End of Life in Birmingham

Joint Strategic Needs Assessment Deep Dive Report

This report is mostly based on data collected prior to the COVID-19 pandemic. There are no references to the pandemic within this report.

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"For many of us, talking about death can feel like a really difficult conversation to have and yet, all of us will experience it at some point in our lives. A lot of people are frightened of saying the wrong thing, worried about upsetting someone, or simply don't know how to bring the topic up – and for those that are dying, sometimes denial can play a part in it too.

By having the confidence to open up these conversations as part of everyday life, we can enable many more people and their loved ones to have the best possible quality of life as they deal with illness and approach dying."

Sharon Hudson, Birmingham St Mary's Hospice[1]

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[1] Dying to talk: Hospice to Host Public Open Day to get Brummies Talking about Death. https://www.birminghamhospice.org.uk/news/dying-matters-open-day-2019 Accessed 22 June 2021.

Forward

Dying is a normal part of life.

All of us will die, and although the timing and way we die varies between individuals it is a reality of being human.

We all hope that when our time comes it will be with speed, dignity, grace and as pain-free as possible. Yet death and dying are often difficult subjects to talk about and too many of us avoid spending time talking with loved ones about what our final wishes are and how we want to be celebrated and remembered when we are gone.

This deep dive report explores the data and evidence around what is causing death at different stages of the life course and in different communities. Some of these deaths are potentially preventable and this report highlights opportunities to take action to reduce these years of life lost as well as ways in which the burden and impact of dying on those left behind can be addressed by communities and organisations.

Our hope is that this deep dive report helps bring the conversation about death and dying in Birmingham into the open and that this report can be used by individuals, communities and organisations to create a better approach across the city to the subject of death.

Across Birmingham we all have a responsibility to work together to prevent avoidable and premature death, to develop communities and organisations that are compassionate and caring for those affected by death and to support individuals to talk openly about death in ways that are honest, open and authentic, and ultimately to become a compassionate city where death is as positive and dignified as it can be.

We all die, and we all have a role to play in improving the experiences of death and dying in Birmingham.

Dr Justin Varney
Director of Public Health
Birmingham City Council
February 2022

Quotes from Experts by Experience

"If there are choices to be made, I want to make them."

"If someone else knows what my future could hold and I don't, they're in control, not me."

"It is sad that Dad spent his last few days in the wrong place, being distressed and uncomfortable. I'm left feeling guilty, wondering whether I should have done more."

"The real worry isn't so much what happens if my husband goes downhill or dies, even though he's the one with heart failure, but what would happen if I did. I do everything – deal with the finances, all the cooking etc. What would he do if I died? He couldn't possibly do it himself. He gets breathless moving from one chair to another."

"My daughter knows what my wishes are, all the music and an irreverent piece from Billy Connolly. She'll have all the emotions, but she won't be wondering what I would have wanted."

Source: Quotes from British Heart Foundation's "Difficult Conversations".[2]

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[2] British Heart Foundation – Difficult Conversations – Talking to People with Heart Failure about End of Life. https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/difficult-conversations---talking-to-people-with-heart-failure-about-the-end-of-life Accessed 9 July 2021.

Executive Summary

This deep dive into end of life in Birmingham is part of a series of enhanced reviews forming part of Birmingham's new approach to its Joint Strategic Needs Assessment (JSNA).

Our long-term ambition is to live in a city where all of our citizens are able to die with dignity, receiving compassionate and high-quality end of life care, and able to talk openly about death and dying with those close to them.

However, the key findings of this deep dive JSNA suggest that this is not the case for some citizens.

- There are too many premature and avoidable deaths that are exacerbated by social, economic and environmental factors.
  - The poorest areas of the city have the lowest life expectancy.
  - Birmingham has one of the highest infant mortality rates in England.
- There is scope for improvement of end of life care services.
  - Services could be more coordinated.
  - Care plans are not routinely offered to patients in need of palliative care and their carers.
  - Various sources have suggested people have difficulty discussing what they want when they die.
- Further support is needed for those left behind.
  - Older people who are bereaved are affected by loneliness and social isolation.
  - There is support for the bereaved and carers in Birmingham but there are gaps in some areas of the city.

In the Opportunities for Action section, we have set out recommendations as to how local partners can work towards our ambition for Birmingham. These include:

a) The promotion of conversations about death and dying.
b) Taking a 'whole system approach' across the city to make it easier for citizens to make healthy choices and live as healthily as possible.
c) Addressing the lack of carer and bereavement support city-wide; and encouraging communities to provide support within different areas of the city.

Contents

1. Introduction

Death and dying are an inevitable part of life, everyone will die. There were 530,841 deaths registered in England and Wales in 2019, 8,267 of these were in Birmingham.[3] Causes of death vary across the population and are influenced by age, gender, ethnicity, and other demographic characteristics as well as poverty and environmental factors such as employment and the built environment.

The inequity of death is seen in those who die much younger than others (premature deaths below the age of 75 years) and the differences in the age of starting to live with ill health and the length of time that people live with the consequences of ill health.[4]

The *Parliamentary and Health Service Ombudsman*'*s* report, *Dying without dignity* (2015),[5] highlighted that whilst many people experience a high standard of care at the end of life, a significant number of people do not share this experience. The report highlighted the need for improvements in end of life care to ensure that everyone can experience a 'good death'.

People approaching the end of their life often experience a range of different challenges and needs including those that are physical, social, emotional and spiritual. Effective support of these needs can require integrated and multidisciplinary support working across sectors regardless of whether the person is in their home, in hospital, a care home, or hospice. Families and carers of people at the end of life also experience a range of emotions and problems, which also need to be addressed.[6]

The quality of life that an individual experiences at the end of their life will have a deep impact upon the individual dying, their family, and also their carers and their carers' wider social networks. Grief and grieving can have rippling impacts on all domains of life such as social, work, health and wellbeing.[7] This document seeks to explore these impacts in Birmingham.

1.1. Joint Strategic Needs Analysis (JSNA)

The purpose of a JSNA is to improve the health and wellbeing of the local community and reduce inequalities through developing local evidence-based priorities for commissioning. This is not an end in itself but a continuous process of strategic assessment and planning.

The aim is to develop local, evidence-based priorities for commissioning, policy and practice which will improve the public's health and reduce inequalities. These will be used to determine actions that the local authority, the local NHS and other parties need to take to meet health

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[3] Office for National Statistics. Deaths registered in England and Wales: 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2019 Accessed 16 June 2021.

[4] Fair Society, Healthy Lives – The Marmot Review. https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf Accessed 22 June 2021.

[5] Parliamentary and Health Service Ombudsman. Dying without Dignity. https://www.ombudsman.org.uk/publications/dying-without-dignity-0 Accessed 16 June 2021.

[6] NICE. End of Life Care for Adults Quality Standard. https://www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-pdf-2098483631557 Accessed 18 June 2021.

[7] Mental Health Resources for Carers. Impacts of Grief. http://mhr4c.com.au/grief-and-loss/impacts-of-grief/ Accessed 18 June 2021.

and social care needs and to address the wider determinants that impact on health and wellbeing.

The *Birmingham Health and Wellbeing Board* has agreed a forward plan of four deep dives each year to supplement the core JSNA content. The deep dive needs assessments are intended to provide a focused and thorough exploration of a specific topic area or population of need to inform commissioning, policy and practice.

1.2. Scope and Definitions

1.2.1. Scope

The scope of this deep dive is to explore the data and evidence around what is causing death at different stages of the life course and in different communities, including reviewing the potential for preventing premature death. The scope also includes dying and the needs and care required at the end of life. The impact of death and dying on families and the wider society is also considered.

1.2.2. Definitions

The following terms are used in the deep dive. This section provides an explanation of their meaning within the document.

Death

Death is defined as the cessation of all vital functions of the body including the heartbeat, brain activity (including the brain stem), and breathing.[8] To officially register a death, a doctor needs to identify this whilst establishing cause and then issue a medical certificate of death. This is used to register the death and issue a death certificate. If the doctor is unsure of the cause of death or hasn’t seen the patient for 14 days, the death must be reported to the coroner. If the coroner sees no need to investigate, the doctor can then issue the medical certificate.[9] If the coroner decides that a post-mortem examination is needed to determine the cause of death, this will be carried out and the relevant documents will then be passed to the registrar. This is then passed to the *Office of National Statistics* and becomes known as a registered death. All death calculations within this document are recognised in accordance with the *Office of National Statistics*.

Disability-Free Life Expectancy

An estimate of the years of a lifetime free from a limiting persistent illness or disability. This is based upon a self-rated assessment of how health limits an individual’s ability to carry out day-to-day activities.[10]

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[8] Dictionary.com. Definition of death. https://www.dictionary.com/browse/death Accessed 16 June 2021.

[9] BMA. Verification of Death (VoD), Completion of Medical Certificates of Cause of Death (MCCD) and Cremation Forms in the Community in England and Wales. https://www.bma.org.uk/media/2843/bma-verification-of-death-vod-july-2020.pdf Accessed 16 June 2021.

[10] Office for National Statistics. Health state life expectancies, UK: 2017 to 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/2017to2019 Accessed 22 June 2021.

Dying

The last stage of life; a process that begins when a person has a disorder that is untreatable and inevitably ends in death. Dying is a process, whereas death is an event. The end of life experience is unique to the individual.[11]

Early Death or Premature Death

Premature deaths are defined as deaths that occur before the age of 75 years. Premature mortality is a good indicator of the overall health of a population, being correlated with many other measures of population health. There are significant differences between the premature death rates in different areas, reflecting a wide range of underlying differences between these populations. To ensure that there continues to be a reduction in the rate of premature mortality, and that inequalities between areas are reduced, there needs to be concerted action in both prevention and treatment.[12]

End of Life

The *National Institute of Health and Care Excellence* (NICE) guidance defines the 'end of life' stage as people with:

- advanced, progressive, incurable conditions; and/or
- those who may die within 12 months; and/or
- those with life-threatening acute conditions[1]

End of life care therefore covers any support and treatment for those nearing death and includes palliative care.

Palliative Care

Palliative Care has been defined by NICE[13] as the active holistic care of patients with an advanced progressive illness, which includes the management of pain and other symptoms and the provision of psychological, social and spiritual support.

The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness at the same time as other curative treatments.

Advanced Care Plan (ACP)

The *Advanced Care Plan* enables patients to decide what they would like to happen in the event that they lose the capacity to make or communicate decisions about their care. Examples of such decisions include:

- The use of intravenous fluids and parenteral nutrition.
- The use of cardiopulmonary resuscitation.

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[11] Miller-Keane Encyclopaedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition. (2003). Dying. (n.d.). https://medical-dictionary.thefreedictionary.com/dying Accessed 22 June 2021.

[12] Public Health England. Mortality Profile. https://fingertips.phe.org.uk/profile/mortality-profile Accessed 16 June 2021.

[13] The National Institute for Health and Care Excellence. What is palliative care? https://cks.nice.org.uk/topics/palliative-care-general-issues/background-information/definition/ Accessed 21 June 2021.

- The use of life-saving treatment (whether existing or yet to be developed) in specific illnesses where capacity or consent may be impaired - for example, brain damage, perhaps from stroke, head injury or dementia.
- Specific procedures such as blood transfusion for a Jehovah's Witness.

Healthy Life Expectancy

A measure of the average number of years a person would expect to live in good health based on contemporary mortality rates and prevalence of self-reported good health.[14]

Life Expectancy at Birth

The average number of years a person would expect to live based on contemporary mortality rates. For a particular area and time period, it is an estimate of the average number of years a new-born baby would survive if he or she experienced the age-specific mortality rates for that area and time period throughout his or her life.[15]

1.3. National Strategy and Guidance

There are 5 key strategies which identify national guidelines and best practice for implementing high-quality end of life care. These are:

- *National End of Life Care Strategy* (2008)[16]
- *NICE Quality Standards for End of Life Care in Adults* (2011)[17]
- *Next Steps on the NHS Five Year Forward View* (2014)[18]
- *Ambition for Palliative and End of Life Care: A National Framework for Local Action 2015-2020* [19]
- *Working Together to Safeguard Children* 2018[20]

1.3.1. ***National End of Life Care Strategy* (2008)**

This *National End of Life Strategy* sought to address the issues of dying in a place of choice and improving communication between services providing end of life care and preventing communication breaking down. The strategy set out key areas, recommendations and actions:

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[14] Public Health England. Public Health Outcomes Framework – Overarching Indicators. https://fingertips.phe.org.uk/documents/PHOF_Overarching_user_guide_Feb_2018_updated%20FINAL.pdf Accessed 21 June 2021.

[15] Public Health England. Public Health Outcomes Framework – Overarching Indicators. https://fingertips.phe.org.uk/documents/PHOF_Overarching_user_guide_Feb_2018_updated%20FINAL.pdf Accessed 21 June 2021.

[16] Department of Health and Social Care. End of Life Care Strategy: promoting high quality care for adults at the end of their life. https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life Accessed 16 June 2021.

[17] The National Institute for Health and Care Excellence. End of Life Care for Adults. https://www.nice.org.uk/guidance/QS13 Accessed 16 June 2021.

[18] https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf Accessed 16 June 2021.

[19] National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf Accessed 16 June 2021.

[20] Department for Education. Working Together to Safeguard Children. https://www.gov.uk/government/publications/working-together-to-safeguard-children--2 Accessed 16 June 2021.

- Raising the profile of end of life care and changing attitudes to death.
- Strategic commissioning challenges.
- Identifying people approaching the end of life.
- Care planning with patients and families.
- Coordination of care between agencies.
- Rapid access to care.
- Delivery of high-quality services in all locations.
- Last days of life and care after death.
- Involving and supporting carers.
- Education, training and continuing professional development of clinical and non-clinical staff.
- Measurement and research of trends and issues.
- Funding challenges.

1.3.2. ***NICE Quality Standards for End of Life Care in Adults*** **(2011)**

This quality standard covers care for adults (aged 18 and over) who are approaching the end of their life. It covers care provided by health and social care staff in all settings and describes high-quality care in priority areas for improvement. These include:

- Identification and assessment.
- Holistic support.
- Access to services.
- Care in the last days of life.
- Care after death.
- Workforce.

1.3.3. **Next Steps on the *NHS Five Year Forward View* (2014)**

This review reported that improving palliative and end of life care was to play an important role in the successful delivery of many *Sustainability and Transformation Partnership* priorities. It called for increased engagement with service-users to support the planning of end of life services; a range of care models to support better integration of services across providers; and shifts of investment from acute to primary and community services. These all have the potential to support improvement to end of life care.

1.3.4. ***Ambition for Palliative and End of Life Care: A National Framework for Local Action*** **(2015-2020)**

This framework was intended to build on the *2008 End of Life Care Strategy*. The emphasis is on providing a national framework for local decision-making and delivery - achieving the standard set out in the *NICE Quality Standard for End of Life Care (2011).*

Six key ambitions were identified to improve the experience of the dying person and carers, families, those important to the dying person, and all who became bereaved. They are expressed as personal "I" statements.[21] (Table 1)

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[21] National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf Accessed 16 June 2021.

Table 1: NICE Quality Standard Ambitions

Ambition	Personal "I" Statement
Each person is seen as an individual	*I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*
Each person gets fair access to care	*I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*
Maximising comfort and wellbeing	*My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*
Care is coordinated	*I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*
All staff are prepared to care	*Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.*
Each community is prepared to help	*I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*

1.3.5. *Working Together to Safeguard Children* (2018)

This national statutory guidance[22] mandates that every local area has a *Child Death Overview Panel* which reviews each child death. It sets out the framework for the local authority and CCGs in local areas for reviewing deaths, displayed in Figure 1 and Figure 2.

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[22] Department for Education. Working together to safeguard children. https://www.gov.uk/government/publications/working-together-to-safeguard-children--2 Accessed 16 June 2021.

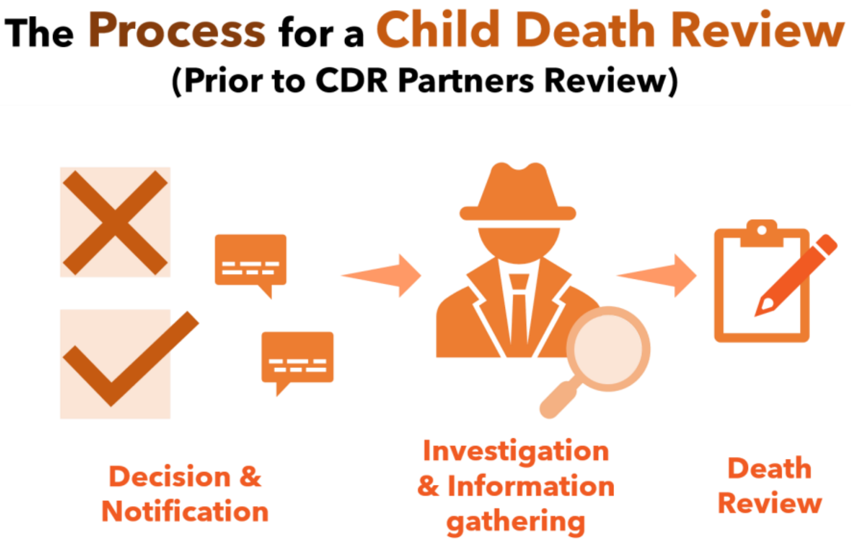

Figure 1: Process for a Child Death Review Part 1

Figure 1 shows the process for a *Child Death Review* (CDR) which focuses on the individual. After a child dies, there is immediate decision making and notifications which lead to investigation and information gathering. After this, there is the child death review meeting which happens prior to a review by the CDR partners. During these steps the family is supported with engagement, information and a key worker.

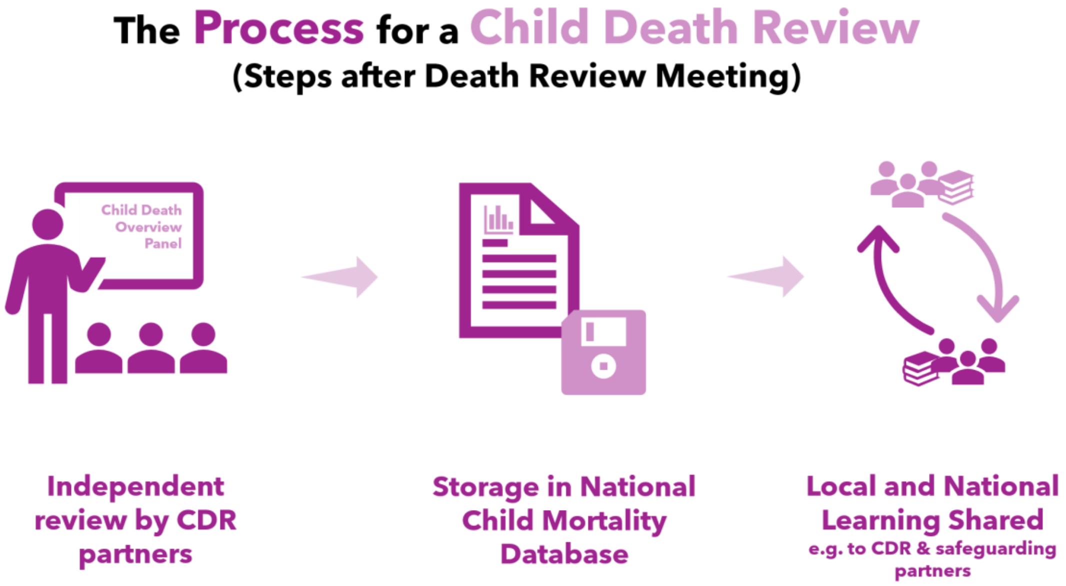

Figure 2: Process for a Child Death Review Part 2

Figure 2 shows the steps which occur to obtain local and national learning. After the CDR meeting, there is an independent review by CDR partners at a Child Death Overview Panel or equivalent. There is also the *National Child Mortality Database*, which gathers and analyses information on all children who die in England, to improve and save children's lives in the future.[23]

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[23] NCMD (National Child Mortality Database). https://www.ncmd.info/ Accessed 16 February 2022.

1.4. Birmingham Strategy and Structures

1.4.1. *Integrated Palliative and End of Life Care Commissioning Strategy for Birmingham* (2014-18)[24]

This local strategy aimed to shape the commissioning intentions and actions of the local NHS for adults. There were five core themes of recommendations:

- Patients and carers feel supported to cope.
- Addressing inequalities and differences in practice.
- Professionals feeling supported and able to learn and provide care.
- Developing and improving systems that support efficient and effective palliative and end of life care.
- Engaging with local communities.

The key outcomes of the strategy are:

- Identification of patients – We will ensure that the number of patients who are identified as having palliative care increases, and that patients will have accessible and appropriate high-quality palliative end of life care.
- Care planning – We will ensure that patients and their carers receive the information and support to manage care according to their choice and needs.
- Providing choice – We will enable more people nearing the end of their life to make the choice to die at their preferred place.
- Delivering choice – Improved care planning and the provision of choice will result in a reduction of the number of avoidable emergency admissions to hospitals for patients receiving palliative or end of life care.

The time frame for this local strategy ended in 2018. However, there is not an updated version available at the time of writing this report (2021) meaning that the 2014-18 strategy remains in use. A consultation on a similar approach for children and young people was started in 2016. The outcome proposal has been delayed due to the local changes in NHS Governance.

Figure 3 (below) shows how patient and carer preferences and needs are central to all the phases of End of Life care set out in the strategy. These phases are identification, stable, sliding, dying and care after death.

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[24] NHS. Integrated Palliative and End of Life Care Commissioning Strategy for Birmingham 2014/15 – 2017/18.

