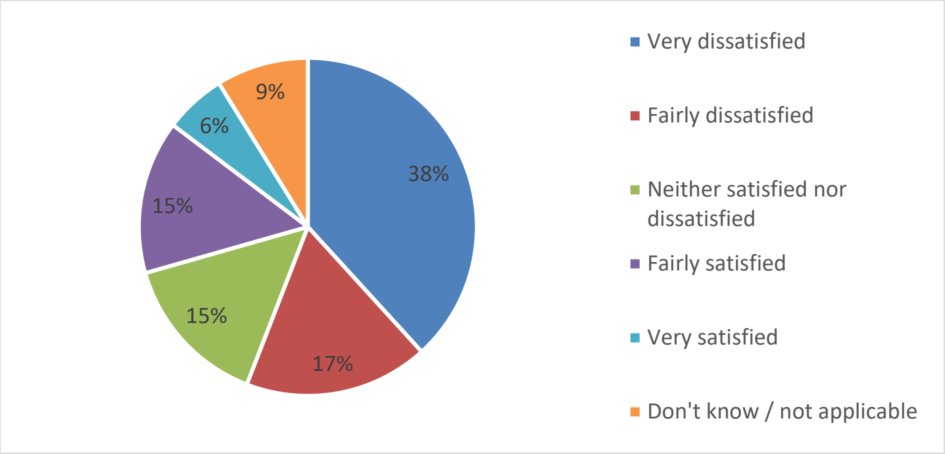


Figure 29: To what extent are you satisfied with the formal financial support that you may have received?

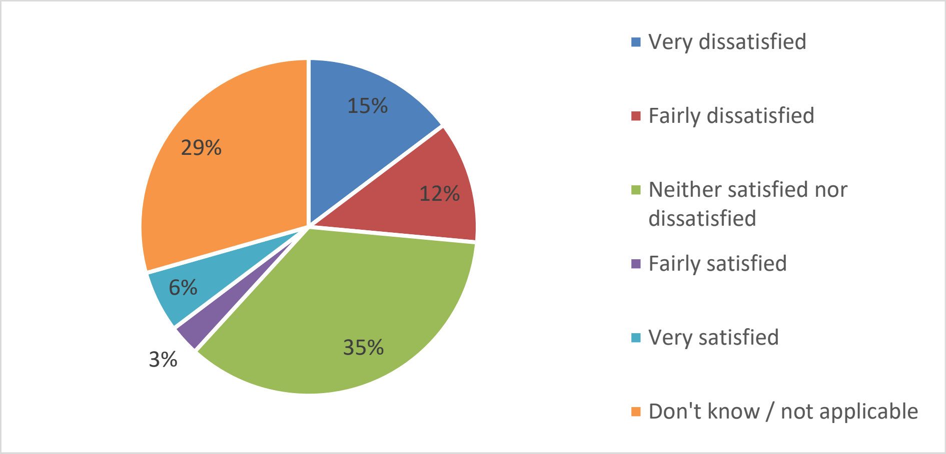


Figure 30: To what extent are you satisfied with the formal social support that you may have received?

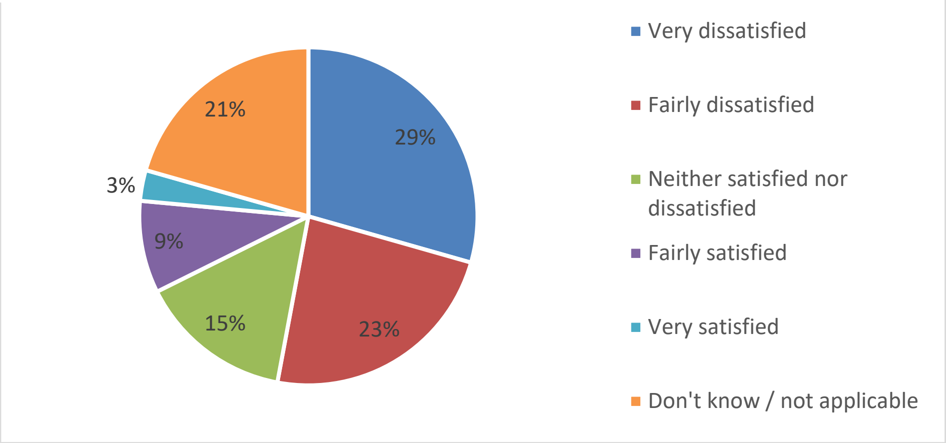


Figure 31: To what extent are you satisfied with the formal practical support that you may have received?

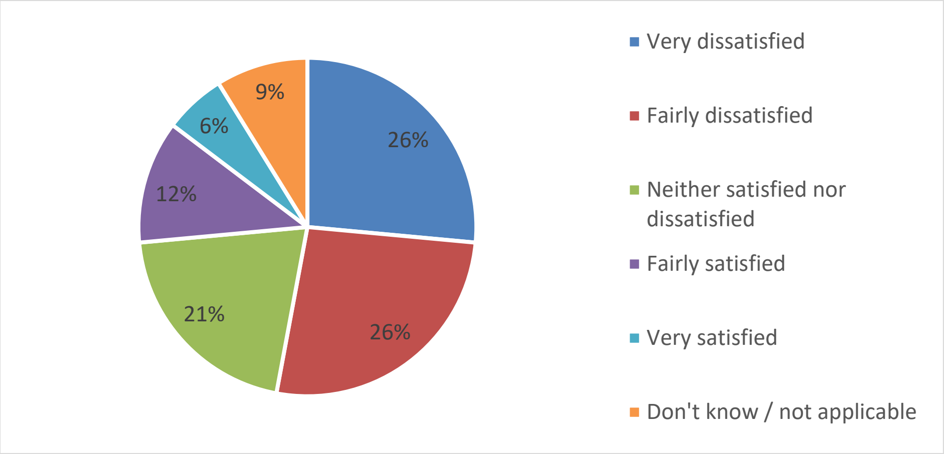


Figure 32: I am happy with the overall level of support that I received prior to my loss. (asked of the 28 whose loved one experienced an expected death)

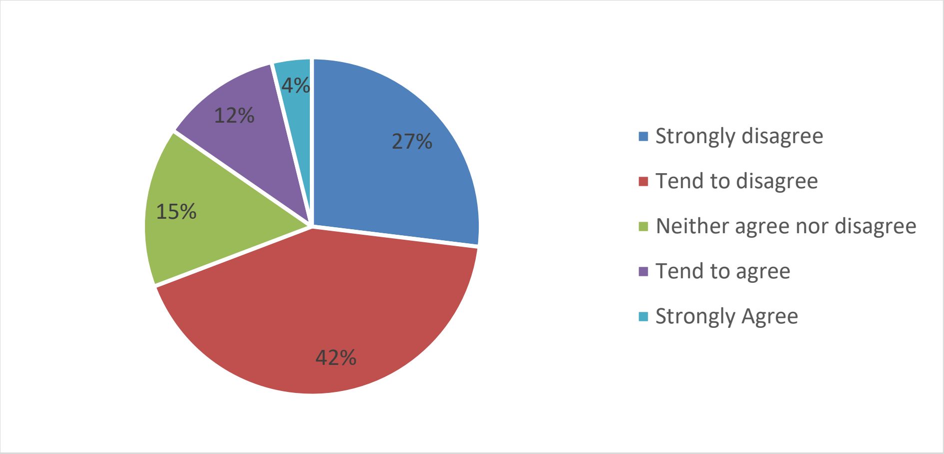


Figure 33: I am happy with the overall level of support that I received following my loss.

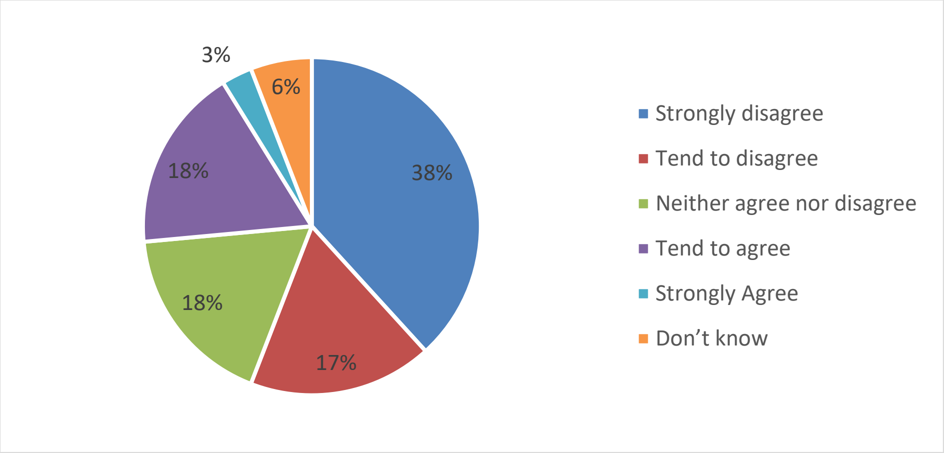


Figure 34: I had a good understanding of the support services available to me.

