

# End of Life Care

## Health Needs Assessment 2023

SOMERSET

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## 1 Purpose, Scope and Context

Death is an inevitable part of life, and a peaceful, dignified death should be considered alongside other aspects of a good life. A majority of people will benefit from specialist End of Life Care (EoLC). [Marie Curie in 2016](#) estimated that at least 74% of people in the UK should receive such palliative treatment, which aims to improve quality of life rather than directly treat (let alone cure) the condition. Improving EoLC in Somerset will involve:

- raising the effectiveness and quality of care provided.
- ensuring that such care is equally accessible to all groups in the population, regardless of their terminal diagnosis.

## 2 Background

Data in this report are largely an update of those used in the [2017 Annual Report of the Director of Public Health for Somerset](#), on EoLC.<sup>1</sup> These set the context in which EoLC health needs can be assessed.

### 2.1 Numbers of Deaths

There are currently about 6000 deaths per year in Somerset, and as shown in Figure 1, this is set to rise at a faster rate than the growth in the total population, one of many consequences of the ageing population, as shown in Figure 2.

**End of Life Care is likely to increase in absolute and proportionate importance in the county's health needs.**

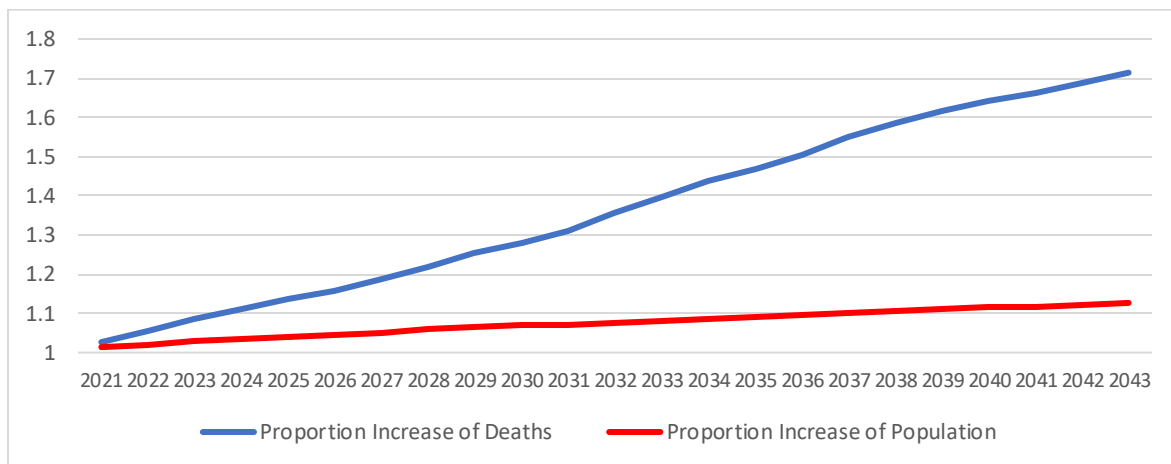


Figure 1: Projected numbers of deaths (Proportion)

<sup>1</sup> There have been some changes to the data available, including:

- The inclusion of mortality data where COVID-19 was the cause of death
- Now has dementia and Alzheimer's disease as a specific cause of death category. Alzheimer's was previously included in the nervous system causes of death and dementia in the "other" category.
- Removal of digestive causes of death due to such small numbers, so now included in the 'other' category
- More generic causes of death  
In the 2017 report, some charts include more detailed break down of cause of death by type. E.g. Circulatory – CHD, Circulatory – Stroke, Circulatory – other.
- In the charts with the more recent data, it's just circulatory as a cause of death, with no sub categories
- The last age bracket for data is 85+ instead of 90+.