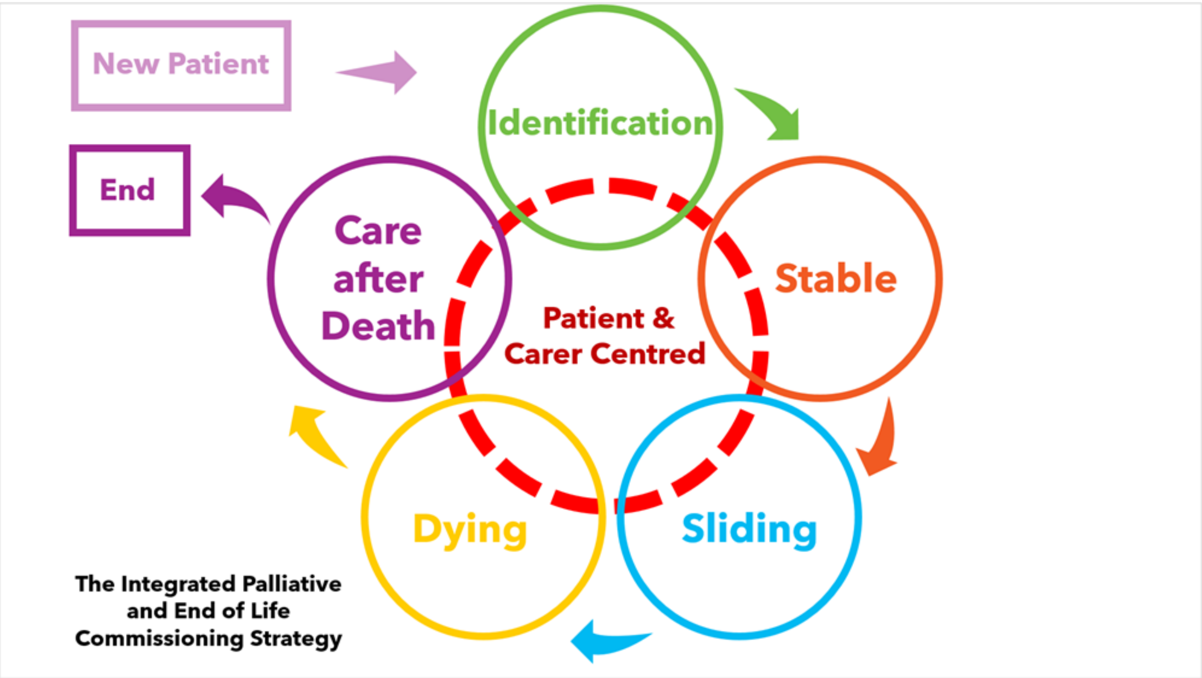

Figure 3: The Integrated Palliative and End of Life Commissioning Strategy

1.4.2. End of Life Care within the *Birmingham and Solihull Sustainability and Transformation Partnership* (STP) Structure[25]

The national framework for local action 2015-2020 identified key areas for improvement in end of life care. An *End of Life Oversight Group* was formed as part of the *Birmingham and Solihull STP Older Peoples Portfolio Board*. The oversight group and their supporting working party group ensured development and delivery of the *BSol Ageing Well Strategy's* plan and priorities. They reported directly to the *BSol Ageing Well and Later Life Board*, responsible for directing the *Ageing Well Strategy*, who liaised directly with the *Sustainability and Transformation Partnership [STP] Board*.

Programme actions and tasks have been mapped against the ambitions.

1.4.3. Solihull Health and Wellbeing Strategy (2019-2022)

Taking a life course approach, this strategy had four priorities;

- Maternity, Childhood and Adolescence
- Adulthood and Work
- Ageing and Later Life
- All Age: Social Connectedness

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[25] Ambitions for Palliative and End of Life Care 2015. https://www.nationalvoices.org.uk/publications/our-publications/ambitions-palliative-and-end-life-care Accessed 18 June 2021.

The priority 'Ageing and Later Life' aims to promote independence, support people to stay home where possible and provide early intervention. Across all ages, this strategy aims to increase the social wellbeing and connectedness of its citizens to reduce loneliness.[26]

1.4.4. Birmingham Health and Wellbeing Strategy (2022-2030)[27]

The *Creating a Bolder, Healthier City* strategy has five core themes for action:

- Healthy and Affordable Food
- Mental Wellness and Balance
- Active at Every Age and Ability
- Contributing to a Green and Sustainable Future
- Protect and Detect

These five core themes run throughout the life course, split into three stages: Getting the Best Start in Life, Working Well, Ageing and Dying Well. Attached to the life course stage Ageing and Dying Well, this strategy's key actions are to strengthen engagement with citizens to better understand ageing in Birmingham, have a clear prevention and early intervention approach supporting healthy independent ageing, become a recognised Age Friendly City and Compassionate City by 2027 and establish a Healthy Ageing Academic Partnership to increase the evidence base for interventions supporting healthy ageing.

1.4.5. Birmingham Suicide Prevention Strategy[28]

The Birmingham Suicide Prevention Strategy has been developed in partnership with the NHS, *Public Health England* and local strategic partners from the community and voluntary sector, academia, business and police. The strategy has six priority areas for action based on local and national evidence:

- Reduce the risk of suicide in high-risk groups.
- Tailor approaches to improve the mental health of specific groups.
- Reduce access to means of suicide.
- Provide better information and support to those bereaved or affected by suicide.
- Support the media in delivering sensitive approaches to suicide and suicidal behaviour.
- Support research, data collection and monitoring.

Simultaneous action across all six priority areas is required in order to effect change. The ambition of this strategy for Birmingham is to:

- Maintain the lowest rate of suicide of any of the core cities in England.

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[26] Birmingham and Solihull CCG. Solihull Metropolitan Borough Council. Solihull Health and Wellbeing Strategy 2019-2022. Accessed April 2022. https://www.solihull.gov.uk/sites/default/files/migrated/InfoandIntelligence_Health-and-Wellbeing-Strategy.pdf

[27] Birmingham City Council. Health and Wellbeing Strategy. 2022-2030. https://www.birmingham.gov.uk/info/50119/health_and_wellbeing_board/1300/health_and_wellbeing_strategy#:~:text=The%20strategy%20also%20focuses%20on,to%202030%2C%20in%20March%202022.

[28] Birmingham City Council. Birmingham Suicide and Prevention Strategy 2019-2024. https://birmingham.cmis.uk.com/Birmingham/Document.ashx? Accessed 16 June 2021.

- Continue to reduce deaths through suicide in the city over the next decade through a zero-suicide approach.

The *Suicide Prevention Working Group* will oversee delivery of an annual action plan.

2. The Birmingham Picture

Birmingham is the largest unitary local authority in Europe and is the UK's second city, home to an estimated population of 1,141,816. According to ONS population estimates, Birmingham has a younger population than most UK local authorities, with a median age of 32.6.[29] The population is more ethnically diverse than the country as a whole.[30] Birmingham is the seventh most deprived local authority in England, with over 40% of its population living in the 10% most deprived areas.[31] Social and economic disadvantage has a negative impact on the health, wellbeing and life expectancy of the citizens of Birmingham.[32]

Between 2015 and 2017, there were 25,609 deaths registered in Birmingham. **Table 2** (below) shows that among children, the age group with the highest proportion of deaths is infants (2% of total deaths). After this, the majority of deaths (64%) were in the over 75 population. mortality).[33]

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[29] Office for National Statistics. 2019 mid-year population estimates. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates Accessed 16 June 2021.

[30] Birmingham Mail. The figures proving Birmingham is more diverse than ever. https://www.birminghammail.co.uk/news/midlands-news/figures-proving-birmingham-more-diverse-15107261 Accessed 16 June 2021.

[31] Ministry of Housing, Communities & Local Government. English Indices of Deprivation 2019. https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019 Accessed 16 June 2021.

[32] Birmingham City Council. Birmingham Public Health Green Paper.https://www.birminghambeheard.org.uk/people-1/birmingham-public-health-green-paper/supporting_documents/Birmingham%20Public%20Health%20Green%20Paper%20.pdf Accessed 16 June 2021.

[33] Office for National Statistics. Deaths. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths Accessed 16 June 2021.

Table 2: Birmingham Deaths by Age 2015-17 Source: ONS Deaths

Age	**2015/17 Deaths**	**2015/17 Percentage of Deaths**
Infants	399	2%
1-4	49	0%
5-9	36	0%
10-14	32	0%
15 -19	54	0%
20-24	97	0%
25-29	117	0%
30-34	182	1%
35-39	229	1%
40-44	348	1%
45-49	538	2%
50-54	774	3%
55-59	966	4%
60-64	1322	5%
65-69	1840	7%
70-74	2218	9%
75-79	2989	12%
80-84	4097	16%
85-89	4458	17%
90+	4864	19%

The majority of deaths occurring between 2015 and 2017 were among people aged 75 and over. These accounted for 64% of total deaths. Among children, infants had the highest rate of deaths, accounting for 2% of the total deaths (Figure 4).

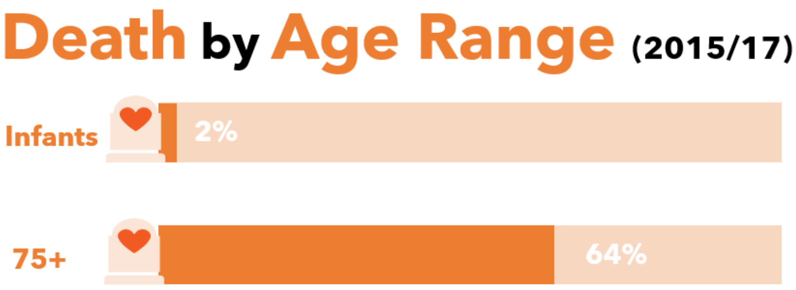

Figure 4: Birmingham Deaths 2015-17 for infants and 75+

In 2017, there were 8,551 deaths in Birmingham with a crude death rate of 7.5 deaths per 1,000 population. This was much lower than the England rate of 9.0 reflecting the younger age profile of the city. However, Birmingham had a much higher infant mortality rate of 7.2 deaths per 1,000 live births (in children aged less than one year) compared to an England rate of 4.0.[34]

2.1. Life Expectancy in Birmingham

Although life expectancy within Birmingham increased after 2001, Figure 5 shows that this improvement plateaued from 2010 until 2017. In 2017, life expectancy for men in Birmingham was 77.6 years and 82.0 years for women, significantly lower than the national average of 79.5 and 83.1 years respectively.[35]

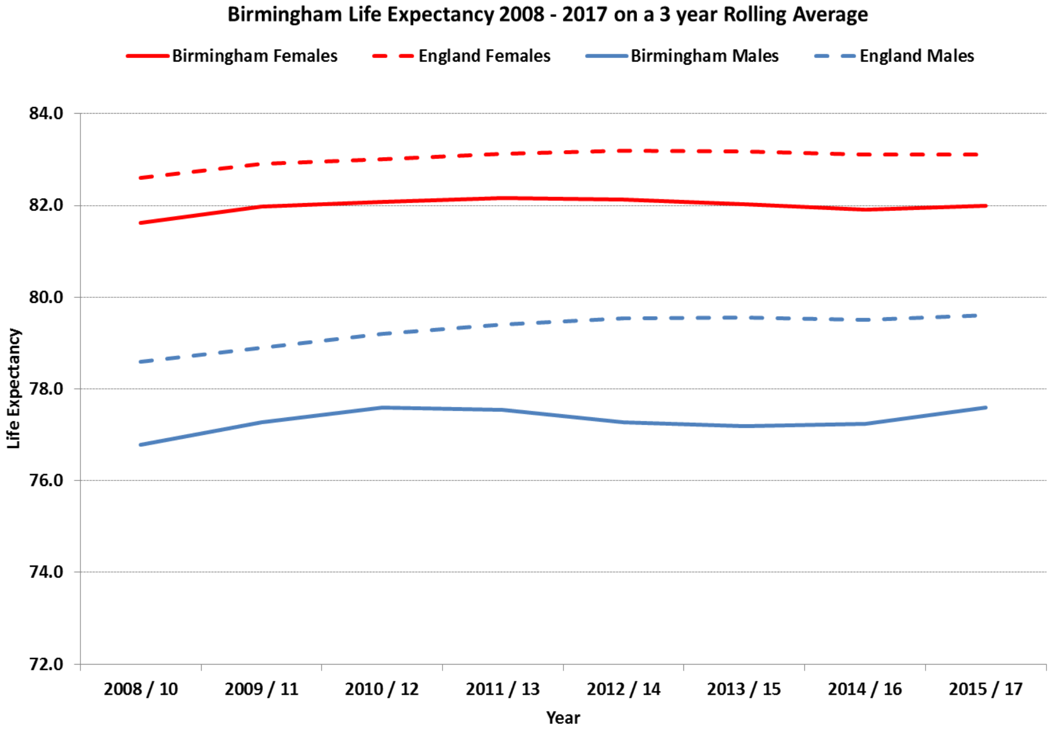

Figure 5: Life Expectancy in Birmingham 2008-2017

There are also significant variations in life expectancy within Birmingham relating to deprivation. The Birmingham average for female life expectancy is 82.1 years, and male is 77.7 years. Figure 6 (below) illustrates how life expectancy can vary significantly between a few train stops. For example, in Erdington, the female life expectancy is 81 years, but a few stops further north in Sutton Coldfield, the life expectancy is five years higher at 86 years.

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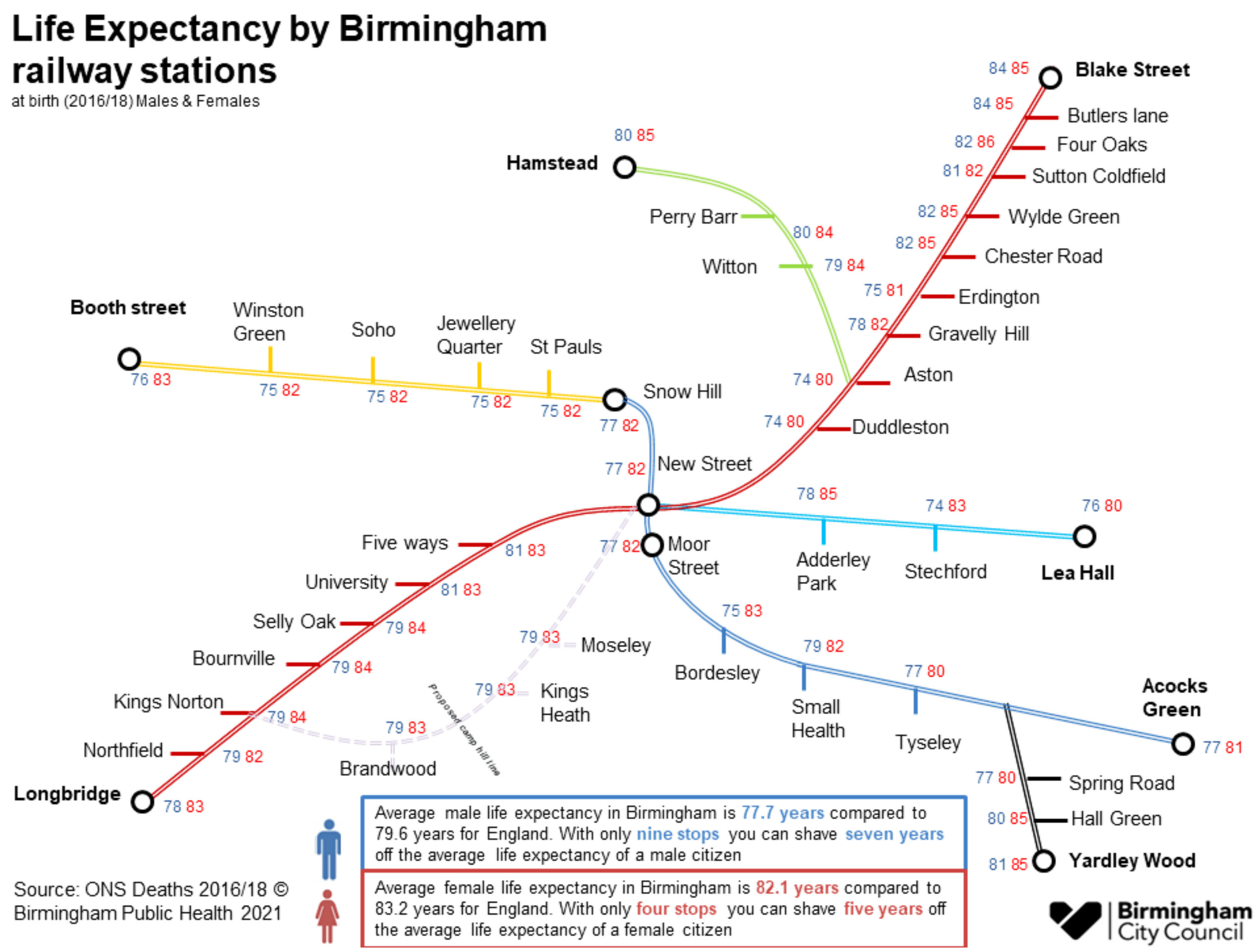
[35] Public Health England. Public Health Outcomes Framework – Birmingham area profile. https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/1/ati/101/are/E08000025 Accessed 16 June 2021.



Average male life expectancy in Birmingham is 77.7 years compared to 79.6 years for England. With only nine stops you can shave seven years off the average life expectancy of a male citizen

Average female life expectancy in Birmingham is 82.1 years compared to 83.2 years for England. With only four stops you can shave five years off the average life expectancy of a female citizen

Source: ONS Deaths 2016/18 © Birmingham Public Health 2021

Figure 6: Differences in Life Expectancy across Birmingham[36]

Wards also show significant differences between life expectancies. In terms of the wards with the lowest and highest average life expectancies, Figure 7 shows that there is a difference of 12.4 years for men from lowest (Castle Vale – 72.2 years) to highest (Sutton Roughley – 84.6 years). It also shows that there is a difference of 7.9 years for women from lowest (Frankley Great Park – 78.5 years) to highest (Sutton Four Oaks – 86.4 years).

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[36] Based on localised calculations from information supplied by the Office for National Statistics to BCC.

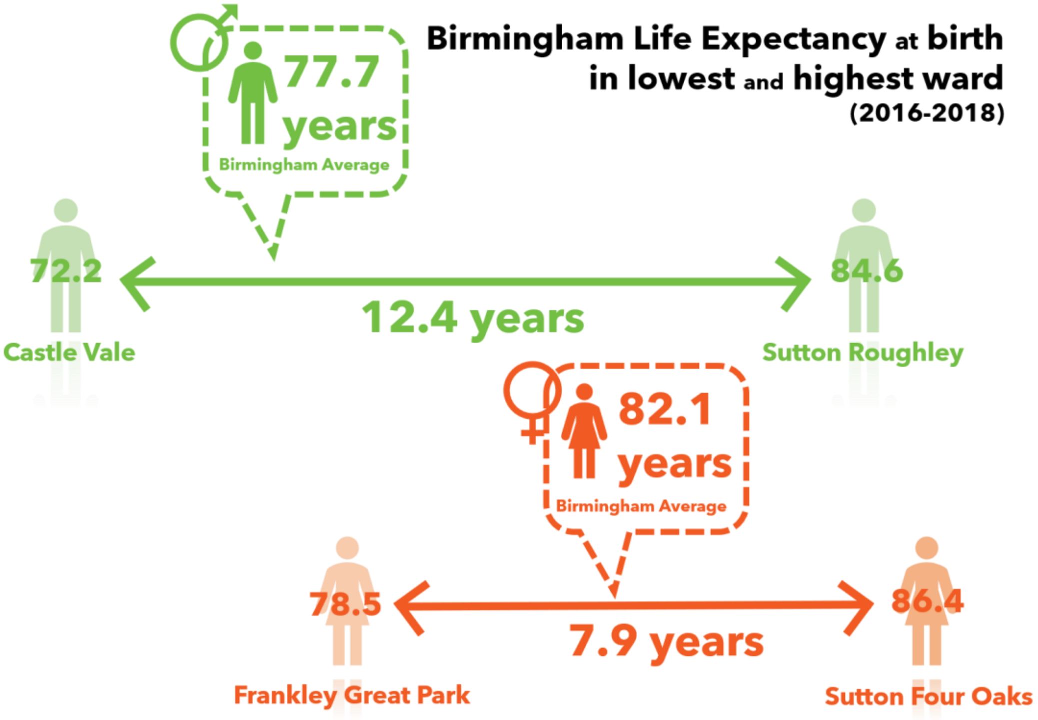

Figure 7: Birmingham Life Expectancy – Wards

Another example is in terms of low and high deprivation. There is a difference of 11.6 years for men and 9.2 years for women between Heartlands ward (with a high level of deprivation); compared to the Sutton Four Oaks/Sutton Reddicap wards, where there is a lower level of deprivation.[37]

2.2. Healthy Life Expectancy in Birmingham

Healthy life expectancy is a measure of the average number of years a person would expect to live in good health. The difference between this and the life expectancy represents the time that citizens can expect to live with the consequences of ill health and with increasing disability (Figure 8).

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[37] Based on internal calculations of Office for National Statistics data on registered deaths and populations at a lower level.