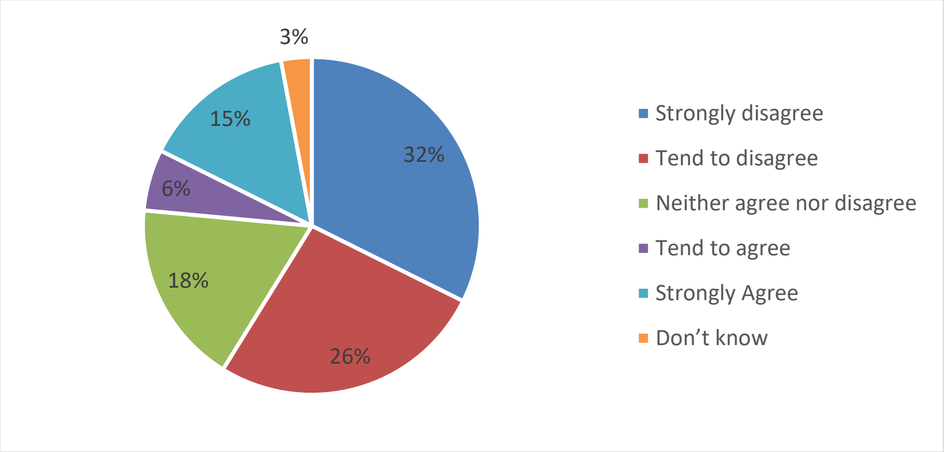
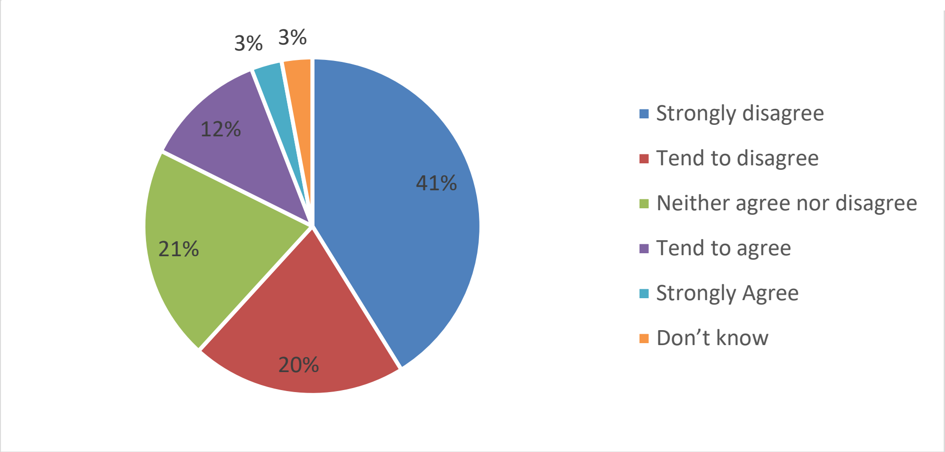


Figure 35: It was clear how I could access support services



Respondents were also asked which aspects of care and support they felt currently worked well, and which need to be strengthened and developed further. Some reported positive experiences of receiving support from their GP and from the hospice where their loved one passed, but the form of support most frequently spoken well of was that provided by family and friends. For many, this informal support was unfortunately all that was received. Indeed, many respondents told us that they had not received any bereavement support. This was not due to their feeling it was not needed, but rather its lack of availability. One respondent for example reported contacting multiple bereavement services to ask for help but never receiving a response.

A common theme was that people didn't know where to look for information regarding available services and how to access them. Some turned to their GP, and whilst many were pleased with the support they provided, others were less positive. Being unable to see a known GP was cited as a barrier for having honest discussions about sensitive topics. Yet others have sought bereavement counselling and whilst this was spoken highly of, people identified long waiting lists (one respondent cited 15 months) as a clear barrier to accessing timely help.

By having a lack of routine follow up after the death of a loved one, some respondents reported feelings of abandonment and being forgotten. Individuals are made to actively seek help, which whilst challenging at the best of times, can be particularly difficult following a traumatic event when even day to day activities may be difficult to undertake. In addition to receiving help in identifying services, respondents identified that they wanted help to access them rather than just being provided with a leaflet or directory.

Quotes provided by respondents:

"The support we received from the local GP really was amazing and they couldn't of done enough for us! Although even when they tried to help us access the services promised to us we were still refused"

"I contacted various bereavement services, Ive emailed and left telephone messages. I have heard nothing back from any of them. I got more support when my cat died."

"Counselling probably saved my life, but it wasn't formally offered."

"All of the support is geared towards short-term intensity, with seemingly very little in the medium and long term when the extended shock of a sudden death has faded."

"where to go for support? contact this number to discuss, visit this centre to discuss, here is what can be provided either from the system or outside. hosting a webpage or handing out a leaflet is not providing practical support and solutions. that's advertising and telling, not communication."

"If you are strong enough to reach out, there is some support available. However, it the is ones who don't/can't reach out who are the most vulnerable, and absolutely no one followed up on aftercare after my loss."

"I started asking for support 12 months ago. All I have had is the offer of stronger antidepressants. I am STILL on the waiting list for counseling. We should be offering immediate counseling, even if it's just telephone or on line. There should be a guide pack (up to date and accurate) on 'What to do when a loved one dies'."

"I eventually sort help with a GP, but was unable to see the GP I wanted. Was just given a information sheet so I could contact another group. Didn't take this up, as wanted to be able to have had support at time of death, and also to talk with someone I knew."

"any kindness or support would have been welcomed - even - how are you?"

3.8. Informal carers

A review of deaths that either occurred in UHL or PLT, or within 30 days of discharge from UHL, found that a common theme was of families and carers struggling to cope with the care of their relative (82). To enhance our understanding of the needs and experiences of local people, an online survey was conducted by Leicestershire County Council. Of those who responded, 22 people have experience being a carer for a loved one nearing the end of life, and identified Leicestershire County as the primary location to which their experiences related. These individuals were asked to reflect on the carer support that they had received, with the results outlined in figures 36-39 (note that this was a self-selected sample, and so may not be representative of experiences across the county).

Figure 36: I received sufficient support / training, such that I felt well equipped to support someone near the end of life.

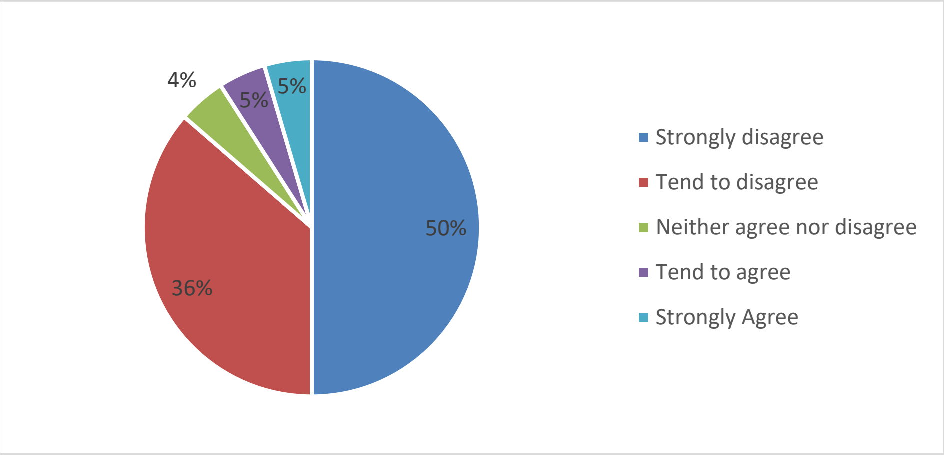


Figure 37: I received sufficient financial support to meet additional costs of being a carer.