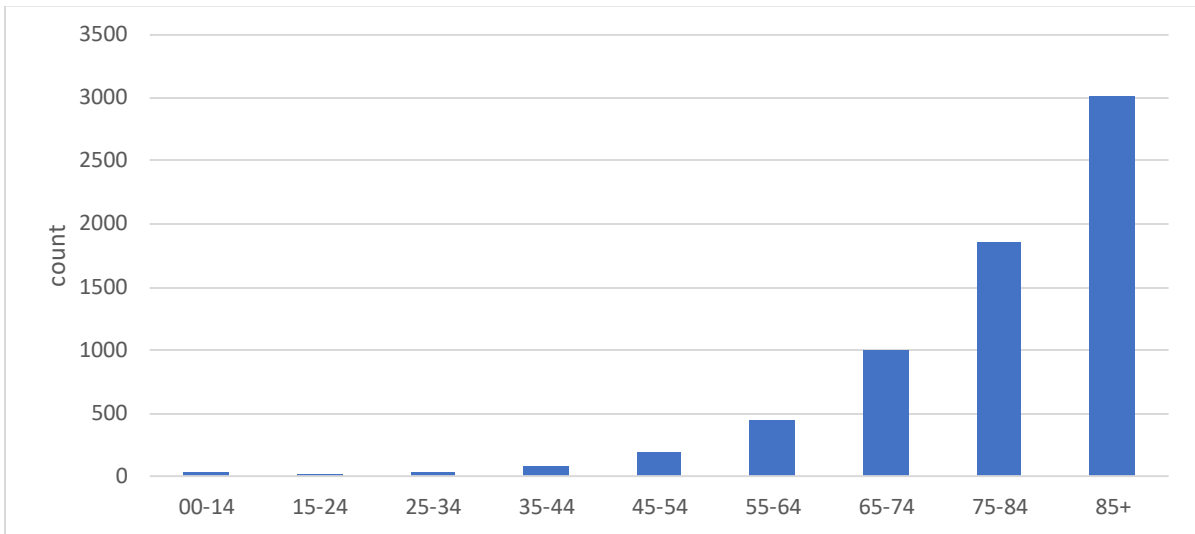


Figure 2: Age of Death in Somerset 2020

## 2.2 Palliative Care

As shown in Figure 3, the number and proportion of people on the palliative care register has grown steadily in the last decade, from 1,099 in 2011/12 to 2,748 in 2021/22. The proportion of people on the register in Somerset is broadly similar to that of England as a whole.