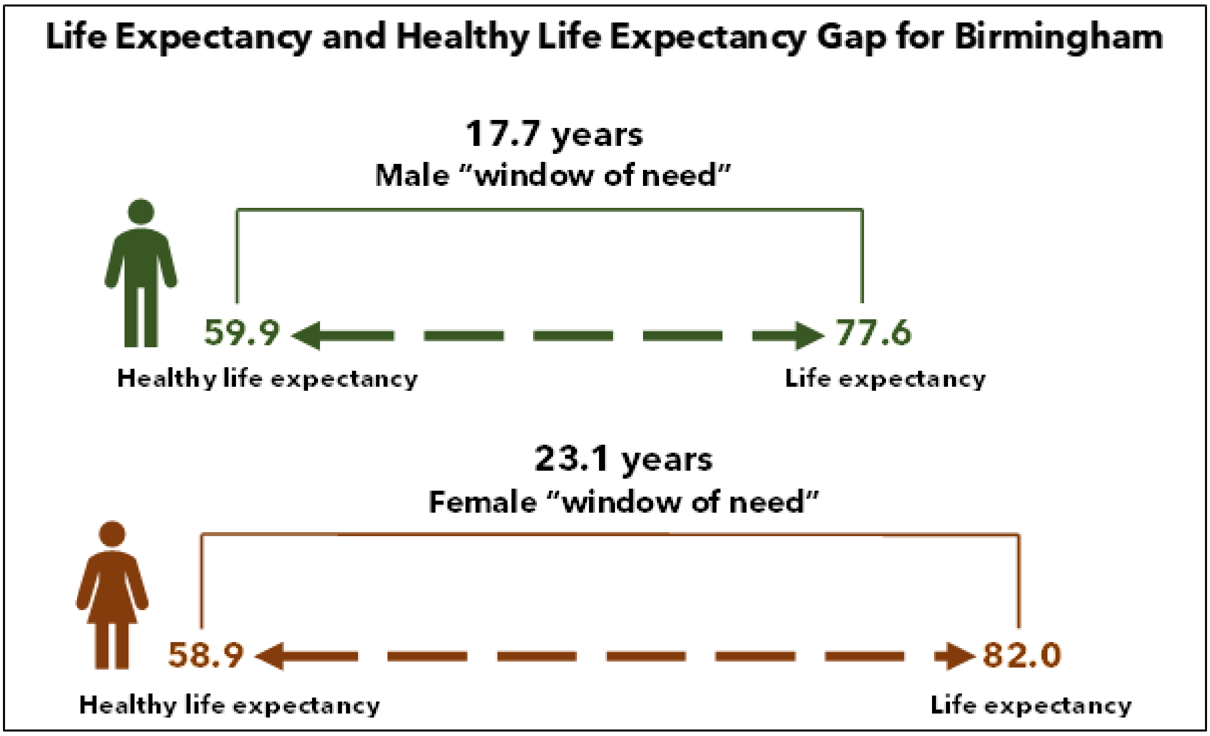

Figure 8: Differences in Healthy Life Expectancy in Birmingham[38]

Healthy life expectancy is significantly lower in Birmingham at 59.9 years for men and 58.9 years for women compared to England (63.4 and 63.8 years respectively). The female "window of need" (which is the difference between healthy life expectancy and life expectancy) in Birmingham is 23.1 years, which is longer than the male "window of need" (17.7 years). This means that the women of Birmingham live longer on average, and experience poor health for longer, than the men.

Thus, in Birmingham, citizens experience both poorer health and more premature deaths than the national average.[39]

2.3. Leading Causes of Death in Birmingham

Table 3 below shows that between 2015 and 2017, the leading cause of death in Birmingham was cancer, representing 26% of all deaths in the city. This was followed by diseases of the circulatory system (25%) and diseases of the respiratory system (14%).[40]

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[38] Based on internal calculations from Office for National Statistics published data.

[39] Public Health England. Public Health Outcomes Framework. https://fingertips.phe.org.uk/profile/public-health-outcomes-framework Accessed 16 June 2021.

[40] Based on causes of deaths information supplied by NHS Digital to BCC.

Table 3: Number and Proportion of the Leading Causes of Death in Birmingham (2015-2017)

Five Leading Causes of Deaths in Birmingham (2015/17)	**Birmingham Deaths**	**% of Deaths**
Cancer	6,689	26.1%
Diseases of the circulatory system (Including CHD)	6,477	25.3%
Diseases of the respiratory system	3,603	14.1%
Coronary Heart Disease (CHD)	3,033	11.8%
Mental and behavioural disorders	2,505	9.8%
All Causes	**25,609**	**n/a**

2.4. Leading Causes of Deaths for Children in Birmingham

There were 538 child deaths (aged under 18 years) in Birmingham between 2015 and 2017. Three quarters (74%) were aged under 1 year and over half of these (57%) were aged under 28 days.[41]

The death of a child is an individual tragedy with serious familial impact. Each death is reviewed by the *Child Death Overview Panel*, established in the *Children Act* (2004) and mandated by the statutory guidance *Working Together to Safeguard Children* since 2010.[42]

The annual reports of the *Birmingham Child Death Overview Panel* identify the key themes, including:

- Premature birth is a major factor in deaths of children below the age of 4 weeks old.
- Extreme prematurity, less than 22 weeks of the normal 40 weeks of development in the womb before birth, remains a challenging aspect and accounted for 12% of all infant deaths in 2013.
- Congenital abnormalities, including complex congenital heart conditions which may be identified during the pregnancy and before birth, account for 17.6% of all child deaths in the city. Factors which might reduce the likelihood of being born with some congenital abnormalities continue to be a sensitive issue and are discussed in detail in the *2018 Annual Report* by the *Director of Public Health* for Birmingham.[43]

Risk and cause of infant death varies considerably depending on the age of a child.

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[41] Based on registered deaths information supplied by NHS Digital 2015-17 to BCC.

[42] Department for Education. Working together to safeguard children. https://www.gov.uk/government/publications/working-together-to-safeguard-children--2 Accessed 16 June 2021.

[43] Director of Public Health Annual Report 2018 – Fulfilling Lives for Under Fives. https://www.birmingham.gov.uk/download/downloads/id/10834/director_of_public_health_annual_report_2018.pdf Accessed 23 June 2021.

2.4.1. Infant Death (Under 1 Year)

Infancy is the first year of life and has three phases:[44]

1. Early neonatal – the first 0 to 6 days after birth.
2. Late neonatal – 7 to 28 days after birth.
3. Post neonatal – 28 days to the end of the first year of life.

Birmingham has a significantly higher infant mortality rate of 7.2 deaths in children aged less than one year per 1,000 live births compared to the England rate of 4.0.

Nationally, most infant deaths occur within the early neonatal period.[45] In Birmingham during 2015/17, 63% of all infant deaths were during this initial period after birth. The majority (69%) of these deaths occurred in their first day of life. Overall, 98% of all the early neonatal deaths occurred in a hospital environment, indicating that only 2% left the hospital they were born in.

The cause of death varies between early and late neonatal. Table 4 shows the causes of death for each phase of infancy in Birmingham.

Table 4: Causes of Early, Late and Post Neonatal Deaths in Birmingham 2015/17

ONS Classification	Early Neonatal	Late Neonatal	Post neonatal
All other codes	5%	7%	44%
Asphyxia, anoxia, or trauma (intrapartum)	10%	13%	2%
Congenital anomalies	20%	20%	21%
Immaturity related conditions	63%	31%	11%
Infections	0%	15%	7%
Other Specific Conditions	2%	11%	4%
Sudden infant deaths	0%	0%	9%
Antepartum infections	0%	2%	2%

The older the infant, the more likely that the death is not related to immaturity. 63% of all early neonatal deaths were related to their gestation at time of birth with only 32% for late neonatal deaths. Congenital diseases, asphyxia, anoxia or trauma grouping are more common causes of death in the late neonatal stages.[46]

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[44] Office for National Statistics User Guide to Child and Infant Mortality Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetochildmortalitystatistics Accessed 16 June 2021.

[45] Office for National Statistics. Child and infant mortality in England and Wales: 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/childhoodinfantandperinatalmortalityinenglandandwales/2019 Accessed 16 June 2021.

[46] Based on calculations from data provided by NHS Digital Births/Infant death information 2015/17.

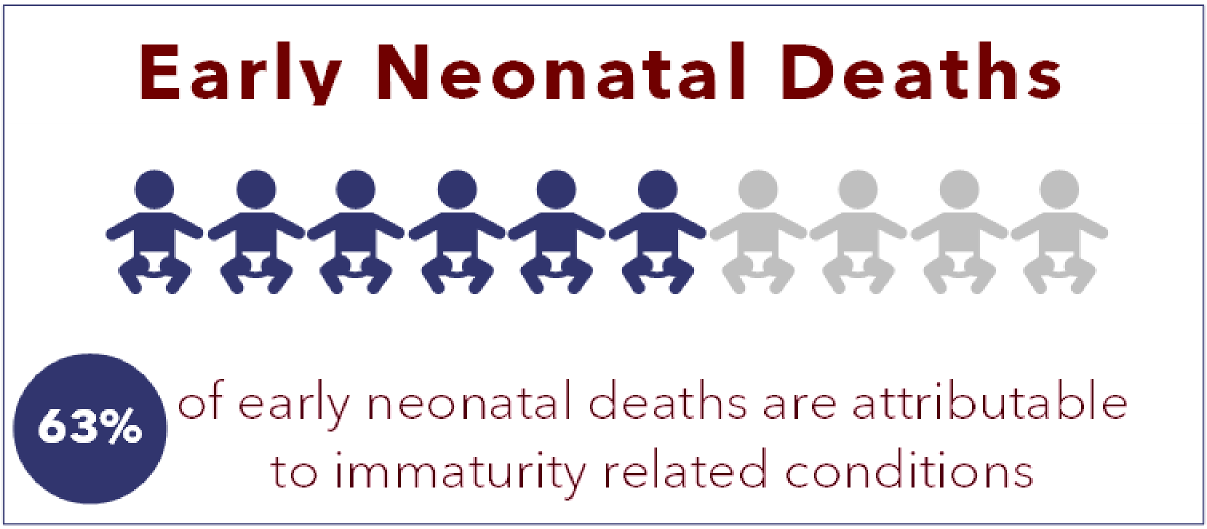

Figure 9: Early Neonatal Deaths in Birmingham 2015/17

Immaturity and genetics have featured consistently in the causes of deaths for the last 20 years in Birmingham. Advances in medical techniques mean that babies born at an early gestation, who would in the past be recorded as a stillbirth, now feature in our infant deaths due to surviving longer.[47] Many of those with severe congenital (hereditary diseases) now survive their first year of life.[48]

2.4.2. Post Infancy Deaths (Aged 1-17)

During 2015/17, Birmingham had a total of 139 post infancy deaths (aged 1 to 17 years). The rate in Birmingham was 16.9 per 100,000 children which is significantly higher than the rate in England (11.2) and the West Midlands (12.3). Figure 10 below breaks down the causes for child deaths and shows that external causes, such as road traffic collisions and other traumatic events accounted for 19% of these deaths. The Birmingham rate for road traffic collisions is 26.5 per 100,000 children compared to the England rate of 17.4 per 100,000.

Cancers were the second most common cause of death in this age group (16% of deaths). Place of death was predominantly in hospital (78%); although 15% of deaths occurred at home, the majority of which were due to cancer.[49]

During 2015-2017, child mortality rates in Birmingham were 16.9 per 100,000 of the city's children population, which is significantly higher than the 11.2 per 100,000 rate for England during those years. This means that the Birmingham local authority had 5.2 more deaths per 100,000 than England as a whole.[50] This could potentially be attributed to many factors such

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[47] Office for National Statistics. Birth characteristics in England and Wales: 2018. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2018 Accessed 16 June 2021.

[48] Glinianaia SV, Morris JK, Best KE, et al. Long-term survival of children born with congenital anomalies: A systematic review and meta-analysis of population-based studies. *PLoS Med*. 2020;17(9):e1003356. Published 2020 Sep 28. https://doi.org/10.1371/journal.pmed.1003356 Accessed 21 June 2021.

[49] Based on internal calculations of 2015/17 NHS Digital deaths data (cause of death) and Office for National Statistics deaths data (rates).

[50] Public Health England. Child and Maternal Health. https://fingertips.phe.org.uk/profile/child-health-profiles/data#page/1 Accessed 16 June 2021.

as deprivation and child poverty in the city. Birmingham is one of the youngest cities in the country[51] and has a high level of social and economic disadvantage[52] that could contribute to early death.

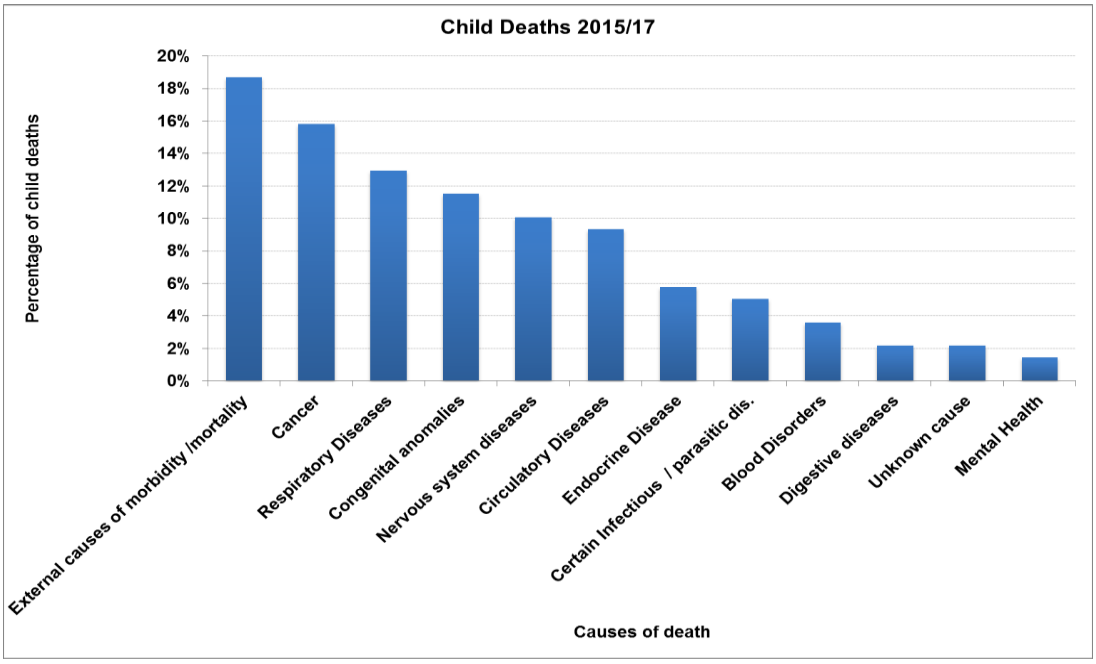

Figure 10: Causes of Deaths for Children Aged 1 to 17 2015/17 ***Source: ONS Deaths***

2.5. Leading Causes of Death for Working Age Adults (Aged 18-64)

Nationally and locally, the biggest killer of working age adults is cancer.[53] Table 5 (below) shows that between 2015 and 2017, a third of all deaths in Birmingham were caused by cancer among those aged 18-64. Diseases of the circulatory system accounted for a further 21.8% of deaths, over half of which are due to coronary heart disease. One way to measure premature mortality is the number of years of life lost (YLL) due to people dying before the age of 75.[54] Using this indicator, it is possible to identify the major health conditions that contribute to the gap between life expectancy experienced in Birmingham compared with that of England. Cancer accounted for over 30,000 YLL (years of life lost).

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[51] Office for National Statistics. Population Mid-Year Estimates 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates Accessed 16 June 2021.

[52] Ministry of Housing, Communities & Local Government. English Indices of Deprivation 2019. https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019 Accessed 16 June 2021.

[53] Public Health England. Public Health Outcomes Framework. https://fingertips.phe.org.uk/profile/public-health-outcomes-framework Accessed 16 June 2021.

[54] NHS Digital. Compendium – Years of life lost. https://digital.nhs.uk/data-and-information/publications/statistical/compendium-mortality/current/years-of-life-lost Accessed 16 June 2021.

Table 5: Number and Proportion of the Leading Causes of Death for Working Age Adults (aged 18-64) in Birmingham 2015-2017. Source: ONS Deaths 2015/17

Five Leading Causes of Death for Working Age Adults (2015-17)	Birmingham Deaths	Years of Life Lost (YLL)	% of Deaths	% of YLL
Cancer	1,546	30,578	33.6%	29.1%
Diseases of the Circulatory System (including CHD)	1,004	20,657	21.8%	19.7%
Coronary Heart Disease (CHD)	568	10,841	12.3%	10.3%
Diseases of the Digestive System	458	10,689	9.9%	10.2%
Diseases of the Respiratory System	375	7,580	8.1%	7.2%
All Causes of Death	**4,605**	**105,047**	**n/a**	**n/a**

Adults with learning disabilities have a significantly lower life expectancy than the general UK population. In 2020, the median age at death (for those of 4 years and over) with learning disabilities was 61 years. From 2018 to 2019, the difference in median age of death between people with a learning disability and the general UK population was 23 years for men and 27 years for women.[55]

Birmingham currently has 8259 residents registered with learning disabilities on the QOF Register, which is 0.6% of the GP registered population. However, population estimates by PANSI and POPPI indicate that the actual population with learning disabilities is much higher; 17,556 (working age) and 3,129 (over 65s). This suggests that learning disabilities are under-reported in GP surgeries across the city and that many patients are not able to access the available health care services, which could potentially provide a better quality and length of life. The *Birmingham Public Health Division's Deep Dive Programme* will be undertaking a needs assessment in 2022 to research this health need in greater depth.

Suicide is a significant cause of death in young adults and is seen as an indicator of underlying rates of mental ill-health. The number of death registrations for suicide and injuries of undetermined intent in 2015-17 was 205, which equates to around 70 per year.

Between 2015 and 2017, the suicide rate in Birmingham was the lowest among the core cities. In Birmingham, the male suicide rate is lower, and the female rate is similar to the England average, with the overall rate being significantly lower in Birmingham compared with England. The most at-risk groups are individuals working in the construction industry and those from Polish and Eastern European backgrounds.[56]

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[55] The Learning Disabilities Mortality Review (LeDeR) Programme. https://www.england.nhs.uk/wp-content/uploads/2021/06/LeDeR-bristol-annual-report-2020-easy-read.pdf Accessed 8 July 2021.

[56] Birmingham City Council. Birmingham Suicide Prevention Strategy 2019. https://birmingham.cmis.uk.com/Birmingham/Document.ashx?czJKcaeAi5tUFL1DTL2UE4zNRBcoShgo=JrBuKs89w20PxzcjJC9JXy0UfkE07GSyIMAYNvGiQbVYo%2F273c1K2Q%3D%3D&rUzwRPf%2BZ3zd4E7Ikn8Lyw%3D%3D=pwRE6AGJFLDNlh225F5QMaQWCtPHwdhUfCZ%2FLUQzgA2uL5jNRG4jdQ%3D%3D&mCTIbCubSFfXsDGW9IXnlg%3D%3D=hFflUdN3100%3D&kCx1AnS9%2FpWZQ40DXFvdEw%3D%3D=hFflUdN3100%3D&uJovDxwdjMPoYv%2BAJvYtyA%3D%3D=ctNJFf55vVA%3D&FgPlIEJYlotS%2BYGoBi5olA%3D%3D=NHdURQburHA%3D&d9Qjj0ag1Pd993jsyOJqFvmyB7X0CSQK=ctNJFf55vVA%3D&WGewmoAfeNR9xqBux0r1Q8Za60lavYmz=ctNJFf55vVA%3D&WGewmoAfeNQ16B2MHuCpMRKZMwaG1PaO=ctNJFf55vVA%3D#:~:text=The%20Birmingham%20Suicide%20Prevention%20Strategy%20builds%20on%20this,a%20collaboration%20between%20organisations%2C%20communities%20and%20citizens%20to Accessed 16 June 2021.

2.6. Leading Causes of Death for Older Adults (Aged 65 and Over)

The three most common causes of death for older adults in Birmingham are the same as for working age adults. Following this, mental and behaviour disorders (including dementia) also make up 12% of all deaths in this age group (Table 6).

During 2015/17 there were a total of 205 deaths from suicides in Birmingham. Of these, older adults (65 years +) accounted for 60 suicides during these years. Sixty percent of deaths in Birmingham are to residents over the age of 65. Leading causes include cancers, cardiovascular (heart) diseases, respiratory diseases and dementia.

Table 6: Number and Proportion of the Leading Causes of Death for Older Adults (aged 65 and Over) in Birmingham 2015-2017. Source: ONS Deaths 2015/17

Five Leading Causes of Death for Older Adults (2015/17)	Birmingham Deaths	% of Deaths
Cancer	5,123	25.0%
Disease of the Respiratory System	3,206	15.7%
Coronary Heart Disease (CHD)	2,465	12.0%
Mental and Behavioural Disorders	2,449	12.0%
Stroke	1,313	6.4%
All Causes of Death (Aged 65+)	**20,466**	**n/a**

2.7. Avoidable Deaths

There are some conditions which can be considered entirely preventable by interventions, particularly:[57]

- Tetanus, polio, and diphtheria through the use of vaccination.
- Tuberculosis through early treatment to limit spread.
- Diabetes early effective treatment to prevent complications.

There are also a number of premature deaths considered to be avoidable, due to the involvement of modifiable factors such as smoking and alcohol (Table 7), which have over 4,000 and 1,300 linked deaths in Birmingham respectively.

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[57] Office for National Statistics. Avoidable mortality in the UK: 2017 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2017 Accessed 16 June 2021.

Table 7: Factors Increasing the Likelihood of Developing Conditions Most Likely to Cause Premature Death.