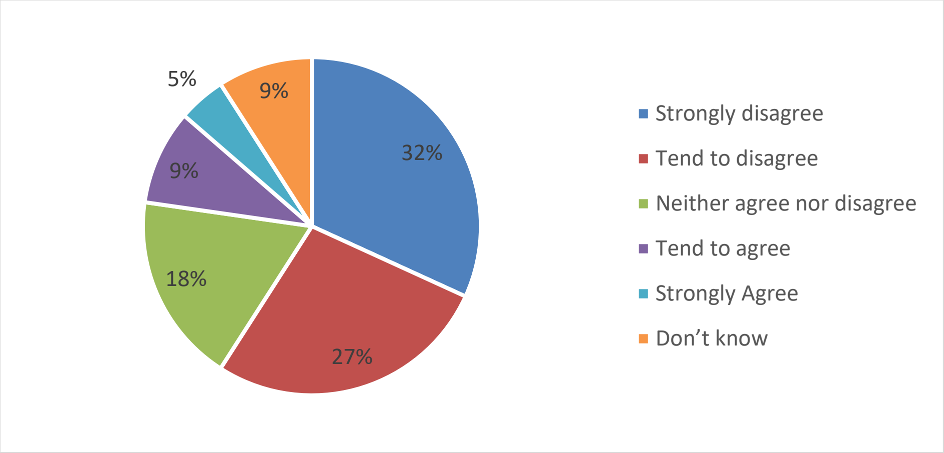


Figure 38: I received sufficient support to be able to take respite care.

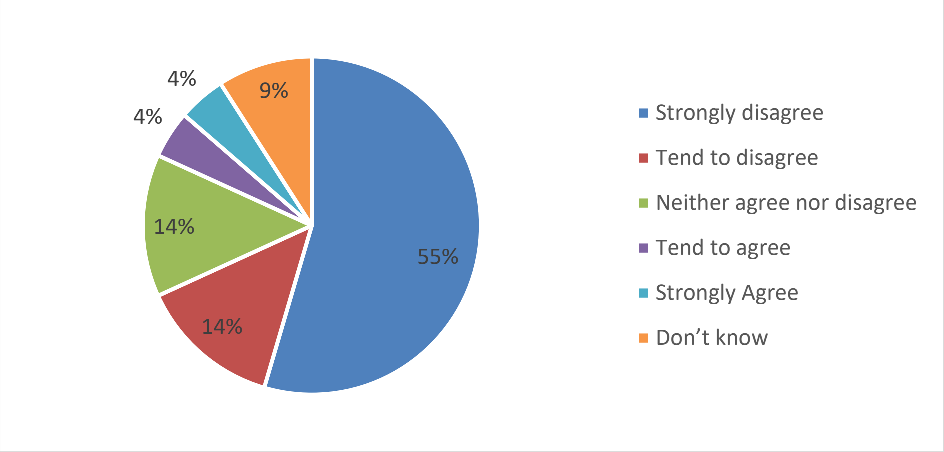
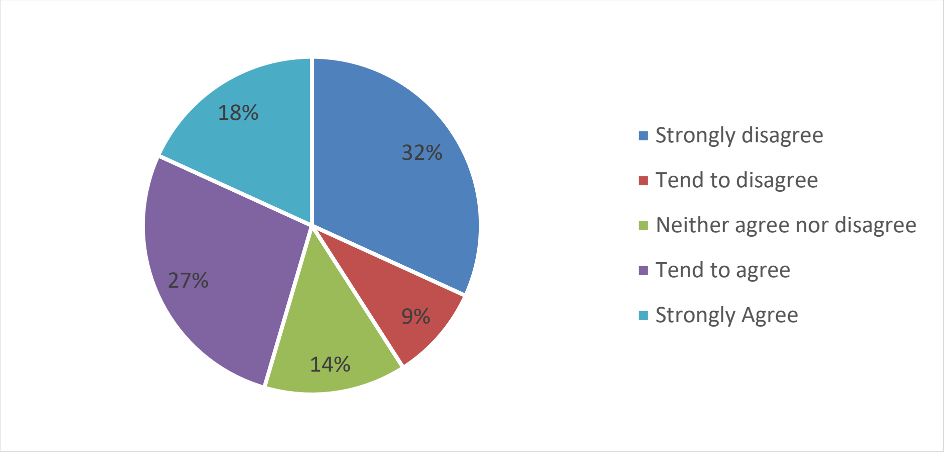


Figure 39: I had a good understanding of what to expect as the person I cared for neared the end of life.



Respondents were also asked which aspects of care and support they felt currently worked well, and which need to be strengthened and developed further. The majority of respondents told us that they received very little if any support whilst undertaking their caring role. Many communicated a sense of being abandoned and forgotten by services, as they were left to care for their loved one alone and without adequate advice or training to support them in the practicalities of that role. It was suggested that having someone to check-in on them occasionally and ask how they were coping would have been appreciated, in addition to being provided with greater information about how to administer medications (especially when discharged from hospital), move and transport their loved one, and about what to expect as their condition progresses.

Informal carers also felt that services aimed at supporting them and their loved ones are disjointed and would benefit from improved coordination. It was felt that there lacks a single point of access by which services can be sought, and that more should be done to improve access to information.

Where respondents had managed to access services, they often fed back positively on these. A strong relationship with the district nursing team built through continuity of care was appreciated by one, whilst others recognised support received from LOROS and the Support for Carers Project.

Quotes provided by respondents:

“Communication between palliative care, district nurse and gp teams needs improving. Support and guidance for us as the informal carers who were looking after our loved one was non existent and we were pretty much left floundering which meant that we were unable to provide suitable care as we didn't know what to do or what to expect. It was a pretty traumatic experience”

“Each gp surgery should have just 1 or 2 doctors doing EOL home visits, I was given drugs to give [them] for pain, as and when??? I felt like a dealer administering these strong pills, it worried me, how much to give”

“Our loved one did not really want fuss or outside help but we were not able or capable of providing everything that was needed. However, because our loved one didn't want assistance we were basically left on our own. No one sat us down and prepared us for what to expect and what we could do to help which meant the dying process was harder for our loved one and for us. This was not fair as people must have known how difficult it is to care for someone who is proud anyway so extra support/guidance for us would have been very much appreciated. My remaining parent virtually destroyed their own health trying to care”

“Someone should take you aside, and explain what happens, the BOX in the kitchen, the loneleness the long nights, NURSES GP whoever say I will see what I can do, and you neceer hear back, or you wait in because they promise to phone and never do, NOBODY asked me how I was”

“Better communication between NHS departments. Better communication between family and NHS. If McMillan are going to provide a service instead of the NHS they need to provide it. No I don't need a hug I need someone to stop my husband vomiting and being in pain. Perhaps recognise people get ill at the weekend?”

“Nobody sat and talked to me, [my parent] came home from hospital, I moved in with [them], it was hard”

“We were sent home from hospital with a bag of drugs including midazolam with no instructions whatsoever. We had no idea what would happen. Is this not the problem. You are asking what went well. It was woeful, disorganised and chaotic”

“I felt the [hospice] staff all allowed me to be a family member and relax with her care needs. They helped me to feel able to do this.”

“As a carer and a cared for person you become invisible. You become worthless”

“It is not always easy to access help and know where to go. There are so many different agencies involved that it is confusing, especially at such a difficult time. I do not always know what each agency knows so that I have to explain our situation to each person who comes to help.”

3.9. Staff working in end of life and palliative care roles

To enhance our understanding of the needs and experiences of local people, an online survey was conducted by Leicestershire County Council. Of those who responded, 36 people work to deliver health and social care in Leicester, Leicestershire, and Rutland. Respondents’ roles were varied, including working in different sectors and with different age groups. These individuals were asked to reflect on the support that they receive to undertake their role, with the results outlined in figures 40-44 (note that this was a self-selected sample, and so may not be representative of experiences across the county).

Figure 40: I receive sufficient support and training, such that I feel well equipped to support someone near the end of life.