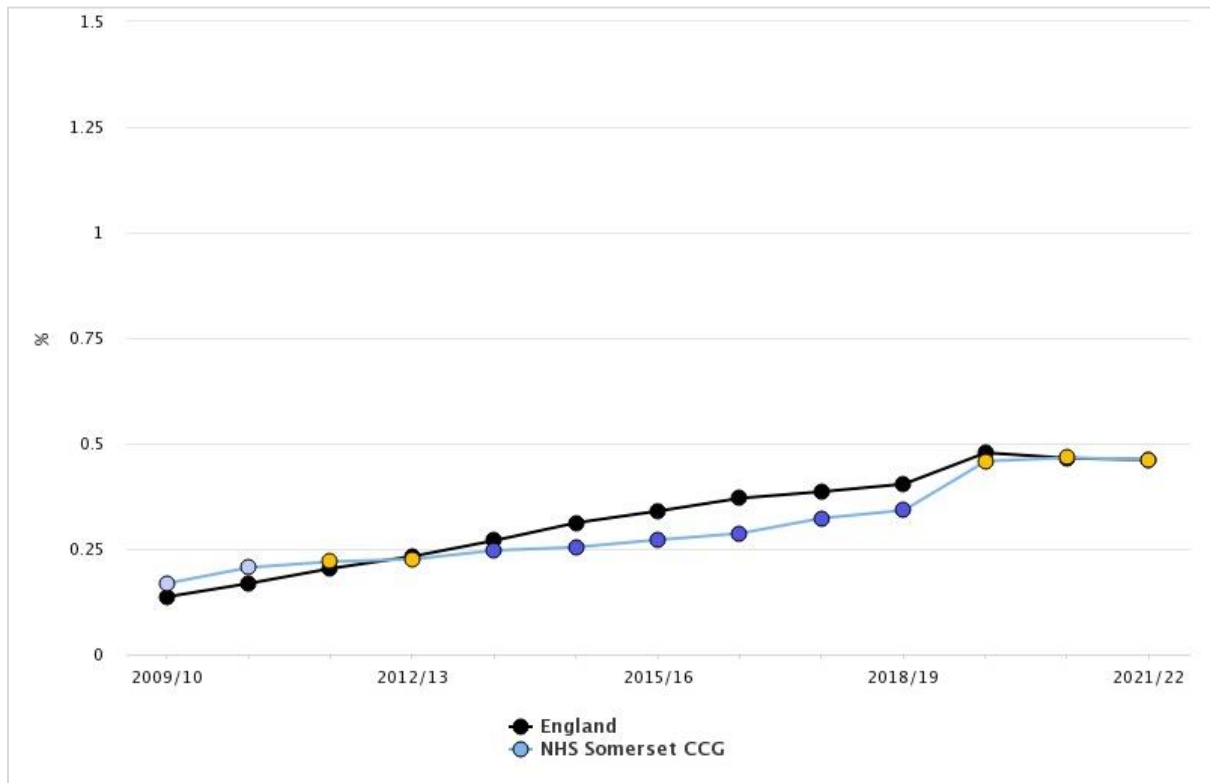


Figure 3: Percentage of population on the Palliative Care register [Public health profiles - OHID \(phe.org.uk\)](https://publichealthprofiles.org.uk/)

The numbers of patients receiving palliative care according to OHID ([Public health profiles - OHID \(phe.org.uk\)](https://publichealthprofiles.org.uk/)) are shown in Table 1. The numbers derived from SIDeR are shown in Table 2. Whilst the total – 4,519 – might imply a huge increase from the OHID figure of 2,748 for 2021/22, these are very different sources and cannot be

compared directly. In particular, the lack of a consistent mechanism for removing patients who have died in the SDeR records may have inflated that number considerably.

*Table 1: Numbers of Patients on Palliative Care Register*

	<b>NHS Somerset CCG</b>	<b>England</b>
<b>2009/10</b>	836	149,814
<b>2010/11</b>	1,024	185,740
<b>2011/12</b>	1,099	226,210
<b>2012/13</b>	1,237	260,466
<b>2013/14</b>	1,360	304,198
<b>2014/15</b>	1,415	354,658
<b>2015/16</b>	1,526	391,146
<b>2016/17</b>	1,633	429,722
<b>2017/18</b>	1,856	450,332
<b>2018/19</b>	1,983	479,644
<b>2019/20</b>	2,674	577,342
<b>2020/21</b>	2,743	564,862
<b>2021/22</b>	2,748	568,676

*Table 2: Electronic Palliative Care Record numbers from SDeR, January 2023*

<b>Name</b>	
<b>AXBRIDGE SURGERY</b>	31
<b>BECKINGTON FAMILY PRACTICE</b>	54
<b>BRENT AREA MEDICAL CENTRE</b>	7
<b>BRUTON SURGERY</b>	15
<b>BURNHAM MEDICAL CENTRE</b>	27
<b>BUTTERCROSS HEALTH CENTRE</b>	61
<b>CANNINGTON HEALTH CENTRE</b>	26
<b>CHEDDAR MEDICAL CENTRE</b>	38
<b>CHURCH STREET SURGERY, MARTOCK</b>	41
<b>CHURCH VIEW MEDICAL CENTRE</b>	6
<b>COLLEGE WAY SURGERY</b>	101
<b>CRANLEIGH GARDENS MEDICAL CENTRE</b>	30
<b>CREECH</b>	37
<b>CREWKERNE HEALTH CENTRE, CREWKERNE</b>	80
<b>CROWN MEDICAL CENTRE</b>	59
<b>DIAMOND HEALTH GROUP</b>	47
<b>DUNSTER &amp; PORLOCK SURGERIES</b>	260
<b>EAST QUAY MEDICAL CENTRE</b>	403
<b>ESSEX HOUSE MEDICAL CENTRE, CHARD</b>	74
<b>EXMOOR MEDICAL CENTRE</b>	154
<b>FRENCH WEIR HEALTH CENTRE</b>	89
<b>FROME MEDICAL CENTRE</b>	213
<b>GLASTONBURY HEALTH CENTRE</b>	26
<b>GLASTONBURY SURGERY</b>	119
<b>GROVE HOUSE SURGERY</b>	52