Modifiable Factor	Impact	Attributable Number of Birmingham Deaths 2015-2017
Smoking	Linked to CHD, lung cancer and COPD. One in two lifelong smokers dies from their addiction – the single biggest avoidable cause of cancer in the world. 14% of adults in Birmingham are smokers.[58]	Over 4,000 deaths linked to smoking.
Alcohol	Men and women drinking high-risk levels of alcohol increased 13x risk of Alcoholic Liver Disease.[59]	Over 1,300 alcohol related deaths.
Air Quality	Links to CVD, COPD, and asthma. Children, pregnant women, older adults and those with pre-existing conditions are most vulnerable to adverse effects.[60]	Almost 500 deaths per year linked to particulate air pollution.[61]
Loneliness	People who feel socially isolated have a 30% higher risk of early death.[62]	Mental health accounted for 0.29% of total deaths across the city.
Physical Inactivity	Physical inactivity and a sedentary lifestyle are strongly associated with poor cardiovascular health. More than a third of adults in Birmingham are physically inactive.	Not Applicable
Obesity	Linked to Type 2 diabetes, CHD, some cancers and risk of stroke. One in four of 10-11 year olds in Birmingham are obese.	Not Applicable

The rates of avoidable deaths are compared nationally and regionally as a mortality rate for causes considered preventable (Table 8). Since 2001-03, Birmingham has continued to have a high mortality rate from these conditions compared to England and the West Midlands region.[63] Table 8 below shows that in 2015-17, Birmingham remained higher (220.8) than England (181.5) and West Midlands average (195.8).

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[58] Birmingham Heart Foundation. Heart Statistics. https://www.bhf.org.uk/what-we-do/our-research/heart-statistics Accessed 16 June 2021.

[59] Public Health England. Local Alcohol Profiles for England. https://fingertips.phe.org.uk/profile/local-alcohol-profiles Accessed 16 June 2021.

[60] Public Health England. Health matters: air pollution. https://www.gov.uk/government/publications/health-matters-air-pollution Accessed 21 June 2021.

[61] Public Health England : Public Health Outcomes Framework 3.01 - Fraction of mortality attributable to particulate air pollution Accessed 16 June 2021

[62] Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci. 2015;10(2):227-237. https://journals.sagepub.com/doi/10.1177/1745691614568352 Accessed 21 June 2021.

[63] Public Health England. Mortality rate from causes considered preventable (2016 definition). https://fingertips.phe.org.uk/search/preventable#page/4/gid/1/pat/6/par/E12000005/ati/102/are/E08000025/iid/92488/age/1/sex/4 Accessed 21 June 2021

Table 8: Comparison of the Rates of Death with Avoidable Factors (per 100,000)[64]

Location	Rate of Death with Avoidable Factors
Birmingham	220.8
Stoke-on-Trent	253.1
Sandwell	245.2
Wolverhampton	236
Walsall	230.4
Coventry	220.6
Dudley	204.4
Telford and Wrekin	199.5
West Midlands Region	195.8
Staffordshire	182.2
Warwickshire	171.8
Herefordshire	168.1
Worcestershire	165.7
Solihull	161.5
Shropshire	161
England	**181.5**

Figure 11 below shows that Birmingham's (220.8 per 100,000) rate of deaths with avoidable factors is higher than England's (181.5 per 100,000).

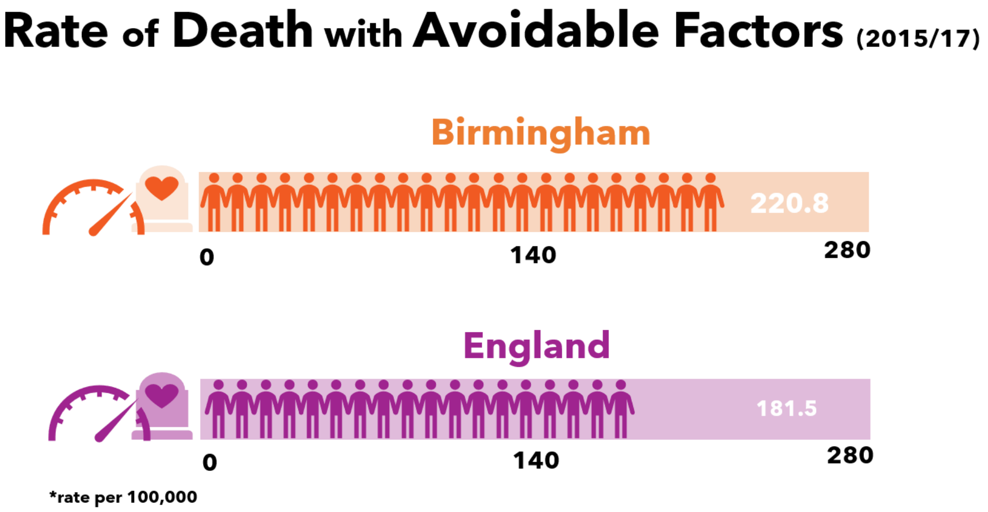

Figure 11: Rate of Death with Avoidable Factors in Birmingham and England (2015/17) per 100,000

Avoidable deaths affect the most deprived areas of the city, particularly Erdington and Ladywood (297 and 265 deaths respectively). There were significantly lower levels of preventable deaths in the more affluent areas of the city, such as Sutton Coldfield and Hall Green (135 and 188 deaths respectively).[65]

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[64] Public Health England. Public Health Outcomes Framework. Topic E: Healthcare and Premature Mortality. https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/1/gid/1000044/pat/6/par/E12000005/ati/102/are/E08000025/cid/4/tbm/1 Accessed 21 June 2021.

[65] Internal calculations of Office for National Statistics Deaths Data for 2015/2017.

3. End of Life Care

3.1. Service Provision

End of life care in Birmingham is delivered across a range of settings and locations, including acute hospital and community settings, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals, hostels and ambulance services. There is a complex mix of service provision; some provided as standalone contracts specifically for end of life or palliative care either in hospital, at home or in the community (e.g., hospice care).

However, there are many other services providing support to those at the end of life stage such as those provided by general practitioners (GPs), nursing and residential care homes, equipment loan stores, secondary care acute services and community healthcare district nurse services.

The main services provided independently from the third sector and hospices include:

- Hospice inpatient units.
- Community Specialist Palliative Care and follow-up, including Hospice at Home services.
- Support services for carers, patients and families.
- Specialist advice.
- Bereavement services.

3.2. Lived Experience

There are several surveys which have been used to provide the people's voice of their experience within this deep dive.

3.2.1. *What's Important to Me: A Review of Choice in End of Life Care* (2014)[66]

This review identified the following key findings from over 1,000 responses. These were:

- I want involvement in and control over decisions about my care.
- I want to be cared for and die in a place of my choice.
- I want access to high-quality care given by well trained staff.
- I want access to the right services when I need them.
- I want support for my physical, emotional, social and spiritual needs.
- I want the right people to know my wishes at the right time (through coordinated care).
- I want the people who are important to me to be supported and involved in my care.

3.2.2. *The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services)*[67]

This survey across England collected views from those who had been bereaved on the quality of care provided to their friend or relative in the last 3 months of life. The survey ran for 5 years and was commissioned by the *Department of Health* (2011-2012), and NHS England (2013-2015). It was administered by the *Office for National Statistics* (ONS).

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[66] The Choice in End of Life Care Programme Board. What's important to me: A review of choice in end of life care (2014). https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf Accessed 17 June 2021.

[67] Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015 Accessed 17 June 2021.

3.2.3. Birmingham and Solihull - A Strategy Consultation (2014)[68]

A local consultation by the Birmingham and Solihull Sustainable and Transformation Partnership during the development of an adult end of life strategy (2014) focused on the views of patients and carers, older people, religious groups and communities, and ethnic minorities. There were 3 key themes identified during the consultation:

- Theme 1: Availability of services
- Theme 2: Joined up, co-ordinated services
- Theme 3: Individualised data.

3.3. The Birmingham Experience

Key themes arising from these consultations are used to frame our exploration of the Birmingham experience.

3.3.1. Coordinated Care – Services Working Well Together

I want the right people to know my wishes at the right time

The *National Survey of Bereaved People (VOICES)* report (2013) considered the question of coordination of services in the last 3 months[69] (Table 9).

Table 9: National Survey of Bereaved People (VOICES) Report 2013

Question	Yes, definitely	Yes, to some extent	No, they did not work well together
When he/she was at home in the last three months of life, did all these services work well together?	41%	42.7%	16.4%
Did the hospital services work well together with his/her GP and other services outside of the hospital	30.5%	36.1%	33.4%

This survey reported concerns about how different services work together during end of life care. A third of bereaved people reported that hospital services did not work well with the GP and other services outside the hospital, but two thirds reported that it did, to some extent. Palliative care registers are intended to assist GP practices to manage the care of patients in their last 12 months of life and evidence suggests that patients on palliative care registers are more likely to receive well-coordinated care. The use of a care coordination process, such as the *Gold Standards Framework*, is not in consistent use in Birmingham either within or across organisations.

Since 2006/7, the *Quality and Outcomes Framework (QOF)* required the maintenance of a register of patients with palliative care needs, which has led to an increase in the number of

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[68] NHS Birmingham and Solihull Commissioning Group. BSol STP Ageing Well & Later Life End of life care workshop feedback April. https://www.birminghamandsolihullccg.nhs.uk/about-us/publications/get-involved/consultations-and-engagement/end-of-life-care Accessed 17 June 2021.

[69] Department of Health. First national VOICES survey of bereaved people: key findings report Appendix A: Findings by PCT Cluster. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216895/VOICES-Survey-Appendix-A.pdf Accessed 17 June 2021.

patients registered. Despite significant improvements in recent years, and going above the English average, the number of patients on palliative care registers (Table **10**) is low in comparison to death rates (Figure 12).

Table 10: Patients on the Palliative Care Register, Birmingham (2006/07–2019/20)

Year	Birmingham	England
2006/07	0.1%	0.1%
2007/08	0.1%	0.1%
2008/09	0.1%	0.1%
2009/10	0.1%	0.1%
2010/11	0.2%	0.2%
2011/12	0.2%	0.2%
2012/13	0.2%	0.2%
2013/14	0.2%	0.3%
2014/15	0.2%	0.3%
2015/16	0.2%	0.3%
2016/17	0.3%	0.4%
2017/18	0.4%	0.4%
2018/19	0.4%	0.4%
2019/20	0.4%	0.4%

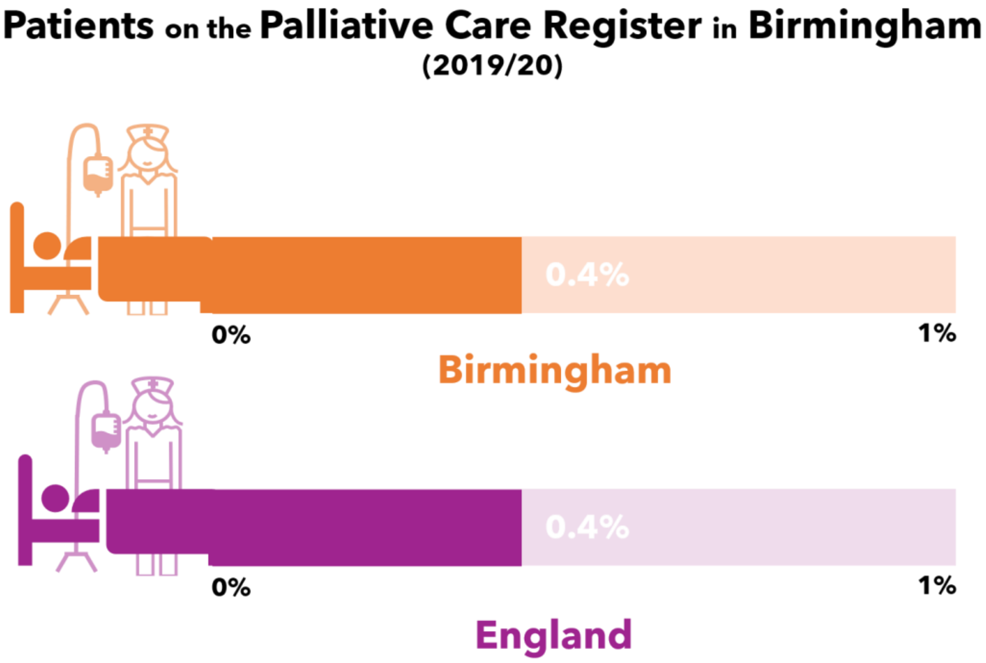

Figure 12: Patients on the Palliative Care Register, Birmingham and England (2019/20)

Birmingham Cross City and *Birmingham South Central CCGs* (now part of *Birmingham & Solihull CCG*) carried out an online survey of GP practice palliative care registers in February and March 2014. 54% of practices responded and 96% of these had a palliative care register. 40% of these practices were using the *Gold Standard Framework Needs Based Coding*[70] in

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[70] The Royal College of Practitioners. Prognostic Indicator Guidance (PIG) The Gold Standards Framework Centre in End of Life Care. https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf Accessed 17 June 2021.

their registers. Other areas of the West Midlands perform significantly better than this, such as Herefordshire and Worcestershire.[71]

3.3.2. Involvement and Control

I want involvement in and control over decisions about my care

Published evidence and the national guidelines recommend that *care plans* should be offered to every patient and carer in need of palliative care. However, this is not currently the case in Birmingham. Identifying individualised care as a key issue for Birmingham residents, the *Birmingham Strategy for End of Life and Palliative Care (2014)* stated:
"We will ensure that patients and their carers receive the information and support to manage care according to their choice and needs".[72]

A 2013 review by *Age UK*[73] found that only 5% of all adults reported having a living will or an *Advanced Care Plan*. This ranged from 1% of 18-34-year olds to 12% of people aged 75+. "*Feeling that death was a long way off*" was found to be the main reason for not discussing these things. Among those aged 75+, 23% also reported that they hadn't discussed these things due to feeling that death was a long way off, but also because "*people don't want to talk to me about my death"* (28%).

When patients receiving hospice care engaged in advance care planning, only 10% of those with a plan die in hospital, compared to 26% of those who have not engaged in advance care planning.

Research into the uptake of advance care planning within Birmingham is extremely limited and anecdotal. The systematic implementation of advance care planning varies significantly across the West Midlands. Some organisations have a specific team who undertake advance care planning as their main role and others will train larger numbers of their staff to do this. Different forms and systems are used city wide for recording patient wishes, making it difficult for organisations to follow them. One standardised form would allow the process to be streamlined.

Recently, *St Giles Hospice* ran a study to identify attitudes, knowledge, facilitators and barriers to advanced care planning practice in a hospice.[74] The key findings which facilitated the advance care planning discussion and process were:

- A shared online system of information.
- A locally agreed advance care planning framework.
- A coordinated approach that is part of the usual care a patient receives.
- Increased public awareness of the importance of making provision for what their choices and wishes would be should they become ill by more members of the public.

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[71] The Strategy Unit West Midlands. Palliative and End of Life Care in the West Midlands. https://www.strategyunitwm.nhs.uk/publications/palliative-and-end-life-care-west-midlands Accessed 17 June 2021.
[72] NHS. Integrated Palliative and End of Life Care Commissioning Strategy for Birmingham. 2014/15 – 2017/18.
[73] Age UK. End of Life Evidence Review. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_oct13_age_uk_end_of_life_evidence_review.pdf Accessed 17 June 2021.
[74] Healthwatch Staffordshire. Advance Care: Planning Exploring the barriers to a universal approach to End of Life Care. https://healthwatchstaffordshire.co.uk/wp-content/uploads/2019/11/ACP-detailed-report-_-VG-Signed-Off.pdf Accessed 17 June 2021.

Personal Health Budgets (PHBs) were first made available in 2014 under an initiative by *NHS England*. People who become eligible for *NHS Continuing Healthcare* funding under the *Fast Track Pathway* have a legal right to have a *Personal Health Budget*.

Successful schemes are running in various areas of England but there are none within end of life care in Birmingham. A recent report by the *Care Quality Commission* highlighted that the number of people receiving personal budgets and direct payments is low in Birmingham as a whole. This meant that fewer people had the chance to exercise choice and control over their care and support.[75]

Case study - Personal Health Budgets (PHBs) for End of Life Care[76]

A project was launched by the then *Director of Public Health* who had secured funding from the *Better Care Fund* to pilot PHBs for Birmingham residents. The pilot was designed to run until 30 patients had accepted a PHB. However, due to the early success of the scheme, evaluation has been requested sooner. *John Taylor Hospice* (JTH) and *Birmingham Heartlands Hospital* (BHH) have worked with other partners particularly *Birmingham Voluntary Service Council*, *University Hospitals Birmingham NHS Foundation Trust* and more recently *Birmingham and Solihull CCG*.

One of the most astonishing aspects of this project is that not one patient offered a PHB chose what would be the traditional offer made by hospitals for patients going home from hospital. Requests included hairdressing, a handyman, domestic help and podiatry.

There is good evidence from this small cohort that the level of control and freedom PHBs offer are a very important part of the future for patients at the end of their lives. However, the time frame chosen for this pilot meant that not all of those who could have benefited were able to receive a PHB.

3.3.3. High-quality Care and Well-Trained Staff

I want access to high quality care given by well trained staff

What's important to me: A review of choice in end of life care (2014)[77] identified access to high-quality care given by well trained staff as one of its key themes. End of life care in Birmingham is delivered across a range of settings and locations - including acute hospital and community settings, care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals, hostels and ambulance services - making delivery of care complex.

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[75] Care Quality Commission. Birmingham: Local system review report 2018. https://www.cqc.org.uk/sites/default/files/20180511_local_system_review_birmingham.pdf Accessed 17 June 2021.

[76] Birmingham Health and Wellbeing Board. Integrated Personal Commissioning - Personal Health Budgets - July 2018. https://birmingham.cmis.uk.com/birmingham/Decisions/tabid/67/ctl/ViewCMIS_DecisionDetails/mid/391/Id/0ee86f5a-3afd-44eb-b1f7-74f862223b2e/Default.aspx Accessed 17 June 2021.

[77] The Choice in End of Life Care Programme Board. What's Important to Me:.A Review of Choice in End of Life Care. http://qna.files.parliament.uk/qna-attachments/795201/original/CHOICE_REVIEW_FINAL_for_web.pdf Accessed 17 June 2021.

The outcomes of recent CQC inspections of end of life care services within the *Birmingham and Solihull STP* area revealed generally good to excellent service:

- NHS acute hospitals - End of life care service ratings - 4 "good", 1 "requires improvement" (5 services)
- Community hospitals - End of life care service ratings - 2 "good" (2 services)
- Hospices - 2 "good", 2 "outstanding" (4 services)

The quality-of-care experience in the last three months of life is addressed within the *National Survey of Bereaved Persons*.[78] The responses from carers in the Birmingham and Black Country area suggest they are experiencing a poorer standard of care compared to the England average (Table 11).

Table 11: Quality of Care Rating Birmingham and Black Country Area Compared with England 2015

Area/ Quality Rating	Outstanding	Excellent	Good	Fair	Poor
Birmingham & Black Country	11.8%	27.4%	33.5%	15.9%	11.4%
England	12.4%	30.8%	33.5%	14.0%	9.4%

3.3.4. Choice of Place to Die

One of the key findings of the *National End of Life Strategy* was that, given the opportunity and right support, most people would prefer to die at home. In practice, only a minority do so with many dying in an acute hospital.

The limited availability of local insight makes it difficult to judge how Birmingham is performing on meeting patient wishes regarding end of life care in the patient place of choice. One hospital trust regularly performs a bereavement survey with the relatives of the patients 2-3 weeks after every death, and an outcome of this survey is that 80% of the respondents felt that the hospital was the most appropriate place for their loved one to die. Although this information should be interpreted with caution, this seems to be in line with the national survey (Table 12).

Table 12: National Survey of Bereaved People (VOICES) Report 2013 – Right Place

Question	Yes	No	Not Sure
On balance, do you think that he/she died in the right place?	82.2%	10.8%	7.1%

There is no current evidence available about whether deceased persons have died in their preferred place of death. There is also no data available on whether patients are receiving end of life care within their place of death for Birmingham.

Over half of deaths recorded by the *Office for National Statistics* for those aged over 65 years occur in hospital (54%). Most infant deaths occur in hospital (94%), indeed never having left hospital. The majority of child deaths occur in hospital also, with only 4% in a hospice or

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[78] Office for National Statistics. National Survey of Bereaved People (VOICES): England, 2015. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015 Accessed 17 June 2021.

elsewhere. However, half of working age adults (aged between 18-64 years) die in hospital, with one third dying at home and 9% in a hospice.[79] Most of the people who died in hospital were likely to be an emergency admission, and either under 24 years of age or between 65 and 84 years.

Patients dying from cancer, dementia, circulatory diseases and respiratory conditions spent a significant proportion of time in hospital in their last year of life. Over the three-year period, from 2013 to 2015, patients dying of these four conditions spent more than 1.9 million nights in hospital in their last 12 months of life, occupying more than 20% of all general and acute beds in the West Midlands. On average, patients spend more than 6 of their last 52 weeks in an acute hospital bed.[80]

Since 2011, Birmingham has experienced consistently higher numbers of hospital deaths than the national average for England. Hospital death rate variations have not changed significantly since 2011, but all have seen reductions at similar rates (Figure 13).