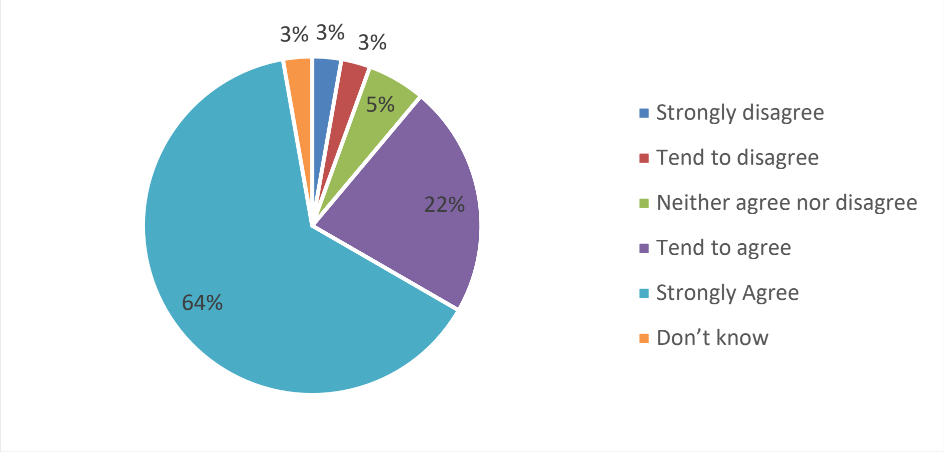


Figure 41: I have access to the resources and equipment necessary to be able to deliver high quality and effective care.

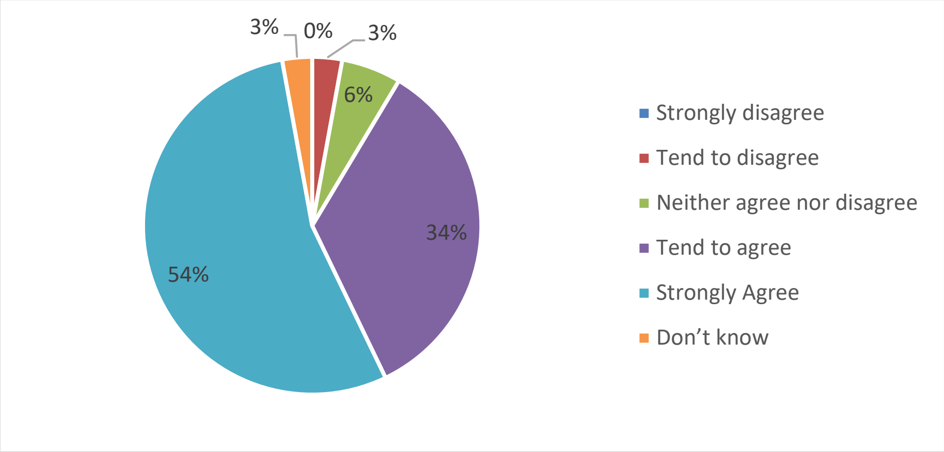


Figure 42: I have enough time with each person in the end of life stage, to be able to provide them with the care they need.

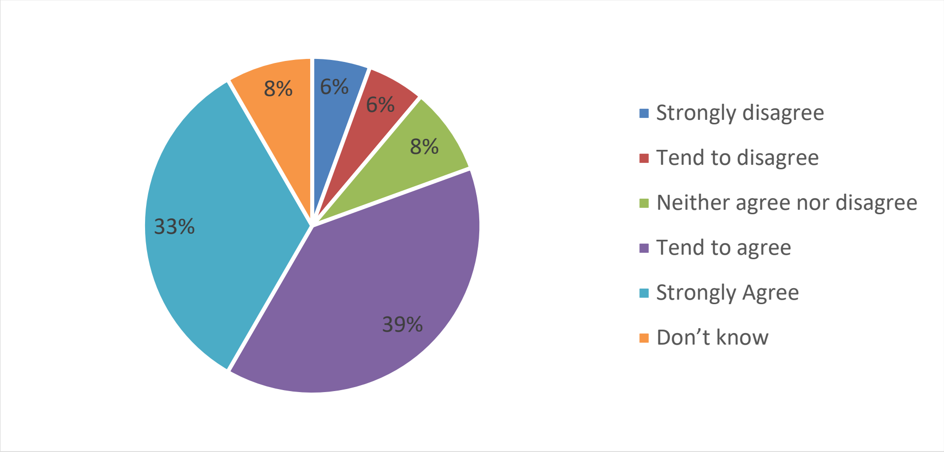


Figure 43: I have a good understanding of what to expect as the people I care for approach the end of life.

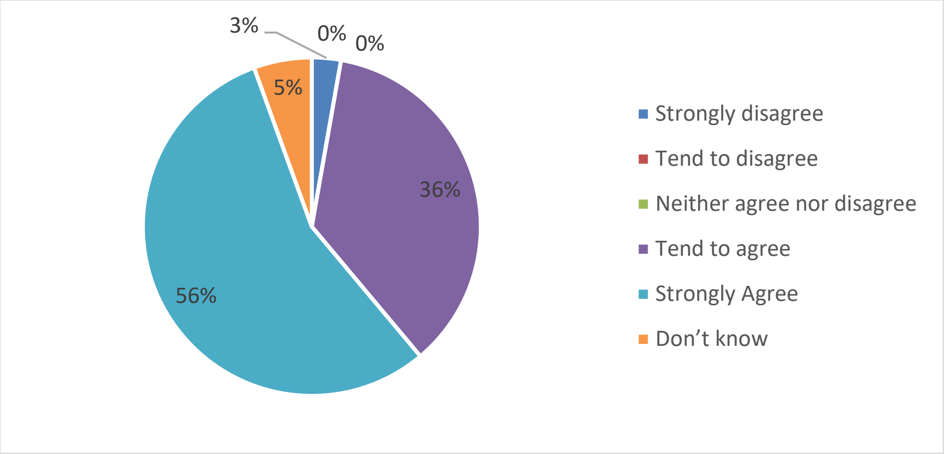
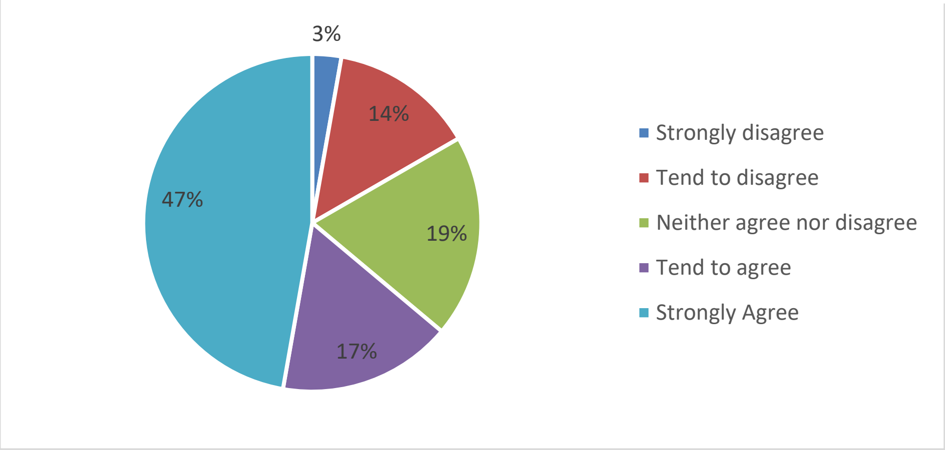


Figure 44: I am happy with the amount of emotional support that I receive.



Respondents were also asked which aspects of their role they felt currently worked well to support them in delivering the best care possible, and which need to be strengthened and developed further. Replies were positive overall, with many praising the teams they work with in providing support. This, combined with having access to the necessary equipment, being able to deliver person-centred care, and working closely with other services were cited as further strengths of existing services by staff.

Many also felt that they received adequate training to support them in caring for those near the end of life, but this wasn’t universally accepted. Those whose primary role is in a specialty other than delivering palliative care in particular felt that they would benefit from additional training and support.

A further challenge cited was a large and increasing caseload of patients. It was felt by several that current staffing does not provide enough capacity to allow sufficient time with each patient, and that the workforce would benefit from expanding. Out of hours services were also specifically mentioned in this context.

Quotes provided by respondents:

"I am supported by a friendly, helpful team that I can call upon at any time should I need support."

"Sometimes not enough time to reflect due to workload."

"Carers need time to both support the individual person and time to process the loss as individuals themselves."

"Obviously COVID has reduced training opportunities and the whole ethos of the [work setting] as far as visiting is concerned. Due to current concerns about increasing COVID numbers it is understandable that restrictions are still required. However as soon as it is safe to do so the services and flexible arrangements for those receiving end of life care needs to return to those pre 2020"

"Outreach, although I see folk from all ethnicities I do wonder if more work can be done to get into ethnic minority communities, I'd expect the see more folk based on the percentages in Leicester."