HAMDON MEDICAL CENTRE, STOKE-SUB-HAMDON	37
HIGHBRIDGE MEDICAL CENTRE	38
LANGPORT SURGERY	135
LISTER HOUSE PARTNERSHIP	20
LUSON	22
LYNGFORD PARK	15
MENDIP COUNTRY PRACTICE	215
MILBORNE PORT SURGERY	27
MILLBROOK SURGERY, CASTLE CARY	105
MINEHEAD MEDICAL CENTRE	315
NORTH CURRY	27
NORTH PETHERTON SURGERY	11
OAKHILL SURGERY	137
OAKLANDS SURGERY	12
PARK MEDICAL PRACTICE	46
PENN HILL SURGERY, YEOVIL	43
POLDEN MEDICAL PRACTICE	196
PRESTON GROVE MEDICAL CENTRE, YEOVIL	90
QUANTOCK MEDICAL CENTRE	15
QUANTOCK VALE SURGERY	28
QUEEN CAMEL MEDICAL CENTRE	49
REDGATE MEDICAL CENTRE	135
RYALLS PARK MEDICAL CENTRE, YEOVIL	26
SOMERSET BRIDGE MEDICAL CENTRE	57
SPRINGMEAD SURGERY, CHARD	15
ST JAMES MEDICAL CENTRE	226
SUMMERVALE SURGERY	12
TAUNTON ROAD MEDICAL CENTRE	46
TAUNTON VALE HEALTHCARE	15
TAWSTOCK MEDICAL CENTRE, CHARD	9
THE MEADOWS SURGERY	13
VICTORIA PARK MEDICAL CENTRE	17
VINE SURGERY PARTNERSHIP	29
WARWICK HOUSE MEDICAL PRACTICE	79
WELLINGTON MEDICAL CENTRE	-
WELLS CITY PRACTICE	76
WELLS HEALTH CENTRE	37
WEST COKER SURGERY	9
WEST SOMERSET HEALTHCARE	10
WILTON SURGERY	52
WINCANTON HEALTH CENTRE	23
<b>TOTAL</b>	<b>4,519</b>

### 2.3 Causes of Death

The leading causes of death for men and women in Somerset are shown in Figure 4 and Figure 5. It should also be noted that many people may have more than one of these conditions that may affect their treatment or contribute to their death, or both.

Of these major causes of death, cancer is generally the condition that has the most clearly defined terminal path, and this, as well as its prevalence, has meant that much EoLC focuses on cancer patients.

**There is a gap in the data meaning that we cannot compare the conditions affecting people on the EoL palliative care register with the causes of death; in consequence we cannot effectively monitor whether the provision of EoLC is equitable by condition.**