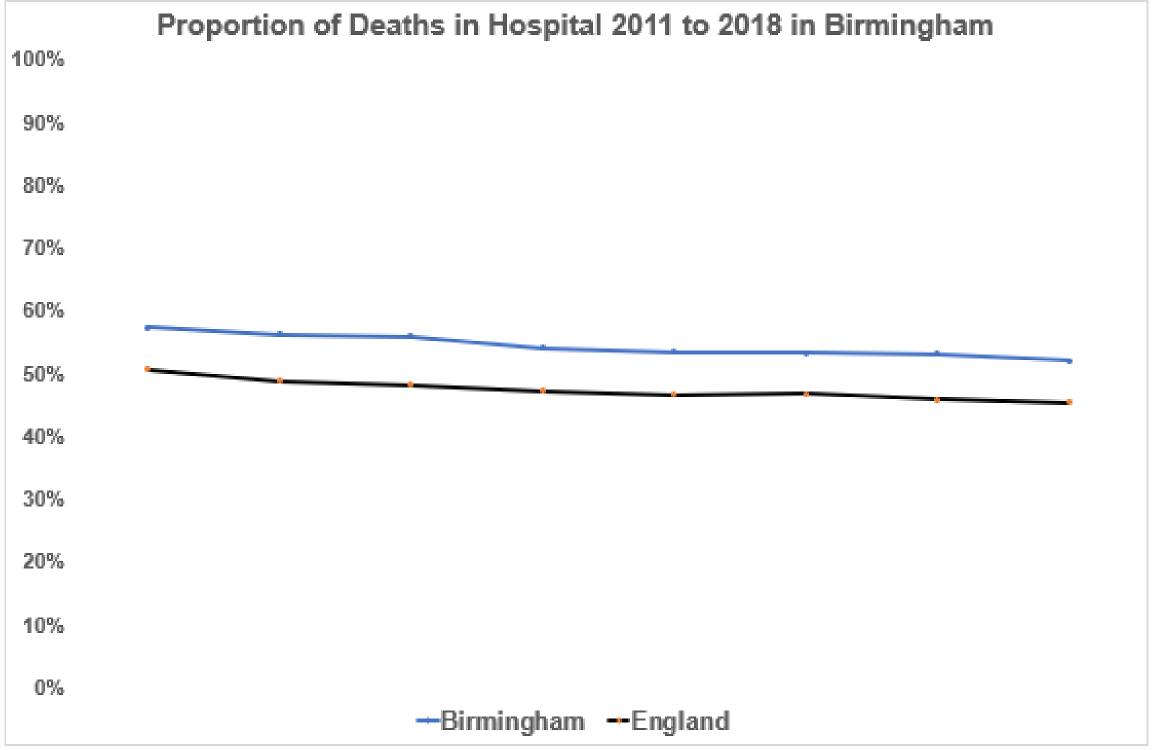

Figure 13: Comparison of the Proportion of Deaths in Hospital in Birmingham and England (2011-2018)

There is generally good coverage by hospices in the Birmingham region, with Birmingham and Solihull having a rate of 7.0, one of the highest rates of hospice beds per 1,000 deaths in the West Midlands region (Table 13). The next highest is Staffordshire and Stoke-on-Trent with a rate of 6.9.

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[79] Based on internal analysis of HES Inpatients data supplied by NHS Digital to BCC.
[80] Based on internal analysis of HES Inpatients data supplied by NHS Digital to BCC.

Table 13: Adult Hospice Beds per 1,000 Expected Deaths by STP

Location	Adult Hospice Beds per 1,000
Black Country and West Birmingham	3.8
Birmingham and Solihull	7
Coventry and Warwickshire	5.3
Herefordshire and Worcestershire	6
Staffordshire and Stoke-on-Trent	6.9
Shropshire and Telford	6.3

3.3.5. Timely Delivery of Services

I want access to the right services when I need them

Respondents identified the importance of this, with comments such as:

- "*Providing a service which is accessible to all, 24 hours a day, seven days a week*"
- "*Too many patients end up in A&E out of hours because families don't know what else to do*"

These comments support the move to a more accessible service closer to home, responsive to patient's views and providing choice which is available 24 hours a day, 7 days a week, and 52 weeks a year in a location other than hospital emergency departments.

Currently, the *Community Specialist Nursing Service* is available from the hospices within the Birmingham area between 08:30-17:00, Monday to Sunday and on-call facilities are available to patients outside these hours. Medical cover is provided by consultants in palliative medicine.

Specialist palliative and end of life care services are not equitably provided and there are major gaps in the provision of:

- Access to 24/7 specialist advice
- Homecare services
- Specialist outreach services (and in reach services to acute trusts)

The findings of the *National Survey of Bereaved People (2013)*[81] (Table 14) suggest that end of life service provision in Birmingham is rated below the English average by service users, despite the higher availability of hospice beds.

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[81] Office for National Statistics. National survey of bereaved people (VOICES): 2013. https://www.gov.uk/government/statistics/national-survey-of-bereaved-people-voices-2013 Accessed 17 June 2021.

Table 14: National Survey of Bereaved People (2013)

Overall, do you feel that the care he/she got when he/she needed care urgently in the evenings or weekends in the last three months of his/her life was...?	Outstanding	Good	Fair	Poor
Birmingham & Black Country	24.5%	34.8%	21.7%	19.1%
England	26.5%	38.8%	19.2%	15.5%

Ambitions for Palliative and End of Life Care identifies 24/7 service access as one of the key elements of its ambitions, stating that '24/7 expert palliative and end of life care services need to be available and that their availability around the clock is key to building a system of high-quality care.'[82]

3.3.6. Support for the Bereaved

I want the people who are important to me to be supported and involved in my care

Nationally, the number of bereaved older people is set to increase by more than 100,000 in the next 20 years, from 192,000 in 2014, to 294,000 newly bereaved people every year by 2039.[83]

There is a variety of bereavement services available in Birmingham ranging from peer support groups to counselling and general advice. These are provided mainly by the volunteer sector, e.g. organisations such as CRUSE, local hospices and the *Birmingham Bereavement Advice Service*.

Currently, there are no clear estimates of how many people are affected by bereavement in the Birmingham region. There are approximately 8,500 deaths in Birmingham per year,[84] and currently around 900-1,000 residents access services such as CRUSE each year. Using data provided by CRUSE, the average time people appear to access support is 2-6 months after bereavement and the year after. Only a third of those that access the service are male and only 23% come from ethnic minority groups.[85]

The *National Survey of Bereaved People* identified a need for improvement in the help and support provided by healthcare teams at the time of death. The survey enquired about support around the time of death (Table 15).

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[82] National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. https://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf Accessed 17 June 2021.

[83] Independent Age. Good grief: Older people's experiences of partner bereavement https://www.independentage.org/policy-and-research/research-reports/good-grief-older-peoples-experiences-of-partner-bereavement Accessed 17 June 2021.

[84] Office for National Statistics Deaths. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths Accessed 17 June 2021.

[85] Based on internal analysis of CRUSE data sent directly to BCC Public Health.

Table 15: National Survey of Bereaved People (2013)

Were you or his/her family given enough help and support by the healthcare team at the actual time of his/her death?	Yes, definitely	Yes, to some extent	No, not at all
Birmingham & Black Country	56.1%	28%	16%
England	59.8%	26.4%	13.9%

A 2018 report by Independent Age, *'Good Grief: Older People's Experiences of Partner Bereavement',*[86] highlighted significant issues with loneliness and isolation:

- Nearly a third of bereaved people over 65 see themselves as very lonely, compared to just 5% of people of the same age who have not lost their partner.
- More than 1 in 5 people said that loneliness was the hardest thing to cope with after the death of their partner.

Birmingham's *Neighbourhood Network Scheme (NNS)*[87] is aiding development of assets within the community. The purpose of NNS is primarily to help develop assets for older people (over 50 years of age) to connect to individuals, groups, organisations, activities and places in their neighbourhoods in order to improve their health and wellbeing and reduce their reliance on statutory care services.

During the assessment of the NNS, bereavement groups were raised as a development need in the city. Using the NNS community mapping, 10 local bereavement groups were identified.[88] In addition to CRUSE, these groups connect with the local hospices and bereavement support provided by NHS hospitals. At present, Hall Green, Erdington, and Sutton Coldfield have the fewest local support opportunities.

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[86] Independent Age. Good grief: Older people's experiences of partner bereavement.https://www.independentage.org/policy-and-research/research-reports/good-grief-older-peoples-experiences-of-partner-bereavement Accessed 17 June 2021.

[87] Birmingham Neighbourhood Network Schemes. https://brumnns.wordpress.com/

[88] Internal analysis of the NNS Community Asset Directory data 2019.

Case Report –The Bereavement Help Point Group (Bereavement Project of the Year 2016) – St Giles Hospice – Carers and Family Experience[89]

This is a peer support group run by support volunteers who are trained to help with bereavement. Approximately 20-30 people attend this weekly group consisting of members who have recently joined as well as members who have been attending for years.

Discussion with the bereavement help point group revealed several key issues with seeking help following bereavement of a family member or spouse.

"The group has been a lifeline for me over the past few years"

A significant proportion of the attendees had been made aware of the group through word of mouth. Two attendees had responded to an advert in the paper.

Three members of the group stated that they had attended their GP practice due to their ongoing grief. However, none had been given details of any bereavement groups. There was a clear theme regarding social isolation, and a general feeling of loneliness following the death of a spouse. Attendance was often not directly after the bereavement, with some stating they felt deeply affected up to 5 years later. Long standing members of the group developed lasting and social relationships with other members of the group.

All members of the group were keen to point out there was a lack of information about the available bereavement support.

3.3.7. Support for Carers and Families

I want the people who are important to me to be supported and involved in my care

> *"for my father in law … [there was] absolutely no support outside the hospital, no social support at all within the community so everything … fell on his daughter … on my wife, and the mother to look after him and whenever he wasn't in hospital that meant almost 24 hour vigils really"*[90]

Data from the *2011 Census* shows that 10% (107,380) of the Birmingham population provide between 1 and 50+ hours of unpaid care per week.[91] The number of older people in need of care was expected to exceed the number of family members able to provide informal care for the first time in 2017. By 2030, an estimated 230,000 older people in England who need care for more than twenty hours a week could be left without family to help. The estimated number of people aged 65 and over without children to care for them will almost double before the end

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[89] St Giles Hospice care. Bereavement support for adults. https://www.stgileshospice.com/how-we-can-help-you/our-care/bereavement-support/support-for-adults/ Accessed 17 June 2021.

[90] Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation: *Palliative Medicine* 2017, Vol. 31(1) 53–62) https://pubmed.ncbi.nlm.nih.gov/27260168/ Accessed 17 June 2021.

[91] Office for National Statistics Census 2011. Provision of Unpaid Care. https://www.nomisweb.co.uk/census/2011/qs301ew Accessed 17 June 2021.

of the next decade and by 2030 there will be more than 2 million people in England without a child to care for them if needed.[92]

The *Adult Social Care Outcomes Framework* indicators[93] provide a valuable snapshot of the experience of carers (Table 16 below). This demonstrates that although Birmingham carers experience a similar quality of life to carers in England and Birmingham's statistical neighbours, the experience of structured support was significantly lower, particularly when leaving hospital. However, in terms of carer/family involvement in decision making in the last few months of life, Birmingham (77.6%) was only slightly lower than the national average (77.9%), according to the *National Survey of Bereaved People* 2013. (Table 16)

Table 16: Adult Social Care Outcomes Framework Indicators (2016/17)

Outcome	**Birmingham Average**	**England Average**	**Statistical Neighbours Average**
Carers - Quality of Life Score (0-12)	7	7.7	7.3
Proportion of carers who report they were included or consulted in discussions about the person they care for	59%	70.6%	68.1%
Proportion of people who use services and carers who find it easy to find information about services	65%	73.5%	74.3%
The proportion of carers who find it easy to find information about support	47.9%	64.2%	47.5%
Delayed transfer of care from hospital per 100,000	20%	14.9%	13.9%
The proportion of carers who report they had as much social contact as they would like	28.3%	35.5%	31.3%

Table 17: National Survey of Bereaved People Responses of Birmingham and Black Country Residents (Voices 2013)

Key Question from Survey	**Key Results**
Q49. Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?	Yes – 77.6% No – 22.2%

During 2019, carers receiving financial assistance from Adult Social Care in Birmingham were asked to complete a survey. A total of 530 carers responded to a variety of questions about

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[92] IPPR Press Release 2014. More people needing social care than family carers available from 2017. https://www.ippr.org/news-and-media/press-releases/more-people-needing-social-care-than-family-carers-available-from-2017 Accessed 17 June 2021.
[93] Birmingham City Council. Adult Social Care Outcomes Framework December 2017. https://www.birmingham.gov.uk/downloads/file/8894/adult_social_care_outcomes_framework_december_2017 Accessed 17 June 2021.

the people they cared for. This included the age of the patient cared for, the reason why they needed care, and whether this care was done by them in their own home or elsewhere. Table 18 shows the age split of patients, with the majority being over 65 years in age.[94]

Table 18: Age of Patients that are being Cared for by Carers in Birmingham (2018-2019)

Age group	**18-24**	**25-34**	**35-44**	**45-54**	**55-64**	**65-74**	**75-84**	**85+**
Percentage	6.8%	6.3%	6.3%	8.3%	12.0%	14.6%	24.9%	20.9%
Number	36	33	33	44	63	77	131	110

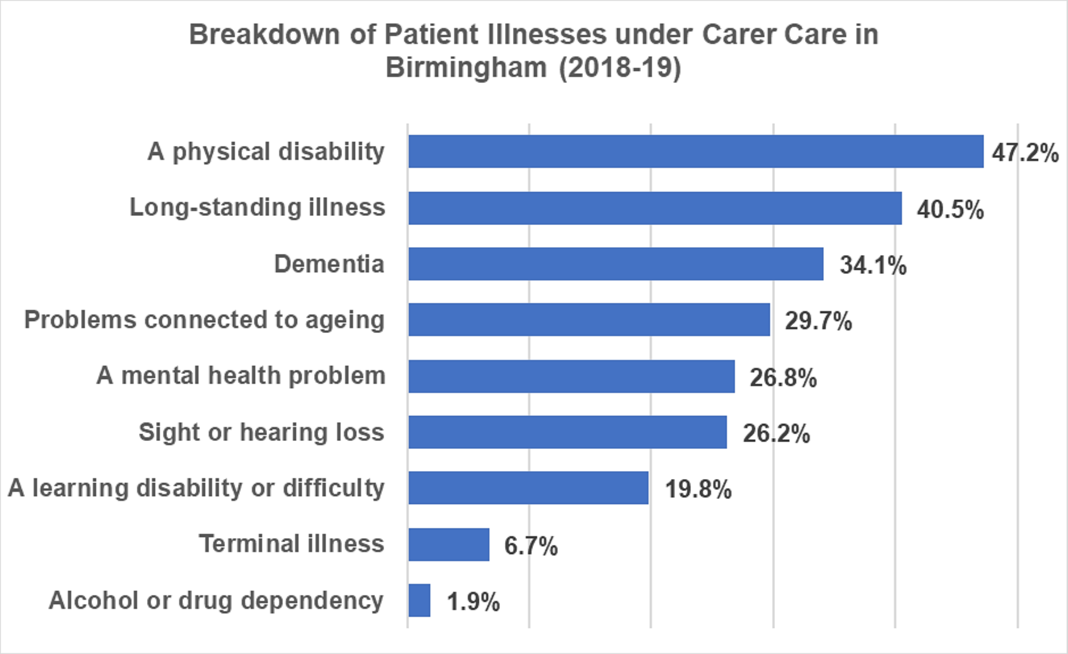

Figure 14: Summary of Patient Illnesses which are Cared for in the Community in Birmingham by Carers (2018-2019).

Figure 14 (above) shows the different patient illnesses under carer care, with physical disability the highest percentage at nearly half of all patients. There are a variety of reasons why additional care is required to ensure that patients can lead a good quality of life with dignity in their final years from long-standing illness and physical disabilities to mental health and dementia.

Frailty, mobility, terminal diseases and cardiovascular diseases require people on hand to provide this care and as with dementia this is usually provided by members of their own family (normally partners or children), often until the disease develops to a point where more clinical assistance is required. In all cases, *Birmingham City Council* attempts to provide support for patients who choose to remain at home for their wellbeing. These direct payments to the patients provide them with the ability to acquire care (professional). Total commissioned places at the end of March 2020 were as follows (Table 19):[95]

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[94] BCC internal calculations based on AsCOF survey. https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19 Access 9th July 2021.

[95] Adult Social Care Market Intelligence data.

Table 19: Care Provision Places in Birmingham Summary (March 2020)
Source: Birmingham City Council Adult Social Care February 2021

Total Funded Places	18 to 64	65+	Total
Care Home	957	2,873	3,830
Other Placement	650	369	1,019
Community	1,317	3,022	4,339
Community- Direct Payment	1,461	1,339	2,800
Total	**4,385**	**7,603**	**11,988**

Dementia and the burden of dementia care form one of the leading public health issues relating to ageing. Many of Birmingham's carers will be dealing with the effects of this illness, which is a growing public health problem. Data modelling suggests that 1 in 3 people born in the UK in 2015 will develop dementia during their lifetime.[96] Forecasting provided by POPPi predicts that in the short term, there will also be an increase in over 65s living with dementia in Birmingham from approximately 11,000 in 2020 to nearly 15,000 by 2040.[97] This is significantly higher than current QOF register figures show, suggesting that dementia is currently under-reported in GP surgeries across the city and that many patients and carers in Birmingham are not receiving the necessary health care services that are available (e.g. diagnosis, medication, *Memory Assessment Service* support, financial support and care agency support).[98]

The *Birmingham & Solihull Dementia Strategy* (2020) included a study of dementia carer and patient views, collected at a number of events across the city during 2019. Responses to questions about the whole dementia journey, from diagnosis to death were recorded.

Participant feedback pointed to both successes and failures in dementia service provision for patients. Participants had mixed experiences of the diagnosis process. Ratings were as follows exceptional (13%), good (38%), average (25%), needs improvement (25%) (Figure 15).

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[96] Office of Health Economics: Estimation of Future Cases of Dementia from those Born in 2015. https://www.ohe.org/publications/estimation-future-cases-dementia-those-born-2015 Accessed 7 July 2021.

[97] Poppi: Projecting Older People Population Information. https://www.poppi.org.uk/index.php Accessed 6 July 2021.

[98] BCC internal calculations based on NHS Digital Quality and Outcomes Framework. https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2018-19-pas Accessed 9th July 2021.

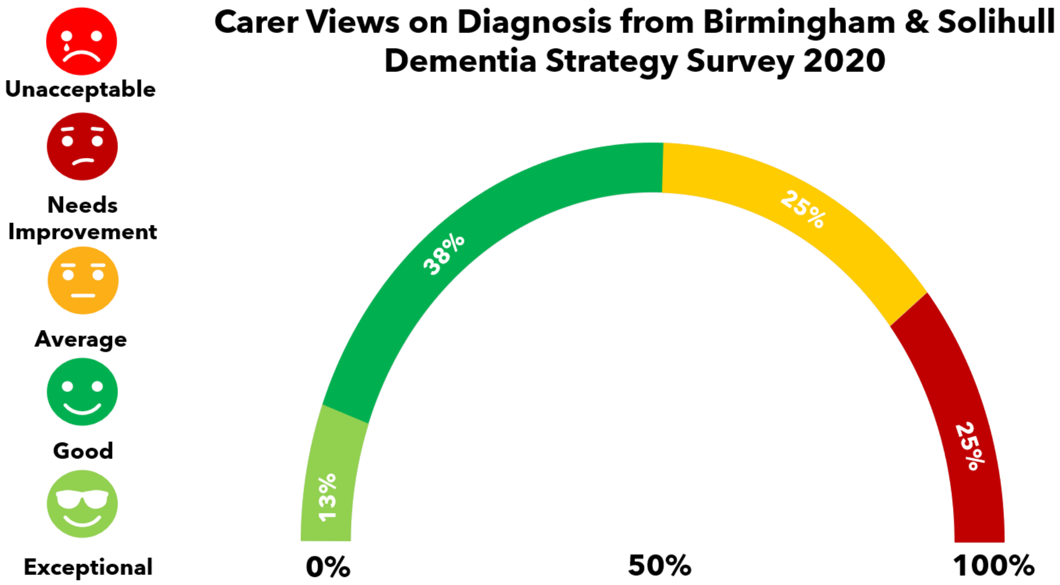

Figure 15: Carer Views on Diagnosis from Birmingham & Solihull Dementia Strategy Survey 2020

Carers views on access to services show cause for concern, with the majority rating this as unacceptable or needing improvement. Exceptional (4%), good (19%), average (19%), needs improvement (51%) unacceptable (8%) (Figure 16).

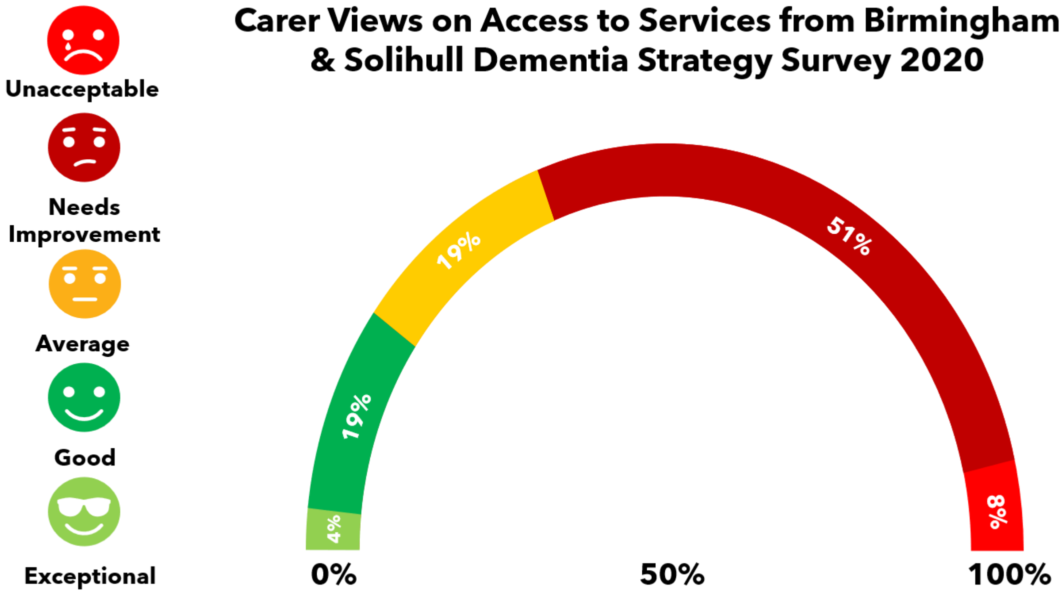

Figure 16: Carer Views on Access to Services from Birmingham & Solihull Dementia Strategy Survey 2020

Ongoing Support was also rated poorly, with nearly 50% of participants rating it as unacceptable or needs improvement. Good (24%), average (27%), needs Improvement (45%), unacceptable (4%) (Figure 17).