"I feel that the main gap in services is that if a person wants to die at home, clinical services overnight are not available at a level which is required or in a timely manner"

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4. How does this impact

4.1. Impact on the individual

When palliative care is delivered well, it is associated with improved patient outcomes including pain and symptom management, improved communication, higher satisfaction with care, improved quality of life, and reduced healthcare costs (84). Many of these features are closely intertwined through pathways such as reduced emergency hospital admissions and length of hospital stays (84). An important component in achieving these outcomes is the enabling of timely communication of what is important to the individuals so that they can make meaningful decisions about the care they receive. This helps ensure that people's priorities are recognised and met where possible.

4.2. Impact on family and friends

The loss of a loved one is a traumatic event. Between 6-20% of adults experiencing a loss develop complicated grief symptoms, described as painful and persistent reactions associated with impaired psychological, social and daily functioning (85). Receiving bereavement support can result in improved quality of life measures, reduced anxiety and depression symptoms, and improved social connections (85).

4.3. Impact on Carers

Carers play an important role in supporting patients at the end of life, allowing care to be delivered at home, and preventing hospital admissions. This is a resource intensive role, that places physical, emotional, and social burdens on the individual. They therefore require support in two areas:

- As carers providing support to patients – this includes ensuring they have the knowledge, skills and equipment necessary to fulfil their caring role.
- As individuals whose own health and wellbeing need to be protected.

4.4. Impact on health and social care

A large share of healthcare expenditure occurs in the last months of life, and so an understanding of the costs and benefits of care that is delivered during this period is beneficial (84). In the last two years of life, around £121 million is spent on hospital services for decedents in Leicester, Leicestershire and Rutland. Urgent service events account for around two-thirds of this (6). Spend per decedent on hospital services was around £15,000, which is significantly lower than the Midlands average of £15,800 (6). The strongest evidence of cost-effectiveness relates to home-based interventions. Home-based services may reduce resource use and costs, and improve pain management and increase death outside of hospital (84).

5. Policy and Guidance

This chapter provides an overview of key policies and guidelines relating to End of Life Care.

5.1. Ambitions for Palliative and End of Life Care: A national framework for local action 2021-226 (86)

The aim of this document is to provide a framework with which to improve palliative and end of life care. It was produced by the National Palliative and End of Life Care Partnership, which comprises of national organisations that have experience of, and responsibility for, end of life care. The framework sets out six ambitions for palliative and end of life care, which are:

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

To compliment this framework, the NHS England & NHS Improvement Palliative and End of Life Care team have worked to develop a self-assessment tool that was initially created by the Cheshire & Merseyside Palliative & End of Life Care Clinical Network. This tool provides a self-assessment framework which supports localities to determine their current level of delivery against the six ambitions for Palliative and End of Life Care.

5.2. Treatment and care towards the end of life: good practice in decision making (87)

This guidance document was written by the General Medical Council (GMC) and is primarily addressed to doctors. It is however recommended that it may benefit other staff working to deliver end of life care, and also patients and the public by supporting them in understanding what to expect of their doctors. It provides a framework to support staff in meeting the needs of their patient towards the end of life, through advice on a range of topics. These include supporting patients who lack capacity, advance care planning, understanding the role of relatives and those close to the patient, and care after death. The framework also contains a section that focuses on aspects of care as they relate specifically to neonates, children, and young people.

5.3. NICE Guidelines

NICE guidelines are evidence-based recommendations for health and care in England. They seek to support health and social care professionals to prevent ill health, promote and protect good health, improve the quality of care and services, and to adapt and provide health and social care services (88). Guidelines with a focus on end of life and palliative care include:

5.3.1. End of life care for adults; NICE Quality Standard (89)

This quality standard covers care for those aged 18 and over who are approaching the end of life. It includes people who are likely to die within the next twelve months, people with advanced, progressive, incurable conditions, and people with life-threatening acute conditions. Topics covered in the standard include the identification of those nearing the end of life, advance care planning, coordinated care, and out-of-hours care. It also covers support for their families and carers.

5.3.2. Care of dying adults in the last days of life; NICE Guideline (90)

This guideline covers the clinical care of those aged 18 and over who are in the last two or three days of life. It seeks to improve end of life care for people by emphasising the importance of communication and including patients and their loved ones in decision making, and of maintaining comfort and dignity. It also covers how to manage common symptoms without causing unacceptable side effects. The guideline is specifically aimed at those who do not have specialist level training in end of life care.

5.3.3. End of life care for adults: service delivery; NICE Guideline (91)

This guideline covers the topic of organising and delivering end of life care services, with the aim of ensuring that people have access to the care they want and need in all settings. It advises on service models for care in acute settings by disease-specific specialists and their supportive services, and in community settings by primary care or specialists in palliative care. It is intended that this guideline is used alongside the NICE guideline on care of dying adults in the last days of life (section 5.4).

5.3.4. End of life care for infants, children and young people with life-limiting conditions: planning and management; NICE Guideline (22)

This guideline covers the planning and management of end of life and palliative care for infants, children, and young people (aged 0 to 1 7 years) with life limiting conditions. It aims to involve young people and their families in decisions about their care and improve the support that is available to them throughout their lives.

5.4. Inspection framework: NHS acute hospitals and independent health; CQC (92)

The CQC are responsible for monitoring, inspecting, and regulating all care providers in the UK. They inspect and regulate services to make sure that quality and safety standards are met, and publish their findings. This framework is used by inspectors to explore key lines of enquiry when assessing services in NHS and independent hospitals.

6. Current Services

6.1. Delivering care at the end of life

6.1.1. Adult Services

Integrated Community Specialist Palliative Care Service

The Integrated Community Specialist Palliative Care service is a team comprising of nurses and healthcare assistants (HCAs) from LPT and LOROS. They care for those with life-limiting illnesses who have complex palliative care needs (especially pain and symptom management). They may become involved in the care of an individual when an appropriate intervention has failed to control symptoms, when symptoms are escalating, when patients or families require psychological and spiritual care, or if there are other problems that other healthcare professionals are unable to manage. Support is delivered via multiple formats, including telephone advice, one-off assessments, and ongoing management and personal care. Access to this service is via referral by a healthcare or social care professional, and patients or carers can re-refer back into the service via the Single Point of Access (93).

Community Nursing Services

The Leicestershire Partnership Trust (LPT) core Community Nursing Service are an integrated and diverse, skilled team of professionals central in the management and care of patients with advanced progressive illness, requiring palliative and end of life care in the home environment. Care is provided throughout the city and county with teams working out of 8 Community Nursing Hubs. The service is available 8am-10pm every day, with care outside of these hours delivered by the "Out of Hours Community Nursing Service" described below.

Palliative and end of life care is an intrinsic part of community nursing and in addition to the practical and clinical delivery of care, the community team offer psychosocial, spiritual support and guidance to patients, families and carers. In 2021/2022, there were 3,729 accepted palliative care/ care in the last days of life referrals into the service (this does not include the referrals for complex, specialist palliative care as patients with specialist needs are seen by the Integrated Community Specialist Palliative Care Team).

Most end of life and palliative care is routinely planned within the nursing caseloads. However, patients and carers also contact the service for unplanned support, particularly in relation to symptom management. These referrals are recorded separately and are additional to the number above. The nationally agreed target for an urgent community response (UCR) is 2 hours and the target for patients to be seen within this timeframe set nationally at 70%. In April 2022 the core community nursing team received 119 urgent referrals for end-of-life care and achieved an overall compliance rate of 73.4%.

The Community Nursing Service have access to five palliative suites for patients at the end of life. These are located in Loughborough, St Lukes, Coalville, Hinckley & Bosworth and Melton Community Hospitals. If these are not available, then an inpatient bed located in a general side-room is used where possible.

Out of Hours Community Nursing Service

During the hours of 10pm and 8am, community nursing is provided by Derbyshire Health United. This is not a dedicated end of life service, but covers all queries. There is one roaming nurse covering Leicester, Leicestershire, and Rutland, predominantly managing pain relief and catheter related issues.

University Hospitals of Leicester Palliative Care Service

The Hospital Specialist Palliative Care Team consists of a hospital-based team at the Royal Infirmary, General and Glenfield hospitals (94). They deliver care to adults with palliative care needs within the hospital and also in the outpatient setting. Referrals are taken for patients with difficult symptoms, psychological distress, and those who are dying. These are usually made by the hospital ward team, who will remain responsible for the person's overall care.

Leicestershire and Rutland Hospice (LOROS)

LOROS is a local Leicester, Leicestershire and Rutland charity who primarily provides specialist palliative care for those over 18yrs, with complex problems who are suffering from a terminal illness when cure is no longer possible.