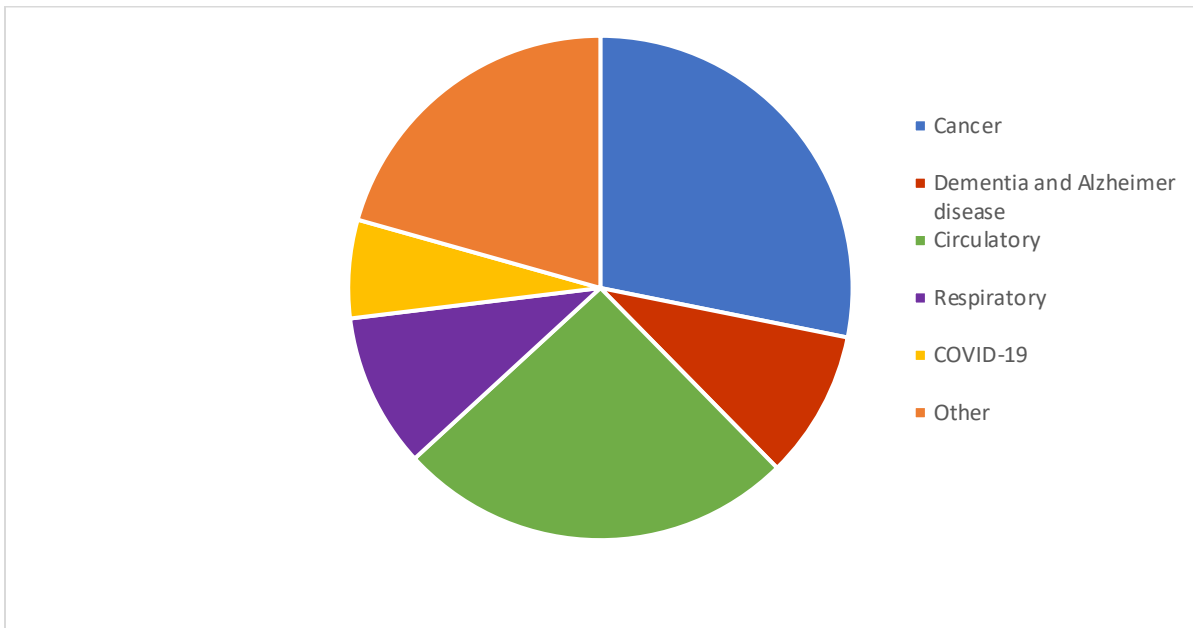


Figure 4: Leading cause of death, Men in Somerset 2020

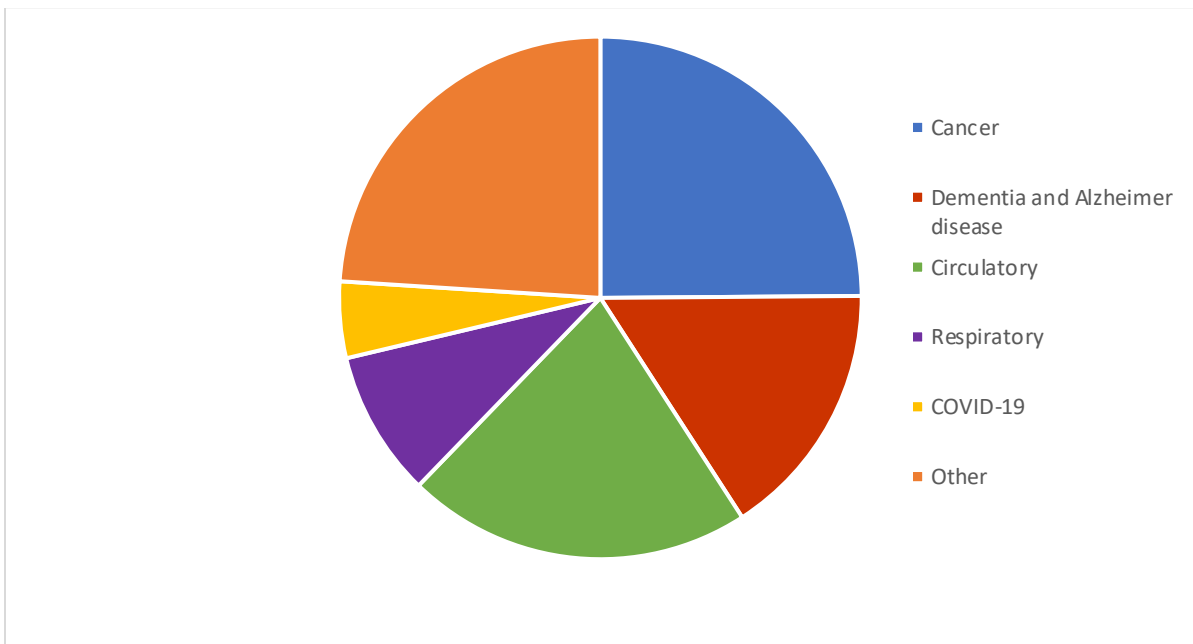


Figure 5: Leading cause of death, Women in Somerset 2020

For 2020, Covid-19 makes a significant contribution, which is unlikely to continue. The comparison of 2015 and 2020 in Figure 6 shows only small changes in the proportion. These figures are averages across the entire population, and there may be variations for particular groups: for example, respiratory conditions were the largest cause of death for people with learning disabilities in 2022/23.