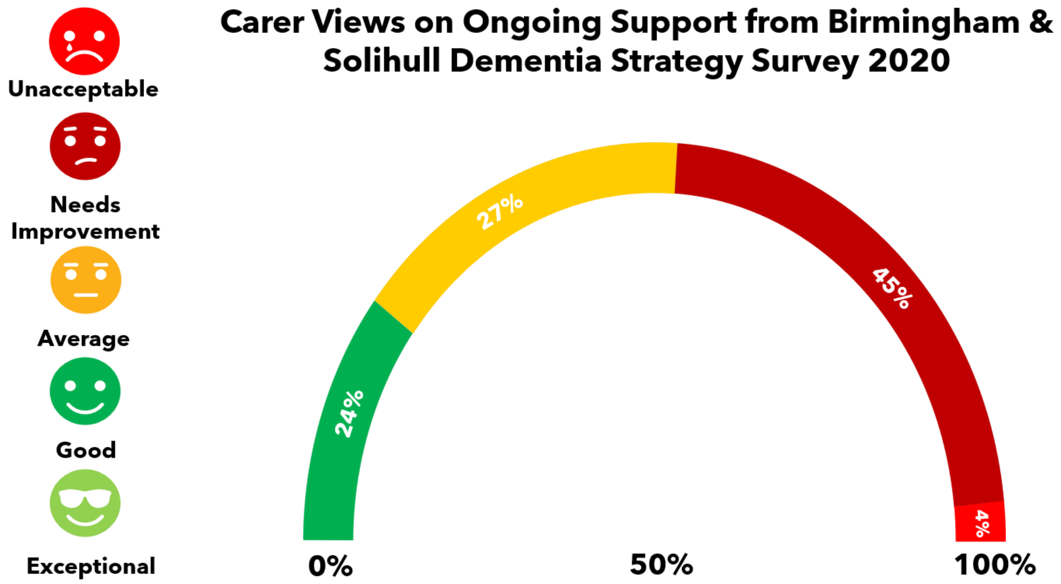

Figure 17: Carer Views on Ongoing Support from Birmingham & Solihull Dementia Strategy Survey 2020

Carers views on Respite for Carers showed cause for concern. Most participants rated this as unacceptable (15%) or needs improvement (57%) and fewer participants rating it as good (13%) or average (15%) (Figure 18).

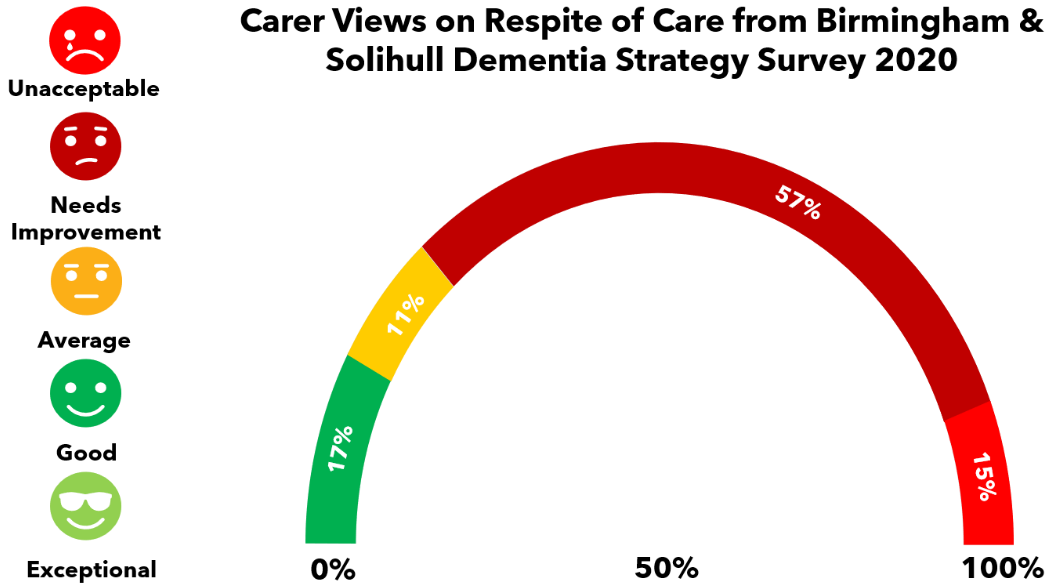

Figure 18: Carer Views on Respite for Carers from Birmingham & Solihull Dementia Strategy Survey 2020

Participants noted that End of Life Care needed improvement, as 15% rated this as unacceptable, 28% needs improvement, 24% average, 28% good and 5% exceptional (Figure 19).

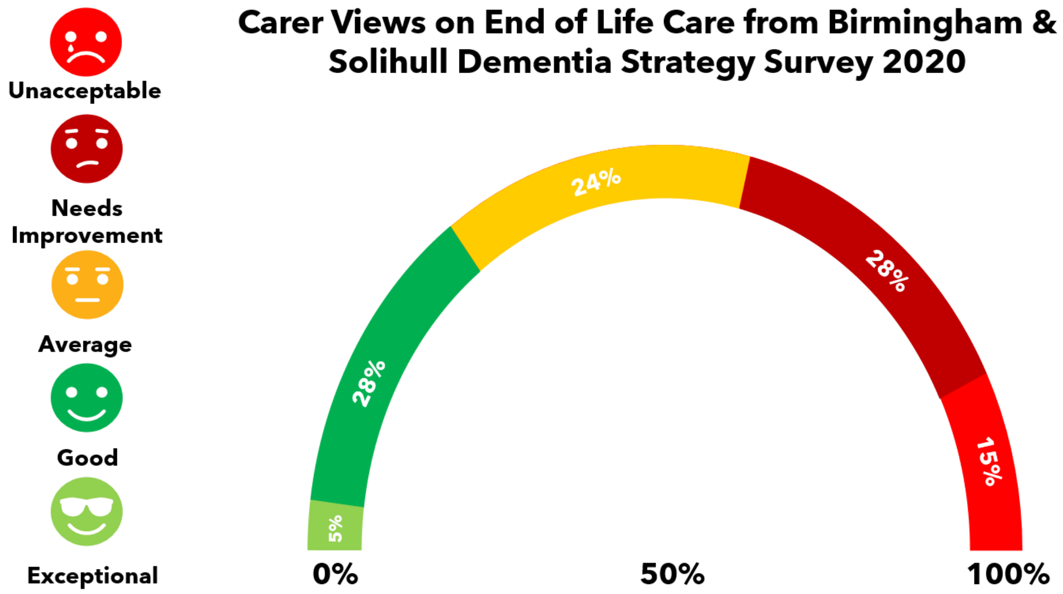

Figure 19: Carer Views on End of Life Care from Birmingham & Solihull Dementia Strategy Survey 2020

The *Neighbourhood Network Scheme* mapped the number of community assets which support carers across Birmingham. These can be seen in Table 20 by constituency. This mapping exercise identified over 100 community carer support assets. The highest number of assets were located in Sutton Coldfield (34) and Northfield (21) constituencies, whereas Erdington (2) and Ladywood (3) contained the lowest number of assets. There appears to be an inequality of support around areas of the city, with less provision located within areas of high deprivation.[99]

Table 20: Community Assets which Support Carers in the Community

Location	Number of Community Assets Supporting Carers
Citywide	3
Edgbaston	11
Erdington	2
Hall Green	8
Hodge Hill	7
Ladywood	3
Northfield	21
Perry Barr	7
Selly Oak	7
Sutton Coldfield	34
Grand Total	**103**

Studies suggest that the potential burden of caring responsibilities can be linked to poor mental health. Interventions that support carers to protect their mental health both during their carer responsibilities and afterwards (e.g., carer grief) need to be developed.[100] A needs

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[99] Neighbourhood Network Scheme Asset Directory. 2019. Accessed April 2022.

[100] Tseliou, F. et al (2019): Mental Health of Carers in Wales: A National Population Survey. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)32889-2/fulltext Accessed 8 July 2021.

assessment into care giving in Birmingham is part of this evidence review work programme, with research currently scheduled to be undertaken in 2024.

3.3.8. Holistic Support

I want support for my physical, emotional, social and spiritual needs

Dying and death can be powerful sources of emotional turmoil and spiritual or existential distress. Many people with a life shortening illness will experience some distress at some point, which can be related to physical, psychological, emotional, social or spiritual reasons, or a combination of these.

There is currently little evidence available regarding the end of life experience nationally, and this is also the case in Birmingham. *Spiritual Care at the End of Life*: a systematic review of the literature completed by the *Department of Health* in 2011,[101] reviewed the connection between spirituality and spiritual care with end of life issues and care. It found a significant gap in this area.

The *National Survey of Bereaved People* (VOICES) discussed spiritual and religious needs in the last 2 days of life. 60% of respondents described themselves as feeling considered and supported (Table 21). However, little information is available regarding the consideration of faith before the last 2 days of life.

Table 21: (Q35) In the last two days of life, were his/her spiritual and/or religious needs considered and supported?

Were his/her spiritual and/or religious needs considered and supported?	**Strongly agree**	**Agree**	**Neither Agree or disagree**	**Disagree**	**Strongly Disagree**
England	29%	30.1%	25.8%	9.4%	5.7%

Data collected from the *2011 Census* tells us that the six biggest religions in England and Wales are Christianity, Islam, Hinduism, Sikhism, Judaism and Buddhism. 46.1% of Birmingham residents reported that they were Christian and more than 1 in 5 people said they were Muslim, making Islam the second largest religion in Birmingham.[102] Spiritual services are provided in hospices, hospitals by the *Birmingham Council of Faiths* and other support within the community.

There is also evidence that the holistic needs of certain minority groups fail to be met at the end of life. The lived experience of ethnic minorities, the homeless and the LGBT community are discussed in Section 5.

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[101] University of Hull. Spiritual Care at the End of Life: a systematic review of the literature. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215798/dh_123804.pdf Accessed 17 June 2021.

[102] Office for National Statistics Census 2011. Religion. https://www.nomisweb.co.uk/census/2011/ks209ew Accessed 17 June 2021.

4. Services

PHE and NICE guidance both recommend that patients who are thought to be in their last year of life should be encouraged to put together an *Advanced Care Plan*. This is designed to ensure that the patients' views on their end of life care and death are respected and followed and enables families (and other stakeholders) to be fully informed of the patient's wishes. The *Advanced Care Plan* is usually put together between a medical practitioner and the patient, often with the patient's family present. The decision can be updated as many times as the patient requests. Health care staff are also advised to be mindful of the effect that death has on the bereaved.

Part of *Birmingham and Solihull CCG End of Life Strategy* over the last six years has been to develop a sustained approach ensuring this happens. The CCG helps clinicians with guidelines on how to approach the subject of death. *Sandwell and West Birmingham CCG* also care for Birmingham residents and in 2018 they were nominated for an HSJ award for their '*Connective Palliative Care'*[103] approach, which drew together the main strategy guidelines and ensured that all services worked together across the CCG to offer the patient and bereaved the best experience possible.

Birmingham's *End of Life Care Strategy* was created by local CCGs and adheres to national guidance. It is circulated to all organisations in Birmingham that offer commissioned/non-commissioned services to the dying and the bereaved. Local CCGs are provided with additional funds to ensure that each patient receives the care, respect and dignity to which they are entitled. During 2019/20, this equated to £526,000 for the population of Birmingham (approx. 0.46 pence per person); whereas the national average (across England) was 0.45 pence per person. However, it is believed that most of these funds in Birmingham would have been used for the 75+ population, meaning that the funds would equate to £5.32 per person.[104]

4.1. Services Offered for Palliative Care

4.1.1. Hospital Care

Hospital care in Birmingham is provided by two NHS Trusts: *University Hospitals Birmingham NHS Foundation Trust* (UHB) and *Birmingham Women's and Children's NHS Foundation Trust*. UHB is the larger of the two trusts, incorporating five hospitals (*Queen Elizabeth Hospital*, *Heartlands Hospital*, *Solihull Hospital*, *Good Hope Hospital* and *Birmingham Chest Clinic*). Each hospital has a specific contact for palliative care - offering advice to staff and patients alike.[105]

Approximately 59% of all deaths in Birmingham between 2016 and 2018 occurred at one of the UHB hospitals.[106] Many of these deaths were from short term illnesses where the ability to perform successful palliative care was not possible due to the sudden nature of death. The care offered often extends to ensuring dignity and help to the bereaved. UHB have specific

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[103] SWBCCG. Sandwell and West Birmingham CCG achieves national recognition for improving end of life care. https://sandwellandwestbhamccg.nhs.uk/news-a-events/2094-sandwell-and-west-birmingham-ccg-achieves-national-recognition-for-improving-end-of-life-care Accessed 17 June 2021.

[104] Produced by Birmingham Public Health intelligence based on analysis from NHS Digital.

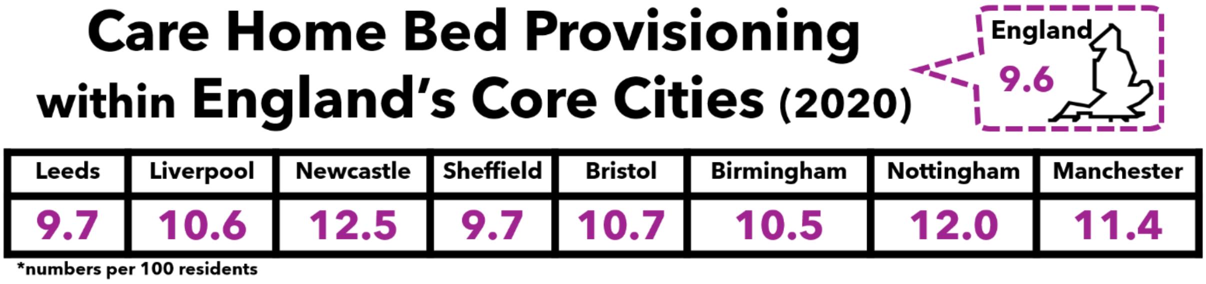
[105] University Hospitals Birmingham NHS Trust. Supportive and palliative care. https://www.uhb.nhs.uk/coronavirus-staff/clinical-info-pathways/supportive-palliative.htm Accessed 17 June 2021.

[106] Produced by Birmingham Public Health intelligence based on analysis from NHS Digital

wards that offer bed space to patients in the end stages of their illnesses. At *Birmingham's Children Hospital*, *Magnolia House* is a "calm and peaceful" facility specifically designed for delivering life-changing or difficult news to parents about their children and making decisions about palliative care. There are opportunities for children and families to access therapies through play, massage, counselling and other activities.[107]

4.1.2. Care and Nursing Homes

Birmingham City Council currently commissions approximately 300 care/residential homes and indirectly commissions (or supports) approximately 200 more. Much of their care programme supports a wide range of disabilities, old age care and frailty.[108] Some of the care homes also provide palliative care and specialise in the care of patients who require this service. Figure 20 shows the number of beds (per 100 of the population) 75+ year olds in each of the core cities. Birmingham's rate (10.5) is higher than the national average (9.6), although not as high as some other core cities.



Care Home Bed Provisioning within England's Core Cities (2020)

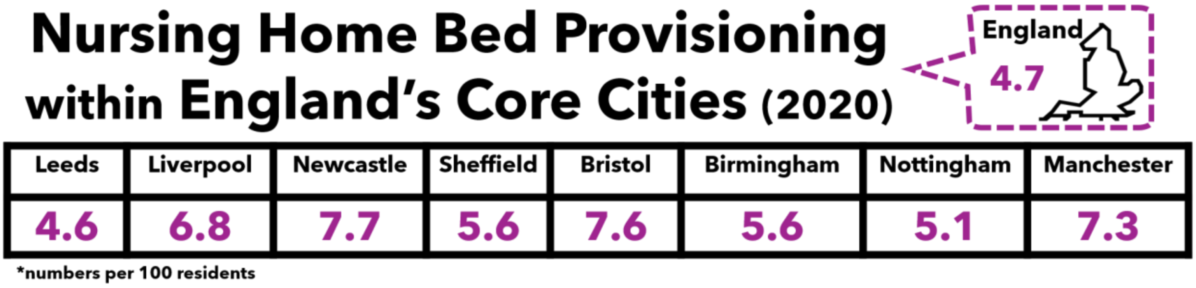
England 9.6

Leeds	Liverpool	Newcastle	Sheffield	Bristol	Birmingham	Nottingham	Manchester
9.7	10.6	12.5	9.7	10.7	10.5	12.0	11.4

*numbers per 100 residents

Figure 20: Care Home Bed Provisioning within England's Core Cities per 100 75+ (Source: Public Health Outcomes Framework (Fingertips) 2020

Figure 21 shows the number of beds in nursing homes in Birmingham available for those over 75 (per 100 of the population). The rate in Birmingham (5.6) is higher than the national average (4.7), but lower than some of the core cities.



Nursing Home Bed Provisioning within England's Core Cities (2020)

England 4.7

Leeds	Liverpool	Newcastle	Sheffield	Bristol	Birmingham	Nottingham	Manchester
4.6	6.8	7.7	5.6	7.6	5.6	5.1	7.3

*numbers per 100 residents

Figure 21: Nursing Home Bed Provisioning within England's Core Cities per 100 75+ (Source: Public Health Outcomes Framework (Fingertips) 2020

4.1.3. Hospices and Respite Care

There are two main hospices in Birmingham that serve the population. The *John Taylor Hospice* is located in the north of the city in Erdington and dates back to the early 1900s. *St Mary's Hospice* is based in the Selly Oak constituency, to the south of the city. Both are funded by grants and charitable local donations (e.g., fundraising and wills).

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[107] Birmingham Women's and Children's Trust. Magnolia House. https://bwc.nhs.uk/magnolia-house Accessed 17 June 2021.

[108] Internal data provided by BCC Adult Social Care.

There are also NHS funded respite homes/hospices located close to hospital sites around the city. These include *Acorns* (the children's hospice) and *St Giles Nursing Home*, which caters for Birmingham residents who, through their *Advanced Care Plans*, have decided that their preferred place of death would be a hospice. NHS hospices are mainly used for cancer patients rather than other terminal illnesses. However, at the time of the last strategy, aims were introduced to extend care to other terminal illnesses too.

Many of the localised care facilities work together in partnerships, to provide patient focused end of life care. In 2018, the *Birmingham & Solihull CCG* relaunched a strategy, which enhanced the strategies that were already in place and included care guidelines to support the bereaved.

Various charities including *Marie Curie* and *Macmillan Cancer Care* also provide respite and home care for palliative care patients. Part of the NHS/NICE guidance is to help ensure that palliative care is patient focused and can be delivered in the community when it is the patient's choice. This is partly funded from *Personal Health Budgets*, from which carers can be employed. These budgets are based on 'need' and rarely cover every possible contingency. Where required, *MacMillan* and *Marie Curie* often provide additional care and support, primarily for cancer patients.

During 2017/8, Birmingham's local hospice, local authorities and NHS ran a series of conferences to involve members of the community in the development of the new strategy for end of life care. Various questions were discussed in order to identify areas where services needed to improve. This method of direct contact with users (the community) is referred to as an '*asset-based approach*'[109]; and had been successfully adopted by the CCG in 2013 when producing the previous *End of Life Care Strategy*, which recommended:

- Better communication between partners and the local community.
- More information around what services are available and how to obtain them.
- A request to further promote discussions around death (which was commented on during the conference as being a 'taboo' subject).

4.2. Coroner, Public Health Funerals and Other Statutory Services

4.2.1. Funeral Services

In Birmingham, there are 11 cemeteries, 3 crematoria, 17 closed churchyards and 489 acres of burial ground. In 2018/19, there were 4,770 cremations and 2,636 burials. Over the past ten years, this has equated to 66% cremations and 34% burials for all funerals taking place. Investment is needed to repair aging infrastructure due to the poor condition of roads, historic chapels, aging cremators, and aging plant vehicles. Work is currently in progress to resolve these matters.[110]

4.2.2. Bereavement Services

Birmingham local authority offers a variety of bereavement services through their website, where step by step guidance is available for registering a death, arranging a funeral, informing necessary organisations of the death and applying for probate. This approach is easy to follow

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[109] Mathieson M, Froggatt K, Owen E, et al. End-of-life conversations and care: an asset-based model for community engagement. BMJ Supportive & Palliative Care 2014;4:306-312. https://spcare.bmj.com/content/4/3/306 Accessed 22 June 2021.

[110] Birmingham and Solihull's Coroner's Service's internal presentation supporting the launch of Birmingham and Solihull Annual Coroners Service 2019 report.

and favoured by most local authorities,[111-112] who tend to deal with the practical elements of bereavement, whereas various city charities and Cruse provide bereavement counselling and support.[113]

4.2.3. Birmingham and Solihull's Coroner's Office

The Coroner is an independent judicial office holder appointed and funded by the local authority. The Coroner is responsible for investigating all violent and unnatural deaths, deaths where the cause is unknown and deaths that occur in custody or state detention. The purpose of the investigation is to identify who the person was and where, when and how they came by their death.