LOROS offers a consultant-led multi-disciplinary service, providing symptom management, psychological support and co-ordination of care for adults with complex palliative care needs that cannot be adequately managed by their usual community/acute healthcare professionals.

In addition, LOROS also provides a range of palliative and supportive care services which helps the patient and their family to cope with their condition through their illness or death and into bereavement.

Referrals are generally made by a GP, hospital consultant or hospital palliative care team, or are facilitated by a community nurse specialist, with the exception of Day Therapy drop in. Patients must be registered with a GP within Leicester, Leicestershire or Rutland.

The Hospice is based at Groby Road Leicester and provides care for over 2,500+ people each year.

There are 31 inpatient beds, of which 19 are single rooms. Short-term specialist care is provided for patients with complex issues (pain and symptom control) and care in the last days of life. Based on need, patients can be admitted both in and out of normal working hours, including weekends and bank holidays. Patients identified with 'urgent needs' will be admitted within 48hrs (dependent on bed availability).

Day Therapy is provided 9.30am to 3.30pm, 4 days a week at Groby Road Hospice. The service is provided by qualified practitioners, support staff and a diverse team of volunteers. There is also access to medical, enablement and chaplaincy support.

Additional services include:

- Outreach support in the patient's home - Clinical Nurse Specialist and Compassionate Neighbours
- Outpatient Clinics at the Hospice
- Palliative Consultant Domiciliary Home Visits (based on patient need)
- Complementary Therapy
- Counselling & Bereavement Support at the Hospice and in the Community

LOROS contributes to the education and training of its own and other health and social care professionals and of volunteers. The charity is also committed to research in order to improve the understanding and practice of palliative care.

Dove Cottage Day Hospice

Dove Cottage is a day care hospice located in Stathern, Melton, to which guests usually go for one day a week (95). It is open three days a week, and provides approximately 3,700 day care places each year. Referrals can be made by health professionals, guests or their families. Guests must be well enough to attend day care and travel to and from the hospice, and places are not routinely offered to people in residential care, with a primary diagnosis of dementia, learning disability or acute mental illness.

Guests can participate in games, crafts and wellbeing activities, and also have access to skilled nurses, chaplaincy support and complementary therapies. Help is also offered to families and carers such as bereavement support, a Family Support Group, and regular groups for those living with dementia.

Palliative Care Consultants Advice Line, Domiciliary Medical Home Visits and Community Support

There is a dedicated daily advice line (M-F) for nurse specialists and other community staff including GPs to call for medical advice and support. LOROS consultants and SpRs can undertake home visits for those too unwell to come to clinic who need a specialist medical assessment.

6.1.2. Paediatric Services

Diana Service

Provided by the Leicestershire Partnership Trust, the Diana service provides a comprehensive community care provision by a multi disciplinary team consisting registered nurses, health care workers, respiratory specialists, physiotherapists, a trained play specialist, pre and post bereavement and counselling skills, and registered Macmillan nurses. This service supports children and young people aged 0-18 with health care needs and their families. For a child or young person at end of life, a 24/7 on-call in the community will be commenced. The Diana service is delivered by a small team in LLR, and due to the complex and time consuming nature of providing end of life care and support, they have capacity to accept a maximum of two children or young people for 24/7 on-call provision.

The service provides planned face to face visits and telephone support, visiting when a child's symptoms change and offer support to the family when a child dies. Although the Diana Service is a nurse led service, the Diana Palliative Care Lead Nurse works alongside a Community Pediatrician for 4 hours each week to manage a discreet caseload of children and young people requiring palliative care to parallel plan, develop and maintain CYPACP, completion and updates of ReSPECT and liaison with other professionals to ensure care is planned to enable changes in care requirements.

Pre and post bereavement support is provided by the child and family support service in Diana for children and young people with life limiting and/or life threatening conditions as well as their siblings and close family members.

Rainbows

Rainbows Hospice for Children and Young People in Loughborough provides end of life care, symptom management and short breaks from birth to 25 years of age. They offer care at home, in the hospice or in hospital for children who are life limited or life threatened and also those who have long term ventilation. Care and support are also offered for all the family.

The hospice consists of a large multidisciplinary palliative care team including family support, complementary and music therapy as well as experienced nurses and carers. They can also offer 'step down' care between hospital and home.

Bodies Hodges

Bodies Hodges supports families bereaved of a child across Leicester, Leicestershire and Rutland by providing a range of services including early therapeutic support to newly bereaved families in their own home and work with siblings. The service also raises awareness of the facts about organ donation and runs an organ donation education program for schools and businesses.

Laura Centre

The Laura Centre provides bereavement support for parents and children on an individual basis as well as offering group work and access to alternative therapies. The service also offers a range of training courses aimed at professionals that may come into contact with families or children facing bereavement.

6.1.3. Condition Specific Services

Dementia Services

There are services covering Leicester, Leicestershire and Rutland which seek to support both those with dementia as their condition progresses and they approach the end of life, and their loved ones.

- Mental Health Services for Older People (MHSOP) in Patient Assessment – This aims to enable people to remain at home, or their usual place of residence, for as long as this is their preferred place of care. The service supports the reduction in admissions and readmissions to specialist inpatient care.

- MHSOP Community Team - Provides multi-disciplinary assessment (with input from medics, nursing staff and allied health professionals, dependent on the patient's need) and interventions for patients with moderate to complex mental health needs requiring medium to long term interventions.

- MHSOP Care Homes - The service provides intensive multidisciplinary assessment and intervention for patients within care homes who have Dementia who are demonstrating behavioural and psychological symptoms that may lead to breakdown of placement leading to admission to hospital.

- Admiral Nurses - Support family carers to gain the necessary skills to assist with dementia care, promoting positive approaches in living well with dementia and improving the quality of life for everyone involved.

- Community Support Age UK – Provide one to one support to maintain social contacts, pursue hobbies. Provide day breaks at day centres, provide activities and classes suitable for dementia patients, trips and outings. provide specialist classes to help improve mood and memory such as, singing for the brain, dance for dementia, art for dementia, seated exercise, and memory cafés.

- Dementia carers Support Age UK - Dementia advisors support friends and family of those with dementia with information and advice about navigating local services and applying for benefits.

Sue Young Cancer Support

Offers counselling, befriending services, disease specific support groups and complimentary therapies to anyone affected by cancer in Leicestershire and Rutland. This includes people with a diagnosis, their family members, and carers. Individuals can self-refer or be referred by a GP (96, 97).

6.2. Bereavement Support

UHL Bereavement Support Service

The bereavement support service seeks to contact the bereaved next of kin of all those who die in a UHL Hospital. This is a multistep process, beginning with medical examiners (MEs) who (unless the death is due to be taken for investigation by the Coroner) phone the bereaved to ask if they understand the cause of death and if they have any questions about care. In 2021/22, 96% of bereaved relatives were spoken to by the ME in this way.

The second stage involves the bereavement support nurses attempting to make verbal contact with bereaved relatives within 8 weeks of the death. In 2021/22, 73% of relatives were spoken to in this way. The purpose of these calls is to identify any unmet bereavement needs and to provide relatives with an opportunity to raise questions or concerns. Where unable to contact verbally, a letter is sent to the relative instead.

LOROS Bereavement Support and Community Bereavement Hubs

The Family Support team liaise with families following a patient's death on the inpatient ward. They provide information and support and ensure patient's property is returned to a family member. They liaise with the funeral directors to ensure a smooth transition from the hospice.

In addition, as part of their growing community support, they have a number of LOROS Bereavement Hubs which offer weekly drop-in sessions supported by trained bereavement volunteers. These drop-in sessions are available to anyone over 18yrs of age, who has been bereaved. As of April 2022, there are 5 based in Leicestershire and 2 in Rutland. The service also has trained volunteers who can offer bereavement support in peoples own homes.

If people are experiencing complex grief they can be referred to the counselling service based at the hospice. This service offers short term therapeutic intervention specifically focused on supporting clients post bereavement.