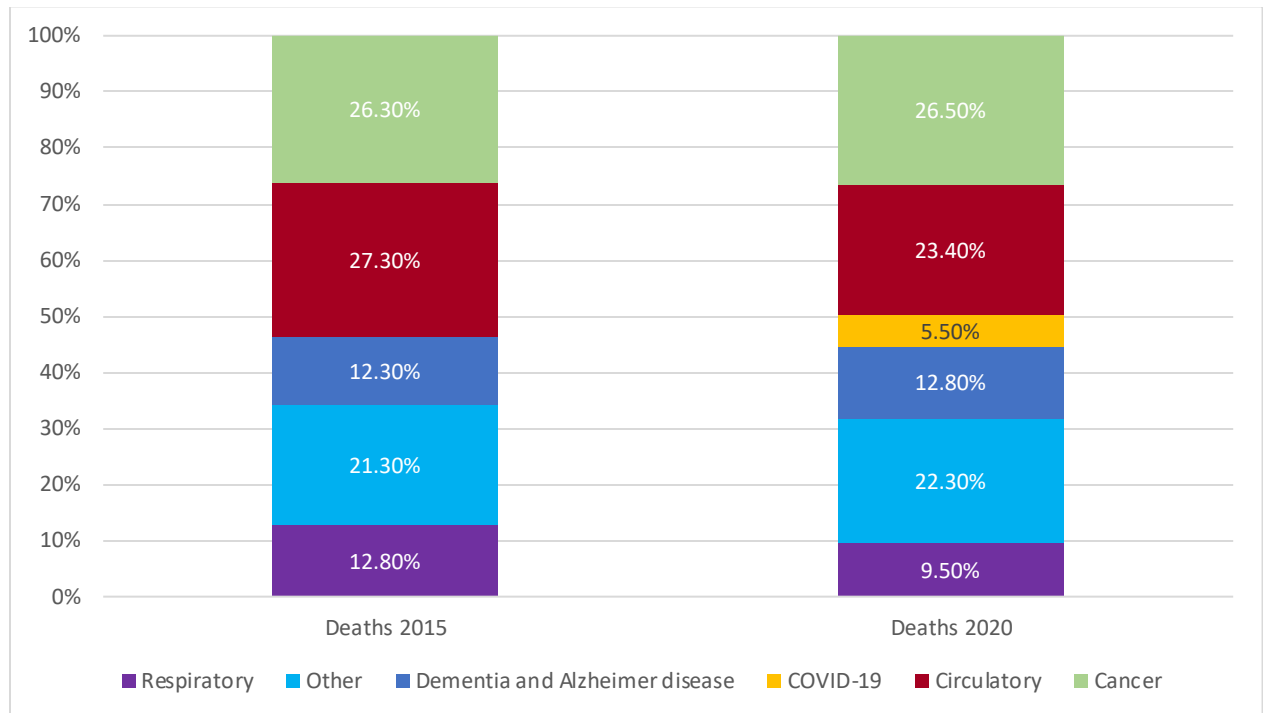


Figure 6: Proportion of deaths by underlying cause of death 2015 – 2020

However, it can be seen in Figure 7 that dementia and Alzheimer’s disease increase in proportion for the over 85s in particular, and it is possible that this will rise in overall importance as the population structure ages.