Birmingham and Solihull is one of the busiest and most complex Coroner areas, covering a population of over 1.3 million. In 2019, they received 5,362 reported deaths which resulted in 1,519 post-mortems and 757 inquests. Birmingham and Solihull have a higher than national average rate of jury cases with 11 in total in 2019. In addition, they are conducting more complex inquests with over 30 cases involving sittings of one day or more and the average time to inquest is just under 12 weeks which is important as families want to understand how their loved one has died as soon as possible.

Part of the coroner's role is also to prevent future deaths. As a result, they work collaboratively with a number of different research projects to promote safer practices and avoid future deaths. This includes working closely with *Public Health England* and *Birmingham and Solihull Mental Health NHS Foundation Trust* on the rising number of suicides. Following a spike in drug related deaths in the homeless, they are also working closely with *West Midlands Police*, *Public Health England* and drug and alcohol recovery services to set up a drug alert service to have a more coordinated approach to drug related deaths.

Alongside the duty to investigate deaths and to answer how the deceased came by their death, the coroner's office also has a statutory function to compile a report to prevent future deaths when there is concern about the possibility of another fatality in similar circumstances. This is a very important part of their role and can bring about important changes that can protect the public. This is often the only consolation a family will get after the loss of a loved one.

The coroner's service is not without its challenges. These include relocating to larger premises in order to cope with increasing demand. There is also a pressing need to address the current shortfall in pathologists (for post-mortems) as well as a requirement for a new mortuary.[114]

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[111] GOV.UK. Find bereavement services from your council. https://www.gov.uk/find-bereavement-services-from-council Accessed 22 June 2021.

[112] LGA Response to Competition and Markets Authority funerals market study. June 2018. https://assets.publishing.service.gov.uk/media/5b966be5ed915d667b464d5c/Local_Government_Association.pdf Accessed 22 June 2021.

[113] Cruse Bereavement Care. https://www.cruse.org.uk/ Accessed 22 June 2021.

[114] Birmingham and Solihull's Coroner's Annual Report 2019. https://www.birmingham.gov.uk/downloads/file/15070/birmingham_and_solihull_coroners_annual_report_2019 Accessed 22 June 2021.

4.3. Good Practice Models of Care

In 2014, the *Leadership Alliance for the Care of Dying People*[115] published a set of guidelines that highlighted to healthcare professionals the standards they should adhere to in order to take care of the dying.[116] This was followed by *NICE Guidance Quality standard QS144*, providing healthcare professional standards of care guidelines.[117] Good practice was defined as:

1. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
2. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
3. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
4. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

These guidelines were sourced from the *Marie Curie* website and come from the leadership alliance guidelines. The guidelines are directly written into the *BSOL CCG End of Life Strategy* but currently there is no measurement amongst health professionals published.

4.4. Effectiveness of Services and Cost Effectiveness

4.4.1. Effectiveness of Services

Under normal circumstances, service effectiveness can be determined by talking directly to the service users and assessing their responses in a qualitative report. Whilst writing this report, various focus groups have been undertaken to establish whether Birmingham's end of life care services are run with compassion and whether patients living through the last year of their life have received the respect and dignity they deserved. However, due to the nature of this subject matter, it was often more practical to talk to the bereaved than to actual patients. Please refer to Section 5 for a summary of the focus group responses.

4.4.2. Cost Effectiveness

In 2017, PHE reported on the cost effectiveness of palliative care services in England.[118] The report reviewed the available evidence in order to identify which services provided the most effective cost improvements versus standard of care. The report found that if a patient is in contact with services from the beginning of that last year of life to their death, overall costs are reduced mainly with regards to accessing hospital services and the costs incurred by inpatients. It outlined that this was normally when care services took place in the patient's own home rather than residential/nursing care which is expensive. The report concluded that more

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[115] Department of Health and Social Care. New approach to care for the dying published. https://www.gov.uk/government/news/new-approach-to-care-for-the-dying-published Accessed 22 June 2021.

[116] Marie Curie. What does high quality end of life care look like? https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/what-does-high-quality-end-of-life-care-look-like Accessed 22 June 2021.

[117] National Institution of Health and Care Excellence. Care of dying adults in the last days of life. https://www.nice.org.uk/guidance/qs144 Accessed 22 June 2021.

[118] Public Health England. Cost-effective commissioning of end of life care. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/612377/health-economics-palliative-end-of-life-care.pdf Accessed 17 June 2021.

access to support services providing nursing care within a patient’s home would be more cost effective; and suggested enabling patients to have personal healthcare budgets in order to facilitate this.

5. Lived Experiences

Several external organisations were commissioned to run a series of targeted focus groups during December 2019 and January 2020. Six specific groups from around Birmingham were chosen for engagement:

1) Working age adults with physical disabilities
2) Residents of Heartlands ward (the Birmingham ward with the lowest life expectancy)
3) People with long-term conditions
4) LGBT community
5) Young people aged 18-25
6) Homeless population

Three research themes; Premature and Avoidable Deaths; End of Life Care; and the Impact of Death and Dying on those Left Behind (and the Wider Community), were chosen for discussion in the focus groups. During the focus groups, each research theme was framed within a series of questions designed to highlight key issues, ensuring that each of these important questions would be discussed during the course of the focus group. The research themes and questions are outlined below:

Premature and Avoidable Deaths:

- What do the participants think about the differences between Birmingham and the national average?
- What do they think about the differences within the city?
- Awareness of causes of premature death and modifiable factors.
- Are they currently living a healthy lifestyle?
- What is preventing people from changing unhealthy behaviours?
- What should change to facilitate more healthy lifestyles?

End of Life Care:

- How do they feel about having conversations about death and dying?
- When do they feel it is the right time to have these conversations?
- Have they had discussions with those close to them about what they would like to happen?
- What support would they like to be available for those approaching the end of life and their loved ones?

Impact of Death and Dying on those Left Behind (and the Wider Community):

- Discussion of the impact that a death may have on family, friends and others.
- How are people affected?
- What could be implemented to alleviate negative impacts?

5.1. Working Age Adults with Physical Disabilities (Targeted Focus Group)

Organised by an external organisation: John Taylor Hospice and BrumYODO

This targeted focus group was organised by the *John Taylor Hospice* and *BrumYODO*. Fifteen working age adults with physical disabilities participated - and their views on the three research themes are summarised below.

5.1.1. Views on Premature and Avoidable Deaths

- Overall the group were unsurprised at the differences in life expectancy across Birmingham and the wider UK.
- The group were aware of the causes of premature death and the modifiable factors they have in relation to lifestyle.
- When asked, 1/3 of the group felt they were living a healthy lifestyle.
- The group demonstrated an awareness of the societal factors that prevented people from changing unhealthy behaviours.
- Just over 10% of the group highlighted examples of where health interventions had positively influenced their lifestyle and led to an improvement of their overall health.
- Living with a hearing impairment has a significant impact on accessing healthcare services.
- Both local and national governments have a role in promoting healthy lifestyles and making this information accessible to the public.

5.1.2. Views on End of Life Care

- Participants had mixed feelings about having conversations about death and dying, although many recognised the importance of having conversations with their loved ones.
- The definition of ‘those closest to them’ varied, with several participants finding comfort and support from friends and organisations.
- Clear and compassionate communication is a key part of supporting patients and families at the end of life.
- More information is needed about end of life care and the associated aspects of death and dying, such as funeral costs.
- It is important to recognise that some vulnerable groups will need greater support to ensure they have access to end of life care, including appropriate information and support services.

5.1.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- Bereavement is individual and will affect people in different ways.
- Loss is not just something felt about ‘close’ relatives.
- There is a need for more extensive counselling services, including those which support the needs of minority communities and vulnerable groups.
- It is important to consider the wellbeing needs of support staff, such as interpreters, who may have to deal with difficult situations and currently do not receive support.

- With the right information and support, communities can support each other through the challenges of loss and bereavement.

5.1.4. Recommendations

Here is the summary of recommendations from the ‘Working age adults with physical disabilities’ focus group to the Joint Strategic Needs Assessment (JSNA) deep dive into Death & Dying in Birmingham:

- The research presented as part of the JSNA and supported by the experiences of the participants of these focus groups, reinforces that social and economic factors affect life expectancy and years of life lived in good health.
- There is a need for local and central governments to encourage people to live healthy lives.
- Access to services at end of life, such as bereavement support or hospice care, must be culturally competent and accessible to all service users.
- Whilst there is fear about death and dying, there is also a willingness to have discussions with those who are closest to us.
- There is also a need for further information to be made available to the general public around advanced care planning and the services which can support people at end of life.
- Culturally appropriate services are available to support citizens from a range of communities and vulnerable groups, however these services require support and funding.
- It is important to recognise the changing nature of family and understand that those who are closest to us may not conform to traditional definitions of ‘close’ family.
- Bereavement is a personal experience and may begin in anticipation of the death of a loved one.
- Bereavement does not just affect those who are bereaved. Health and social care staff, support workers, employers, friends and family can all be affected by grief and loss.
- Communities are able to support themselves, but would benefit from advice, guidance and training in order to be truly effective in supporting those who are at the end of life or are suffering from a bereavement.

5.2. Residents of Heartlands – the Birmingham Ward with the Lowest Life Expectancy (Targeted Focus Group)

Organised by an external organisation: The Active Wellbeing Society, Birmingham

This targeted focus group was organised by the *Active Wellbeing Society*. Thirteen Heartlands residents participated in the research, all of whom were female. Their views on the three research themes are summarised below.

5.2.1. Views on Premature and Avoidable Deaths

- Overall, the group were very surprised at the health inequalities in the city and the differences in Life Expectancy across Birmingham and the wider UK.
- There was a limited awareness of the modifiable factors that contribute to premature death. While there seemed to be an awareness of the impact of healthy diet and a

focus on recognising that there were a lot of fast-food outlets, people were unsure of the other factors leading to early death such as air quality and loneliness. More needs to be done to make the issues relevant to people and communities, and to bring information to where the people are - such as in GP surgeries and schools.

5.2.2. Views on End of Life Care

- There was a general lack of awareness of the support that is available for end of life care. There was also a general lack of willingness to talk about death and dying including how people want to die. There needs to be more awareness of the implications of not discussing how people want to die (i.e., a lack of personal autonomy over their own decision making, implications for other family members who have to often make decisions on behalf of loved ones once they are already incapacitated).
- More needs to be done to raise awareness of care plans and how these can be discussed and accessed. The group were unaware of care plans, except for one participant.
- Similarly, no one had heard of Personal Health Budgets, yet were interested and could think of scenarios or anecdotes where they would be beneficial. More conversations need to be had about what they are and why they are beneficial, as well as clear information on how they can be accessed, or there is a risk that these budgets will continue to be underutilised – not because there isn’t a demand or need for them, but because people do not even know they exist.
- While many participants from varying cultures felt strongly about dying at home, there was a lack of discussion about how hard it is to care for someone dying at home and how time consuming it can be. Many people described having work and family commitments that added to feeling a large amount of pressure.

5.2.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- Participants described the way that families and loved ones often find themselves in adverse financial situations as someone is dying – taking time off work to spend with dying relatives or losing a loved one who is the breadwinner without support, or conversations about how families will get by once the person has passed. If people were to receive more support to have these conversations, it may help to deal with the aftermath of death that goes beyond grief, including financial matters and maintaining a household.
- Grief is very personal but often finding others that understand your grief can help - more needs to be done to make people aware of the support that is out there and bring people in similar situations together, especially services by third sector organisations that can help people through this difficult time.
- In grief there is often isolation. For older adults who lose a lifelong partner, this can be particularly difficult. Many people will struggle with isolation and experience a loss of purpose. Social support and contact with others are very important in these situations.

5.2.4. Recommendations

Here is the summary of recommendations from the ‘Residents of Heartlands ward (lowest life expectancy)’ focus group to the Joint Strategic Needs Assessment (JSNA) “deep dive” into Death & Dying in Birmingham:

- None of the Heartlands focus group participants were aware that their ward’s life expectancy and inequalities indicators were significantly lower than both city and national comparisons.
- Clearly, there is a need to do more to make information available and accessible at a community level and to find the right channels to share and discuss subjects such as health inequalities. Having the right information would empower people to make the right choices and change behaviours to have an impact on health. Suggestions about suitable places included education, settings like schools, GP practices and community venues.
- It shouldn’t be assumed that health organisations, like GP practices, are aware of all key facts, and more partnership work should be done to ensure their patients are better informed.
- More needs to be done to raise awareness of Care Plans and Personal Health Budgets, and how these can be discussed and accessed.
- In acute settings, patients dying are not in the care of the GP and therefore information needs to be available from hospital staff.
- In the community or at home, the GP or other care providers, such as Adult Social Care, should have more information available for those that are dying and their loved ones or carers. This will help them to have discussions and make better informed choices.
- More needs to be done to make people aware of the support that is out there and bring people in similar situations together, especially services by third sector organisations that can help people through this difficult time.

5.3. People with Long-Term Health Conditions (Targeted Focus Group)

Organised by external organisations: AGE Concern, Birmingham and John Taylor Hospice & Brum YODO CIC

Two focus groups were organised to engage with people living with long-term health conditions. *Age Concern* and the *John Taylor Hospice* led the focus groups and a total of twenty-three participants were involved. Their views on the three research themes are summarised below.

5.3.1. Views on Premature and Avoidable Deaths

- The group had mixed levels of awareness with regard to the difference in Life Expectancies across Birmingham and the wider UK.
- The group was aware of the causes of premature death and the modifiable factors they have in relation to lifestyle.
- Unhealthy eating habits are prevalent and affected by the abundance of fast food take-away shops.
- The group demonstrated an awareness of the societal factors that prevented people from changing unhealthy behaviours, such as cost, health and access to transport.

- Living with a long-term condition prevented many participants from living healthier lifestyles.
- Transport was highlighted as a major factor affecting citizen's lifestyles, particularly with regard to accessing services.
- Both local and national governments have a role in promoting healthy lifestyles and making this information accessible to the public.
- Some participants highlighted that they would like to see more fitness and lifestyle opportunities aimed at older people.
- When people feel isolated, especially older people and those with mental health illness, this can impact on their health and wellbeing.

5.3.2. Views on End of Life Care

- Participants had mixed feelings about having conversations about death and dying, although all recognised the importance of having conversations with their loved ones.
- Clear and compassionate communication was a key part of supporting patients and families at the end of life.
- There needs to be better budgeting for people being discharged from hospital when at the end of life. Simpler, safer, discharges are needed to prevent confusion and delay.
- Discharge teams need to be more supportive of families. The impact of having a qualified Palliative Care Nurse involved in the discharge of a relative was highlighted by one participant as significantly improving the quality of discharge.
- More information is needed about end of life care and the associated aspects of death and dying, such as funeral costs.
- It is important to recognise that some vulnerable groups will need greater support to ensure they have access to end of life care, including appropriate information and support services. This includes carers, people with disabilities and long-term conditions, and ethnic minority communities.

5.3.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- Bereavement support is crucial and there are a number of services which support citizens through bereavement.
- There is a need for more extensive counselling services, including those which support the needs of minority communities and vulnerable groups.
- It is also crucial that bereavement services are adequately funded.
- Members of the group highlighted the barriers they faced when trying to set up support groups within the community.
- More information is needed in the public sphere that discusses death, dying, bereavement, and the support that can be accessed.
- With the right information and support, communities can support each other through the challenges of loss and bereavement.
- Ongoing support for carers is crucial and they are particularly vulnerable to the effects of bereavement and isolation.

5.3.4. Recommendations

Here is the summary of recommendations from the ‘People with long-term health conditions’ focus group to the Joint Strategic Needs Assessment (JSNA) “deep dive” into Death & Dying in Birmingham:

- The research presented as part of the JSNA and supported by the experiences of the participants of these focus groups, reinforces that social and economic factors affect life expectancy and years of life lived in good health.
- There is a need for local and central governments to encourage people to live healthy lives.
- Access to services at end of life, such as bereavement support or hospice care, must be culturally competent and accessible to all service users.
- Whilst there is fear about death and dying, there is also a willingness to have discussions with those who are closest to us.
- There is also a need for further information to be made available to the general public around advanced care planning and the services which can support people at end of life.
- The process of discharging patients from hospital at the end of life requires clear communication, appropriate funding, and the input of professionals who can support patients and families at the end of life.
- Culturally appropriate services are available to support citizens from a range of communities and vulnerable groups, however these services require funding in order to maintain this level of support.
- Bereavement is unique and individual and may begin in anticipation of the death of a loved one.

5.4. LGBT Community (Targeted Focus Group)

Organised by external organisation: Birmingham LGBT

This targeted focus group was organised by *Birmingham LGBT*. Sixteen members of the *Birmingham LGBT* community participated in the research – and their views on the three research themes are summarised below:

5.4.1. Views on Premature and Avoidable Deaths

- Introduce restrictions on fast foods by preventing schools and workplaces from selling ‘junk food’.
- Implement a sugar tax to subsidise healthy foods thus making healthy foods cheaper. This should coincide with improvements in effective food labelling.
- Make more space for community-based support including food hubs with free cooking classes to improve education around healthy diet.
- Enable greater cooperation between NHS, local authorities and other key stakeholders to promote health issues and matters along with support.
- Reclaim parks and maintain them well, encourage and motivate local communities to love their habitat and open spaces and use them.
- Transport: Car clean air zone, more bike lanes and better public transport/urban/road planning.

- Having healthy eating role models and encouraging more mobility within the workplace – for example standing workstations, utilising the stairs not lifts, walking/cycling to work schemes, parking further from the workplace to include a walk etc.

5.4.2. Views on End of Life Care

- There was a broad recognition and agreement amongst participants that society tends to be very closed around the topic of end of life care, and its ramifications for grieving, and that there are few spaces to discuss this particular topic.
- There is a lack of LGBT sensitivity with funeral directors, hospitals, hospices and others that needs to be addressed through better education of these service providers. This could be achieved through statutory bodies undertaking a review of standards, assessments and induction processes (e.g., CQC, NHS etc.) to ensure they include LGBT matters and needs.
- A suggestion to create a system that flags up when we pass away which triggers an LGBT community service to manage affairs and the deceased's estate and carry out the wishes of the deceased if they have no family or friends to do it on their behalf.
- General consensus of the need for us all to write a will/write down our wishes for arrangements, dispersal of possessions etc.
- Allow more choices for ways and places to die (at home, respect wishes for do not resuscitate, alternatives to institutions).
- There is a need for more awareness of where to seek help around planning and support to plan – solicitors, powers of attorney, writing wills and other legal, financial and funeral specific planning support.

5.4.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- Creating an inclusive befriending service (no-one dies alone) – inclusive in terms of LGBT friendly.
- Facilitating greater public awareness of what hospital services are available and where they can be accessed.
- Providing education and raising awareness about the grieving process, alongside appropriate support services contact details.
- Assisting individuals in creating end of life plans and ensuring they are in place before an individual dies. There was a further recommendation linked to this around there being honesty around the process of death and funerals, powers of attorney etc., and the need for greater encouragement for everyone to have 'the conversation' and to make their final end of life wishes known.
- Development of a checklist that could be distributed on how to prepare for end of life – legal, financial and other requirements such as lasting power of attorney, wills, funeral arrangements etc., and make this freely and widely accessible for everyone to utilise.
- Becoming more inclusive (specifically regarding acceptance of sexual identity by family re faith/culture/personal views – the broader impact of family taking over arrangements and excluding partner and/or friends etc.)
- The creation/encouragement of greater and broader support by:
  - Encouraging faith communities to support their LGBT parishioners.
  - LGBT training for counselling providers.
  - Death and dying training for LGBT counselling services.

- Greater support for one another within our community.
- Encouraging ‘older peoples’ support charities (examples given included *Age UK* and *Age Concern*) to be more aware and welcoming of LGBT people.
- Create more mentors/buddies/support groups for LGBT community and awareness/inclusivity training for other providers of support to make LGBT individuals and families feel welcome and included.
- People could benefit from understanding ways of acceptance of grieving and the process.

5.4.4. Recommendations

Here is the summary of recommendations from the ‘LGBT Community’ focus group to the Joint Strategic Needs Assessment (JSNA) “deep dive” into Death & Dying in Birmingham:

- Government and community support relating to healthy eating is key, including school education, food hubs, and developing support for those in food poverty through community initiatives. Strong networks between stakeholders will help enable this.
- Extra community support would be beneficial for LGBT people and building in specialist processes and sensitivities to end of life services on factors that could impact an LGTB person’s ability and willingness to plan for death.
- This includes concern over the complexity of more traditional faith and cultural backgrounds that, due to the faith or cultural background of LGBT persons, they could be ostracised from their family/community with no support, or that the life they led might be denied and/or covered up at the end of their life.
- Access to services at end of life must be sensitive overall to the cultural differences of the individual and their family, as well as the complex impact of bereavement on those left behind.
- Further information and assistance would be helpful for the public around planning for end of life, including services and procedures.

5.5. Young People Aged 18-25 (Targeted Focus Group)

Organised by external organisation: The Afterlife Project

This targeted focus group was organised by The *Afterlife Project*. Sixteen young people aged between 18 and 25 participated in the research – and their views on the three research themes are summarised below.

5.5.1. Views on Premature and Avoidable Deaths

- Participants showed very little knowledge on the negative impacts of alcohol.
- There was general awareness that smoking is dangerous, although many participants continue to smoke.
- There was broad recognition that community deprivation has an impact on their lives.
- Most of the participants stated that they visit a fast-food restaurant almost daily (some claim twice a day).
- There was broad recognition that unhealthy food is an attractive option because it is cheap.

5.5.2. Views on End of Life Care

- The participant group felt that discussing death is "weird" and something they were uncomfortable with.
- None of the participants had previously discussed their funeral wishes with loved ones or been part of any discussions about death and dying.
- There was general openness to the idea of preparing for death, but the group was unsure where to begin.