Local Bereavement Support Groups

There are also multiple local bereavement support services for people living in Leicestershire as outlined in the table below (96):

Table 3: Local Bereavement Support Services

Organisation / Group Name	Location	Description
Hinckley Support	Hinckley	A monthly luncheon group

Al-Anon Family Groups	Hinckley	Provides help and support for families and friends of those who have died of alcohol related illness
Birstall Bags	Charnwood	A support group for those who have been bereaved through a life-limiting illness that meets twice monthly.
The Compassionate Friends	Varies based on location of bereaved parents registered	Bereaved Parents provide support for other parents and siblings after the death of a child.
Contact the Elderly	Blaby, Enderby & Hinckley	Monthly group that connects lonely and isolated people aged over 75 years with volunteers for afternoon tea.
Haven Counselling Centre	Ashby and Loughborough	Counselling for bereavement, stress and depression.
The Jolly Dollies	Leicestershire	A social network for widows, with groups across the country and in Leicestershire.
Leicestershire AIDS Support Services	Leicester	Offers a free and confidential service, including bereavement support, for people affected by HIV / AIDS in Leicester, Leicestershire and Rutland.
Leicester Counselling Centre	Leicester	A charity that provides counselling to people in Leicester, Leicestershire and Rutland for a nominal charge.
New Beginnings	Melton	Bereavement support and social group for all ages.
New Chapter	Charnwood	A social group for people of all ages that have experienced a bereavement.
The Shama Centre	Leicester	Offers free bereavement counselling support, with a special emphasis on minority ethnic communities.
The Victim Support Group	Leicestershire & Rutland	Offer emotional and practical support to those who have been bereaved due to a crime that has been committed.

Source: Dying Matters Leicester, Leicestershire and Rutland

6.3. Support for Informal Carers

6.3.1. Practical, social and emotional support

Support for Carers Leicestershire

This service is run by Voluntary Action South Leicestershire and seeks to support carers throughout the county (98). Their service is free and includes:

- A telephone advice line
- Carers support groups
- Telephone befriending service
- Buddying scheme
- Care for carers
- Online forums
- Free courses for carers

Providing Care

A Leicester, Leicestershire and Rutland resource for carers that includes information about available courses and training (99).

The Carers Centre

The Carers Centre supports people looking after a relative, friend or neighbour with care needs across Leicester, Leicestershire and Rutland. They host a range of online social events, training and support groups (100).

Carers Choir

A self-funded support group for carers and former carers that meets fortnightly in Lutterworth, Harborough (96).

6.3.2. Respite Care

In 2020, Leicestershire County Council became a partner organisation to Carefree to support carers seeking respite care. Carefree uses charitable funding to provide breaks for carers of usually 1-2 nights through hotel rooms that have been donated. Whilst individuals do not need to pay for care or accommodation, they must cover additional costs such as transport, food, and travel insurance. Carers can self-refer, but must be aged 21 or over, and must also be fulltime (35+ hours per week) unpaid carers (101).

Some providers and care agencies in Leicestershire also deliver flexible support at home to provide people with a break from carer. Some are eligible to be supported in this way through Adult Social Care as part of a person's carers assessment (101).

Local day activities may also be an option for some, including attending Dove Cottage Day Hospice (see section 6.1.1). Alternatively, short term care may be arranged by self-funding a place at a residential home (respite care in this form may be significantly more expensive than long term permanent care) (101).

6.4. Support for Staff

AMICA

Confidential emotional support and counselling for those employed by UHL, LCC, LPT, and LOROS. Employees can discuss any difficulties that they are faced with, including workplace stressors and personal issues. Support is delivered over the phone, with lines open 8.30am – 8.30pm every day (96, 102).

6.5. Information Services

Dying Matters in Leicester, Leicestershire and Rutland

The website **www.dyingmattersleicestershireandrutland.com** is dedicated to improving end-of-life experiences for people of all ages, their families and loved ones. It was initiated and is led by Dr Sarah Furness, Her Majesty's Lord-Lieutenant of Rutland.

The website offers detailed information on important topics surrounding dying, death and bereavement, including; end of life planning, caring for a loved one, living well with a long term health condition, what to do in an emergency, how to arrange a funeral and support with bereavement. The website also provides comprehensive lists of local health and care support contacts.

The website aims to serve as a sign-post and does not recommend any support providers or rate their service.

End of Life Care Task Force and Co-production in palliative and end of life care

The End of Life Care Task Force is a group comprising of commissioners, providers of health and social care, and voluntary service members. It seeks to define and plan to deliver a longer term End of Life Care pathway across the health and care system. One such piece of work that is being developed is a hub and spoke approach to take forward co-production in palliative and end of life care. This will aim to utilise existing groups and touch points (such as medical examiners and information centres) to build on current knowledge and expertise within end of life care. By delivering feedback from those with lived experience and existing data sources to one place in the system, a greater understanding of arising issues can be gained, and co-production projects identified and taken forward. This will also support a two-way flow of information. Such an approach will also allow organisations or individuals to join over time or withdraw should they no longer wish to contribute.

7. Unmet needs/Gaps

This section outlines the areas for improvement in current End of Life care and support provision in Leicestershire, based on the findings discussed thus far in this JSNA chapter. Whilst this section has been divided into different components of End of Life care and support, many of the themes and issues discussed are common to many if not all.

7.1. Advance Care Planning and ReSPECT

The importance of undertaking advance care planning early has been a recurring theme throughout this JSNA chapter. It has been shown that having conversations with those who are themselves approaching the end of life and their loved ones in a timely manner, makes it more likely that a person's wishes will be understood and followed. This in turn contributes to improved quality of care for individuals and those important to them. Despite this, as few as 9.7% of people have an advance care plan in place prior to their final hospital admission (11). Different factors are thought to contribute towards this low uptake.

The ReSPECT form is a summary of the management for someone at the end of life, referring specifically to the wishes of the person in a medical emergency. It is often completed in addition to the advance care plan.

As was highlighted in Section 2, it is often difficult to predict the course and length of the end of life stage. Non-cancer diagnoses for example often have more variable prognoses. Some populations meanwhile have less frequent interactions with healthcare staff, which leads to disease often progressing further before it is identified. It is also important not to overlook deaths that occur suddenly. In each of these instances, waiting until there is certainty about the person's condition before discussing their end of life preferences is too late. In many cases, patients are unlikely to be able to contribute meaningfully to these conversations as a result of their own poor health and distress, and services are unable to act in a proactive manner to support the wishes and decisions arising from these. More must therefore be done to not only support early identification of those approaching the end of life, but to also support these conversations taking place whilst individuals are healthy and well.

Evidence also suggests that whilst people report feeling comfortable talking about topics relating to the end of life, there is poor understanding of the options and services available. Indeed, in one survey, as many as 55% of those in the last years of life reported not knowing where to find information on how to plan in advance for care at the end of life (12). Whilst these resources do exist, it seems that there is a gap in terms of connecting people to them. Only with adequate access to high quality information, can people make informed decisions about their end of life care.

7.2. Utilisation and delivery of End of Life and Palliative Care Services

End of Life and palliative care often involves receiving input from multiple organisations and services. Whilst the quality of support received from these services once in receipt of care from them is generally rated highly, a common complaint is that they are difficult to access in the first place. We have again heard that people are unaware of the services which are available to them. As such, they are often unable to seek help from as early a time point as they could otherwise benefit from. This may then be exacerbated by long waiting lists, leading to their only receiving input for a short time towards the very end of their life.

It has also been frequently reported both nationally and locally, that services coordinate poorly with one another. The challenge here is twofold and appears to be a particular issue when patients move from primary to secondary care or vice versa. Firstly, an inability to access patient records from other services means that staff must often work with incomplete information. We have discussed for example how being unable to access an already completed Advance Care Plan can lead to inappropriate transfer to hospital by ambulance crews, and subsequent admission to a ward by the Emergency Department team. This not only results in negative experiences and outcomes for the affected individual and their loved ones, but also places additional pressures on staff delivering care.

The second challenge resulting from a lack of coordination is not having anyone with a complete overview and understanding of the persons’ needs. This risks services focusing solely on their own role and remit, and thus overlooking any needs of the patient which fall outside of this. Patients and their loved ones can again be uncertain as to who they should seek help from, must take time to navigate multiple services to find that which is most appropriate, and then again face lengthy waiting lists. It is therefore helpful if a named individual takes overall responsibility of the patients’ care, so that responsibility for coordinating services in this way doesn’t fall upon the patient and their loved ones during what is already a difficult and distressing period. Thus, in addition to coordination of care, continuity of care is also important. Improving the coordination of services in both these ways will support them in transitioning towards a more proactive rather than reactive approach to care, increasing the chance that the preferences of those nearing the end of life can be realised.

For children and young people, the challenges include nationally rising numbers of children and young people on end of life pathways with increasing complexity. Locally, this will require an evolution of wrap-around community services to keep up with demand. In Leicester, Leicestershire and Rutland, there is currently not a paediatric palliative care consultant which forms a minimum requirement in NICE guidance (22).

Finally, we have heard of challenges in accessing support out-of-hours. This is not only a matter of service users being unsure of how to access it, but also includes a lack of available services. Between the hours of 10pm and 8am for example, community nursing is currently limited to just one nurse covering the whole of Leicester, Leicestershire, and Rutland. When faced with uncertainty such as new onset of symptoms whilst unable to access advice and support, people are likely to present to hospital. Whilst this will be appropriate for some, others could be supported to stay at their place of residence if they were to receive timely input from community services. For children and young people, the existing out of hours service relies on nurses that are often due to be working the next day, impacting on service provision the following day if they are called out.

7.3. Support for those who are bereaved

Those who are bereaved have rated the level of support that they received poorly, particularly that in relation to their emotional, social, and practical needs. Once again, service users appear to be happy with the quality of care they receive once they are in receipt of it, but often find themselves unsure of what is available, facing uncertain referral routes, and made to join lengthy waiting lists. In addition to formal services provided by healthcare organisations, there is a wide range of local community groups which are also available. It is unclear however, how widely these are known about. More therefore needs to be done to provide residents with complete and accurate information, and to facilitate the process of connecting them to sources of help and support.

People who have experienced a bereavement have also reported feeling abandoned by health and social care staff following the death of a loved one, due to a lack of routine follow up. Local people have informed us that they would have benefited from someone such as their GP contacting them following their loss, to check-in. Instead, residents must actively seek support, which can be challenging during such a difficult time. Furthermore, when people do reach out to their General Practice, a lack of continuity with individual GPs can make it difficult for them to feel comfortable enough to have honest conversations about the personal challenges they are facing.

7.4. Support for informal carers

The support that carers require can be divided into two broad categories. The first of these is support to undertake their caring role, including through adequate training and the provision of sufficient equipment. The second, is support for them as an individual who is experiencing a traumatic life event as their loved one is unwell. Both forms of support are required if they are to help their loved one and remain well themselves. Sadly, local people report being unhappy with the levels of either type of support that they are receiving.

Strikingly, 86% of respondents to a survey undertaken to support this JSNA chapter reported that they either strongly or tended to disagree with the statement “I received sufficient carer related support / training, such that I felt well equipped to support someone near the end of life”. Whilst it is important to note that the survey used a self-selected sample and so is subject to responder bias, this remains a notable statistic. Local people have reported feeling that they are “left to [our] own devices”, and to care for their loved one without sufficient advice on practical issues such as how to administer medications or move and transfer the person they are caring for. Not only does this negatively impact on the quality and experience of end of life care received, but it is distressing for both the carer and their loved one. Furthermore, carers may be left feeling guilty following the death of their loved one for not being able to provide as high a level of care as they would have liked, and feeling as if they had in some way let that person down.

Finally, the burden of coordinating health and social care services for someone approaching the end of life, often falls onto carers. Similarly to the other groups discussed in this section so far, carers report not knowing what services are available and find identifying the various sources of support and navigating their access routes to be challenging. Existing methods of collating and sharing methods of support with carers are therefore in need of review.

7.5. Support for staff working in End of Life care

The roles of staff in end of life care are diverse, and as it was drawn from a self-selecting sample, caution must be taken when interpreting the results of the local survey that was undertaken due to the risk of responder bias. Across work areas however, responders were generally happy with the resources and equipment that they received to help them undertake their role. Differences were seen though in terms of the training received, when considering the person's job description. Those whose primary role is not delivering end of life care, reported feeling that they had insufficient training to adequately support people towards the end of life. As we are faced with an ageing and increasingly co-morbid population which interacts with multiple health services and specialities, staff will increasingly work with patients who are approaching the end of life even if that is not the focus of their role. This is therefore likely to be a growing problem, and it is important that those within the health and social care system feel adequately supported in this area.

8. Recommendations

This JSNA chapter has identified the local needs and current gaps in service provision relating to end of life care and support. The following recommendations have been produced on the basis of these findings, to support improved outcomes for the people in Leicestershire.

8.1. Further exploration of the issue

- Undertake a tailored piece of engagement to capture the views, preferences, and experiences of those who are themselves approaching the end of life.
- Produce a health equity audit to further explore inequalities in end of life care and how services can be tailored to better address the needs of disadvantaged groups.
- Further explore the reasons for deaths taking place at hospital / hospice / home / care home, to better understand if this is due to patient choice or factors such as a lack of community services meaning there is insufficient capacity to support people dying at home. To particularly consider those who live elsewhere but die in a care home as discussed in Section 3.5.2.

8.2. Facilitating conversations

- Seek to modify social norms by utilising behaviour change theory and social marketing, to improve the acceptability of discussing death and end of life preferences.
- Consider how conversations relating to end of life preferences and planning can be initiated at times surrounding major life events, by incorporating a Making Every Contact Count (MECC) approach.
- Seek to increase the number of people with an advance care plan.
- Encourage healthcare staff to initiate advance care planning discussions during early interactions, particularly for those with degenerative conditions such as dementia who will be less able to contribute meaningfully as their condition progresses.

8.3. Increasing public understanding

- Undertake local campaigns aimed at enhancing the public’s understanding of what is meant by end of life, the terms frequently used in relation to it, and the role of different services.
- Improve awareness of existing, locally available services.
- Build on work by Dying Matters to provide a central source of information and signposting advice to end of life and bereavement services.

8.4. Delivering services

- Develop a more robust community out of hours offer so that support for those approaching the end of life and their carers is available throughout the week.
- Improve the coordination of services working together to deliver end of life care, to reduce the burden currently placed on patients and their loved ones.
- Promote continuity of care within services, particularly with primary and community services, to support the building of trusted relationships between patients and their health or social care provider.
- Consider how to introduce a form of routine follow up with those who have undergone a recent bereavement.
- Consider the need for a paediatric palliative care consultant and the need for community paediatric and nursing support that responds to the rising numbers of children and young people on end of life pathways with increasing complexity.

8.5. Supporting carers and staff

- Improve the advice and support available to informal carers, so that they feel better equipped with the skills and knowledge to support their loved one.
- Consider how regular check-ins with informal carers can take place.
- Support informal carers in taking respite care, so as to ensure their own wellbeing.
- Ensure training is available and accessible for staff who do not regularly deliver end of life care as a core part of their role.

GLOSSARY OF TERMS

CCG	Clinical Commissioning Group
CQC	Care Quality Commission
ELRCCG	East Leicestershire and Rutland Clinical Commissioning Group
GP	General Practitioner
HWB	Health and Wellbeing Board
IDACI	Income Deprivation Affecting Children
IDAOPI	Income Deprivation Affecting Older People
IMD	Index of Multiple Deprivation
JHWS	Joint Health and Wellbeing Strategy
JSNA	Joint Strategic Needs Assessment
LLR	Leicester, Leicestershire and Rutland
LPT	Leicestershire Partnership Trust
LSOA	Lower Super Output Area
MSOA	Middle Super Output Area
NHS	National Health Service
ONS	Office of National Statistics
PHE	Public Health England
WLCCG	West Leicestershire Clinical Commissioning Group

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જો આપ આ માહિતી આપની ભાષામાં સમજવામાં થોડી મદદ ઇચ્છતાં હો તો 0116 305 6803 નંબર પર ફોન કરશો અને અમે આપને મદદ કરવા વ્યવસ્થા કરીશું.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਸਮਝਣ ਵਿਚ ਕੁਝ ਮਦਦ ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ 0116 305 6803 ਨੰਬਰ ਤੇ ਫ਼ੋਨ ਕਰੋ ਅਤੇ ਅਸੀਂ ਤੁਹਾਡੀ ਮਦਦ ਲਈ ਕਿਸੇ ਦਾ ਪ੍ਰਬੰਧ ਕਰ ਦਵਾਂਗੇ।

এই তথ্য নিজের ভাষায় বুঝার জন্য আপনার যদি কোন সাহায্যের প্রয়োজন হয়, তবে 0116 305 6803 এই নম্বরে ফোন করলে আমরা উপযুক্ত ব্যক্তির ব্যবস্থা করবো।

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Jeżeli potrzebujesz pomocy w zrozumieniu tej informacji w Twoim języku, zadzwoń pod numer 0116 305 6803, a my Ci dopomożemy.

Strategic Business Intelligence Team
Strategy and Business Intelligence Branch

Chief Executive’s Department
Leicestershire County Council
County Hall
Glenfield
Leicester
LE3 8RA
bi@leics.gov.uk
www.lsr-online.org