5.5.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- There was a broad understanding within the group that bereavement causes a range of negative emotions such as sadness, loneliness, anger, shock and desperation.
- The negative effects of bereavement could be alleviated somewhat by prior knowledge of the deceased's wishes.

5.5.4. Recommendations

Here is the summary of recommendations from the 'Young people aged 18-25' focus group to the Joint Strategic Needs Assessment (JSNA) "deep dive" into Death & Dying in Birmingham:

Targeted Community/School Sessions:

- It's clear from this particular group of young people that work still needs to be done in terms of raising awareness of the dangers of smoking. Despite vaping being an increasingly popular way of quitting for people in the 40+ age range it seems the message hasn't yet reached younger people with none of the focus group participants mentioning vaping as a potential lifestyle change. None seemed worried about the impact of smoking on their health and were more concerned about the cost of cigarettes.
- Similarly, the risks of excess alcohol weren't clear to the participants, with none of them being able to explain what Alcoholic Liver Disease was. This was worrying and indicates an immediate need for increased Alcohol Awareness amongst 18-25 year olds.
- By entering into the community (school workshops, community centres, youth centres) and engaging at grass roots level with young people, raising awareness could be the best way of avoiding premature death through modifiable factors, for this generation.

Regular 'Death Cafes':

- "One stop shops" within the community where people can speak either on a one-to-one basis in confidence or as part of a safe, accepting group, about Death & Dying - their fears, anxieties, worries and uncertainties. These would begin to dissolve the taboo nature of the subject, encouraging conversations around healthier lifestyles, end of life care, funeral plans and more. The best way to raise awareness is to get people talking within their own communities about these issues.

5.6. Homeless Population (Targeted Focus Group)

Organised by external organisation: ABIC Ltd

This targeted focus group was organised by *ABIC Ltd*. Nine participants from Birmingham's homeless population took part in the research – and their views on the three research themes are summarised below.

5.6.1. Views on Premature and Avoidable Deaths

- Homeless people by and large do not lead healthy lives and are aware of that. Much is driven by circumstance i.e. poverty, poor accommodation, poor access to good nutrition, a tendency to use tobacco and/or alcohol linked to mental ill health and/or a general depressive outlook.
- Despite their awareness of and desire to enjoy better nutrition and healthy eating, their limited finances and particularly their limited access to cooking facilities make healthy eating an unachievable ambition.
- People who are homeless are likely to have a range of additional complex and challenging needs present in their lives and indeed homelessness is more likely to be the result of these rather than the source. Over half of the group reported suffering with long term mental ill health.
- This group and previous work undertaken by the researchers has highlighted that people with multiple and complex needs can often present with low motivation, potentially linked to depression, and so even where opportunities exist to improve their lifestyle, the motivation is not there to take advantage of those opportunities.
- For these groups additional incentives may be required and someone like a personal mentor or support worker can be helpful. However, the specific individuals acting in this role need to be able to stay engaged with their mentee long term because there may be only a narrow window of opportunity, when an individual is in the right frame of mind to make changes, which needs to be recognised and acted upon.
- Electronic cigarettes/vaping were seen as a particularly large threat to public health both to the user and through "secondary smoking". Whilst Vaping is recognised as less risky than smoking tobacco – it's marketing as something 'sexy and cool' risks more young people taking up vaping than would ever have started smoking.

5.6.2. Views on End of Life Care

- Talking about death with a relative or friend is very hard to do. Those who have attempted it have been rebuffed because the subject just felt too uncomfortable to discuss. It may be that all that can be done is to let people know that, should they want to discuss their end of life etc. they will find a willing listener.
- Older people may make a will, make financial provision for their funeral and may have thought about what kind of funeral they want, but very few people have thought about a *good death* (i.e., what kind of end of life care they want. This is only likely to happen when diagnosed with a terminal illness or made to face your own mortality in some way).
- Some third sector organisations such as *MacMillan* and *Marie Curie* and others that are involved in the hospice movement especially are universally recognised as providers of positive experiences and support at the end of life.
- Unsurprisingly, young people rarely think about (their own) death, if at all.

5.6.3. Views on the Impact of Death and Dying on those Left Behind (and the Wider Community)

- Grief is personal and there are no rules. It can stay with you long term or never appear until triggered by something possibly totally unrelated to the person who died. However, bereaved people need to be able to talk about it whenever they feel the need, to support healthy emotional wellbeing.
- Having people around to support you after a death is helpful. People need to talk – however they also need the opportunity to find solitude and sanctuary and to be able to reflect on their own.
- Being homeless is often indicative of estrangement from the person’s family and so, when a death occurs within the family, it can be all the more painful and emotionally challenging for the homeless person who is confronted with the reality that those relationships can never be rebuilt.
- Bereavement can bring families together but can also drive them apart. This often happens when the deceased had very different relationships with different members of the family, whether positive or negative.
- Immediately after death may not be the most important time to offer support to bereaved people. At that time there is often a lot happening with funeral arrangements, wills and probate etc. and family members appearing to be helpful or after money.
- However, it is in the weeks after the funeral that reality of a death can hit an individual and that is when emotional/counselling support needs to be available and clearly signposted.
- Homeless people struggle with the bureaucracy and cost of death. Paperwork is written in “legalese”, and you often need access to the internet. Benefits and funding for funerals for low-income people is unclear. Next of kin have to deal with a whole range of people without access to the internet and personal transport – lawyers, hospitals, doctors, coroners, registrars, funeral directors etc. Some Landlords demand people vacate social housing far too soon after a death, although it is recognised that the demand for social housing makes this inevitable and indeed is of benefit to other homeless people awaiting more settled accommodation.

5.6.4. Recommendations

Here is the summary of recommendations from the ‘Homeless population’ focus group to the Joint Strategic Needs Assessment (JSNA) “deep dive” into Death & Dying in Birmingham:

- Premature death is a live issue when you are homeless.
- Homeless people struggle to follow healthy lifestyles, often driven by circumstances.
- Making changes to lifestyles even where opportunities exist can be difficult for homeless people due to a lack of motivation, potentially exacerbated by depression for some.
- Homelessness may involve being estranged from relatives for periods of time and can make the death of a relative all the harder to come to terms with.
- The bureaucratic challenges and costs that accompany bereavement are made all the greater for homeless people in the context of their other stresses and lack of resources. Benefits and funding for funerals for low-income people is unclear.

5.7. Collective Summary of Focus Group Recommendations

A summary of the key recommendations from all the above focus groups for our Joint Strategic Needs Assessment (JSNA) “deep dive” into Death & Dying in Birmingham are as follows:

- There is a need for local and central governments to encourage people to live healthy lives.
- Access to services at end of life, such as bereavement support or hospice care, must be made available and accessible to all service users.
- There is also a need for public awareness raising around advanced care planning and the services which can support people at end of life.
- Community services are well placed to offer support to those who need it, before and after the bereavement, however they require the funding and guidance to do so.
- Have reviews of afterlife services to ensure processes consider the sensitivities of different socioeconomic circumstances, faith and culture, and complex health needs, particularly for groups that may be more isolated from traditional means of support.

6. Unmet Needs Relating to Death and Dying

This section focuses upon gaps in research that have been identified from stakeholder's experiences and limited discussions with members of the community. In accordance with the *Birmingham and Solihull STP* strategy consultation process an equalities analysis was completed, where the key areas of focus were:

- Carers
- Race/ ethnicity
- Religion or belief
- Human rights
- Sexual orientation
- Learning disabilities
- Homelessness

Several of these issues have been discussed within the Lived Experience section of this report. However, after discussion with stakeholders, three of the key themes for development from this list were identified for further discussion. The three key themes for improvement were: end of life care within the homelessness, ethnic minority groups and the Lesbian, Gay, Bisexual, and Trans (LGBT) community. It is also our intention that other key themes, notably carers and learning disabilities, shall become the focus of subsequent deep dive evidence reviews carried out by this team during the next couple of years.

6.1. Homelessness

Exact figures for homelessness are difficult to calculate and obtain. However, a report from Shelter (2017)[119] estimated that Birmingham's homeless population (including people in temporary accommodation) was 12,785; the third highest homeless population within the UK.

The *Birmingham Health and Social Care Overview & Scrutiny Committee* conducted an investigation into the health of the homeless population in Birmingham in 2015. Their work underlined the well-established link between homelessness, physical and mental ill health and premature death. This is exacerbated by homeless people encountering barriers to healthcare that hinder their access to appropriate services. Homeless people have an increased risk of premature death, resulting in a life expectancy of 43-47 years old. People are dying on the streets, in hostels and hospitals without access to the necessary end of life support services, which often reduces the likelihood of patients receiving a dignified death.

Death data specific to Birmingham's homeless population is not currently published. A study by Ivers et al (2019)[120] looked at the causes of death in the homeless community in Dublin. There were 201 deaths that occurred among homeless people between 2011 and 2015. Drug and alcohol related deaths accounted for more than one third of deaths in homeless individuals, with opioids being the most common cause. The level of mortality for men was between 3 and 10 times higher and for women 6 to 10 times higher than the general

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[119] Shelter. Press release: 320,000 people in Britain are now homeless, as numbers keep rising https://england.shelter.org.uk/media/press_release/320,000_people_in_britain_are_now_homeless,_as_numbers_keep_rising Accessed 17 June 2021.

[120] Ivers J, Zgaga L, O'Donoghue-Hynes B, et al. Five-year standardised mortality ratios in a cohort of homeless people in Dublin. BMJ Open 2019;9:e023010. https://bmjopen.bmj.com/content/bmjopen/9/1/e023010.full.pdf Accessed 22 June 2021.

population. The *Care Quality Commission* report, *A Second Class Ending (2017)*,[121] highlights the role of hospices in championing equality by engaging minority and excluded communities to deliver equitable end of life care. Some cities, (e.g., London and Plymouth) have examples of palliative care services for homeless populations.

There was a scoping exercise for homeless people's end of life care by the *Hospice at Home Team* at *Birmingham St Mary's Hospice*, February to April 2018.[122] This was a two-year study, which involved visiting existing services and identifying the needs in Birmingham for an end of life service to support the homeless population.

Key Findings:

- Evidence obtained from existing services suggests collaboration and early introduction to services leads to the best outcomes.
- Requirement to recognise the complex needs of those who are homeless.
- In partnership with *John Taylor Hospice* and existing homelessness organisations, deliver and enable more effective, responsive individualised services at end of life for Birmingham (citywide approach) using a multiagency three-layered approach.

St Mary's Hospice has since set up a homelessness support service in collaboration with partners in the health and third sectors to bring hospice care to homeless people in the area.[123]

6.2. End of Life Care for the Lesbian, Gay, Bisexual, and Trans Community

Marie Curie recognised in 2010 that there was a gap in research on the experiences of LGBT people at the end of life. They funded research by the *University of Nottingham*, *The Last Outing,*[124] to look in detail at the particular needs of LGBT people at the end of life. The study found that 26% of survey respondents had experienced discrimination relating to sexual orientation and/or gender identity from health and social care professionals. A *Stonewall* report found that 57% of health and social care practitioners said they didn't consider someone's sexual orientation to be relevant to a person's health needs[125].

A key element of the *Marie Curie* study was that LGBT people felt that understanding sexual orientation was necessary to be able to address personal health needs. Advanced care

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[121] Care Quality Commission. A Second Class Ending. https://www.cqc.org.uk/sites/default/files/20171031_a_second_class_ending.pdf Accessed 17 June 2021.

[122] St. Mary's Hospice Limited. Report and Consolidated Financial Statements Year ended 31 March 2018. https://s3-eu-west-2.amazonaws.com/stmaryshospice-offload/ST_MARYS_HOSPICE_Accounts_2018_FINAL-1.pdf Accessed 17 June 2021.

[123] Birmingham St Mary's Hospice. Hospice launches new Homelessness Support Service https://www.birminghamhospice.org.uk/hospice-launches-new-homelessness-support-service/ Accessed 17 June 2021.

[124] University of Nottingham. The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people. https://www.nottingham.ac.uk/research/groups/ncare/documents/projects/srcc-project-report-last-outing.pdf Accessed 17 June 2021.

[125] Stonewall. Unhealthy Attitudes, The treatment of LGBT people within health and social care services. https://www.stonewall.org.uk/our-work/campaigns/unhealthy-attitudes Accessed 23 June 2021.
health and social care services. https://www.stonewall.org.uk/system/files/unhealthy_attitudes.pdf Accessed 17 June 2021.

planning was also an ongoing theme, with a focus on providing protection for partners and significant others who might otherwise not be recognised. 82% of respondents agreed that it was particularly important for LGBT people to make and record plans for future care. However, only 18.5% of the respondents had written down and recorded their preferences.

These findings were formulated into the report - '*Hiding who I am – the reality of end of life care for LGBT people'*,[126] where the following themes were explored:

- Assumptions about identity and family structure
- Anticipating discrimination
- Increased pressure on LGBT carers due to late presentations
- Varied support networks
- Unsupported grief and bereavement
- Complexities of religion and LGBT end of life care

There are no specific community engagement initiatives in Birmingham presently to engage the LGBT community discussing end of life care. The study by *LGBT Birmingham* in 2011, *Out and About,*[127] provided a valuable insight into the lives of Birmingham LGBT individuals and communities across the city. There were over 600 respondents and it provided a thorough and detailed analysis into a wide range of areas in people's lives including general health. A concerning element of the report relates to suicide. One in five respondents indicated that they had attempted suicide, significantly above the national average. Respondents who had been the victim of a homophobic hate crime were more likely (58%) to report that they had attempted suicide than those who had not been victims (42%).

Of those with long-term health conditions, nearly half (49%) declared a health problem which limited the activities of everyday life, and nearly 5% had been diagnosed with cancer or a progressive illness such as multiple sclerosis (MS). While end of life was not specifically part of the study, respondents did discuss having difficult interactions with healthcare professionals. Several questions in the survey examined respondents' opinions of their GPs. Almost two in five (39%) answered that they thought their GP had non-judgmental attitudes to LGBT people, although over one half (52%) were not sure.

Several hospices are working with *LGBT Birmingham* to address end of life care engagement in the LGBT community. *Marie Curie Hospice West Midlands* recognised that their hospice services were not actively promoted as LGBT friendly. This led to initiatives at both regional and national level to address this, including developing a hospice LGBT working group for staff, volunteers and service users; awareness training programme for staff and volunteers; collaboration with *Birmingham LGBT*; and facilitating co-design of palliative care services with the local LGBT community.[128]

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[126] Marie Cure. Hiding Who I Am, The reality of end of life care for LGBT people. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf Accessed 17 June 2021.

[127] Birmingham LGBT Community Trust. Out & About Mapping LGBT Lives in Birmingham. https://blgbt.org/wp-content/uploads/2015/10/outandaboutreportfinalweb.pdf Accessed 17 June 2021.

[128] BMJ. SPCARE 2019;9(Suppl 4):A1–A110. Pg A18. https://spcare.bmj.com/content/bmjspcare/9/Suppl_4/A18.2.full.pdf Accessed 17 June 2021.

6.3. End of Life Care Needs of Ethnic Minority Groups

Birmingham is home to the largest population of ethnic minorities (over 450,000 people) and third largest proportion (42%), outside of London.[129] The unmet needs and disparities in access to palliative and end of life care for people from an ethnic minority background is a well-recognised issue[130] and poses a significant challenge in the delivery of palliative care in an equitable, accessible and culturally sensitive way.

Marie Curie[131] performed a literature review of the unmet needs and disparities in palliative and end of life care experienced by ethnic minority groups in the UK. The authors recognised the importance of understanding social inequities (such as deprivation, differences in access to care in general, social exclusion and racism) when analysing unmet needs and disparities. Using this method there were two main themes identified:

- Access to care
- Receipt of care

Ethnic minority groups were recognised as having lower access to palliative and end of life care services when compared to White British people. This was associated with lack of referrals, lack of awareness of relevant services, previous bad experiences when accessing care, a lack of information in relevant languages or formats and family and/or religious values conflicting with the idea of hospice care.

The *Marie Curie* review also examined the experience of receiving care. The most common issue was poor communication between the healthcare professional and the patient (and their family). This was associated with lack of sensitivity to cultural and/or religious differences, lack of availability of translators and low availability of training for healthcare professionals.

In relation to the population in Birmingham, there is limited information available regarding ethnic minority groups' experiences of end of life care.

Research has identified multiple challenges relating to the access and receipt of care, including lack of referrals, lack of information, religious and family issues, communication, and engagement with advance care planning or end of life decision making. Existing evidence-based recommendations for policy and practice - such as community engagement, communication and staff training in the context of Birmingham's ethnic minority population - needs to be considered carefully and implemented.

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[129] Office for National Statistics Census 2011. Ethnic group. https://www.nomisweb.co.uk/census/2011/ks201ew Accessed 17 June 2021.

[130] Marie Curie. Next Steps, Improving end of life care for Black, Asian and Minority Ethnic people in the UK. https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/next_steps_report.pdf Accessed 17 June 2021.

[131] Marie Curie. Palliative and End of Life Care for Black, Asian and Minority Ethnic Groups in the UK. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2013/palliative-and-end-of-life-care-for-black-asian-and-minority-ethnic-groups-in-the-uk.pdf Accessed 17 June 2021.

7. Opportunities for Action

This section identifies the areas of need to address through commissioning or other actions for local organisations.

7.1. What Would We Like to Achieve?

We would like to live in a city where…

- There is equity in life expectancy and there is a reduction in avoidable deaths
- Citizens are able to die with dignity
- Compassionate high-quality end of life care is available across the city
- Understanding and support is readily available for those who are bereaved
- We can all talk openly about death and dying with those close to us

7.2. Key Findings

Here we set out the findings from the JSNA deep dive and make recommendations as to how local partners can address and help us achieve our local ambitions.

Key Finding 1: There are too many premature and avoidable deaths.

Life expectancy in Birmingham is significantly lower than the national average. The poorest areas of the city have the lowest life expectancy and the gap between highest and lowest ward is 11.6 years for men and 9.2 years for women. The gap is even greater for years of life lived in good health. Many of the premature deaths are caused by modifiable factors such as smoking, alcohol, physical inactivity, loneliness and poor air quality. If these factors are reduced, this would lessen the likelihood of avoidable conditions occurring.

Birmingham has one of the highest infant mortality rates in England. Causes of infant deaths have hardly changed for the last 20 years and the reasons for this are not fully understood.

Birmingham has a lower suicide rate than the national average. However, every suicide is one too many. Death through suicide reflects the ultimate loss of hope and leaves significant and lasting impact on families, communities and employers and society.

Recommendations:

To reduce premature and avoidable deaths, we recommend:

- Action to address and reduce inequalities in different communities particularly for the modifiable factors affecting mortality.
- Taking a “whole system approach” to work across the city to co-create situations/circumstances that are more health generating without active choice, thus making it easier for citizens to make healthy choices and live as healthily as possible.
- Further exploration of the local causes of infant mortality (including pre-pregnancy circumstances and the care of pregnant women) and the development and implementation of effective interventions that are culturally acceptable.
- Continued commitment to maintain the lowest rate of suicide of any of the core cities in England and to reduce deaths by suicide in the city and over the next decade through a zero-suicide approach.

Key Finding 2: There are opportunities for improved end of life care by local services.

Services need to work together well to fully support the person at the end of their life and also provide support to their families during this time and afterwards. There is evidence to suggest that people do not think that services work well together.

Service delivery is dependent on diagnosis and health needs. Some illnesses (e.g., dementia) are under-diagnosed, meaning that patients often receive late diagnoses, or no diagnosis at all. In these situations, patients potentially miss out on health services that could improve their quality of life and help provide dignity in their final years.

Care plans are not routinely offered to patients in need of palliative care and their carers. The uptake of personal health budgets in Birmingham is low. A local pilot has shown potential benefit through increased choice and control.

Surveys of the general public reveal that, given the opportunity and the right support, most people would prefer to die at home. In practice, only a minority do so with many dying in an acute hospital. There is limited local insight on patient wishes regarding place of death.

Dying and death can be powerful sources of emotional turmoil, social isolation and spiritual or existential distress. There is little evidence to tell us whether end of life care is currently meeting those needs. Some groups are more disadvantaged than others.

Recommendations:

To improve end of life care services in Birmingham, we recommend:

- Promotion of conversations about death and dying. Citizens should be made aware of the importance of planning their choices and wishes.
- Promote the early identification of patients with palliative care needs and the use of care coordination processes such as the Gold Standard Framework.
- Continuation of the work of the Birmingham and Solihull STP End of Life Oversight Group to implement the national framework key areas for improvement.
- Development of co-ordinated 24/7 access to homecare and specialist outreach services.
- Consideration to groups that are less engaged with palliative care services i.e. the homeless population, the LGBT community and ethnic minority groups.

Key Finding 3: Death and dying impacts those left behind and there is a demand for carer support and bereavement services in the city.

Grief following bereavement can be a long process lasting for many years. Older people who are bereaved are often affected by loneliness and social isolation. There is bereavement support in Birmingham but there are areas of the city with less coverage than others. *Birmingham's Neighbourhood Network Scheme* is developing community assets around the city which includes bereavement services.

10% of Birmingham’s population are providing unpaid care. However, there is no evidence on how many of these are supporting someone at the end of life. Generally, Birmingham carers’ quality of life is similar to the national average for carers. However, their experience of structured support, particularly on leaving hospital, is much lower. There is support for carers in Birmingham but there are gaps in some areas of the city.

Recommendations

To support carers and bereaved people in the city, we recommend:

- Addressing the lack of carer and bereavement support citywide and encouraging communities to provide support within different areas of the city.
- Increasing awareness of carer and bereavement support available through development of a resource for the public and professionals.
- Coordinating with adult social care to provide improved services for carers.
- Development of specific bereavement services to deal with the trauma of losing an infant.