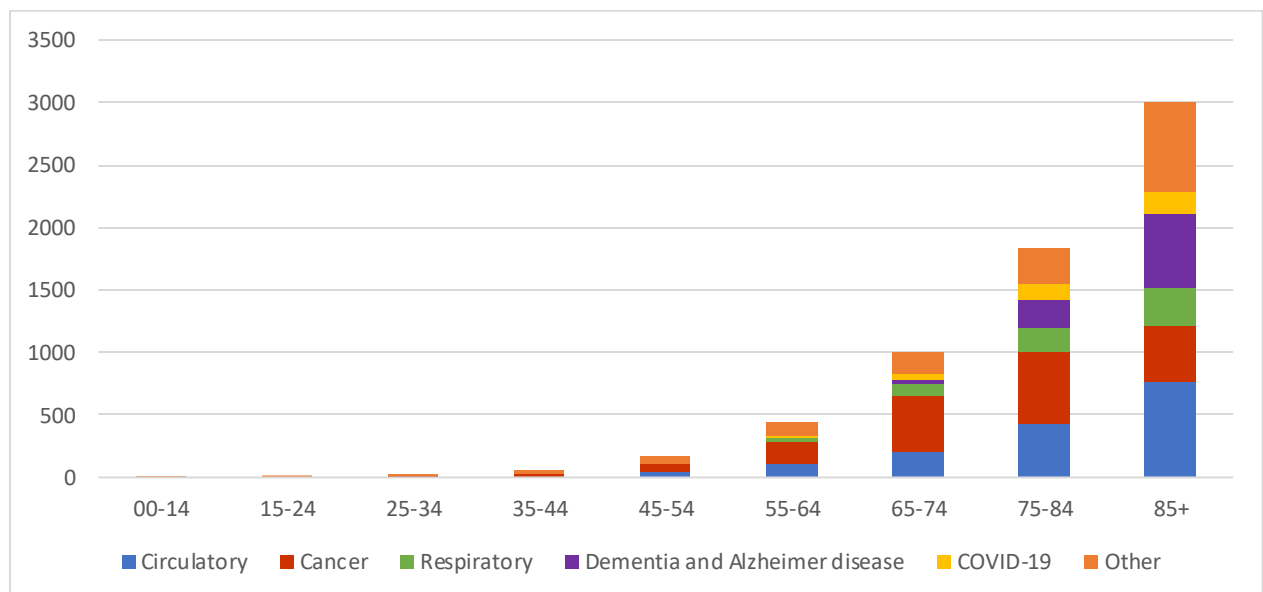


Figure 7: Major causes of death in Somerset by age, 2020

These graphs show the primary causes of death, and as such may oversimplify the picture by overlooking the fact that many patients will be ‘complex’ – having a number of long-term conditions, which can multiply the considerations needed in deciding on the best treatment.



Table 3: Causes of Death - Somerset benchmark against England and Wales (2016)

ONS Cause of Death Classification	Somerset			England and Wales		
	Males	Females	Total	Males	Females	Total
<i>Dementia &amp; Alzheimer disease</i>	9.10%	15.90%	13.00%	8.20%	15.60%	12.00%
<i>Ischaemic heart diseases</i>	12.80%	7.30%	10.40%	13.70%	8.40%	11.00%
<i>Cerebrovascular diseases</i>	5.70%	7.80%	7.00%	5.40%	7.00%	6.20%
<i>Chronic lower respiratory diseases</i>	5.80%	5.10%	5.60%	6.10%	5.90%	6.00%
<i>Malignant neoplasm of trachea, bronchus and lung</i>	5.20%	4.10%	4.30%	6.50%	5.20%	5.80%
<i>Influenza and pneumonia</i>	4.80%	4.80%	4.70%	4.90%	5.60%	5.20%

As shown in Table 3: Causes of Death - Somerset benchmark against England and Wales (2016)Table 3, the broad causes of death are similar in their proportions to England and Wales as a whole. The somewhat higher Somerset rates of dementia

**Based on changes in the previous five years, it can be inferred that EoLC is unlikely to have to respond to significant changes in the proportion of different conditions in the near future, although dementia and Alzheimer’s may become a greater element in deaths and complexity.**

**The main causes of death are typically conditions that develop over time, and most of those patients for whom EoLC is appropriate will also have had treatment for long term conditions, or identified as ‘frail’, or both. Joining up EoLC with these fields may mean that preparation for EoL, such as Advance Care Planning, can be made earlier in the patient journey.**

and Alzheimer’s disease reflect the generally older age profile.

## 2.4 Place of Death

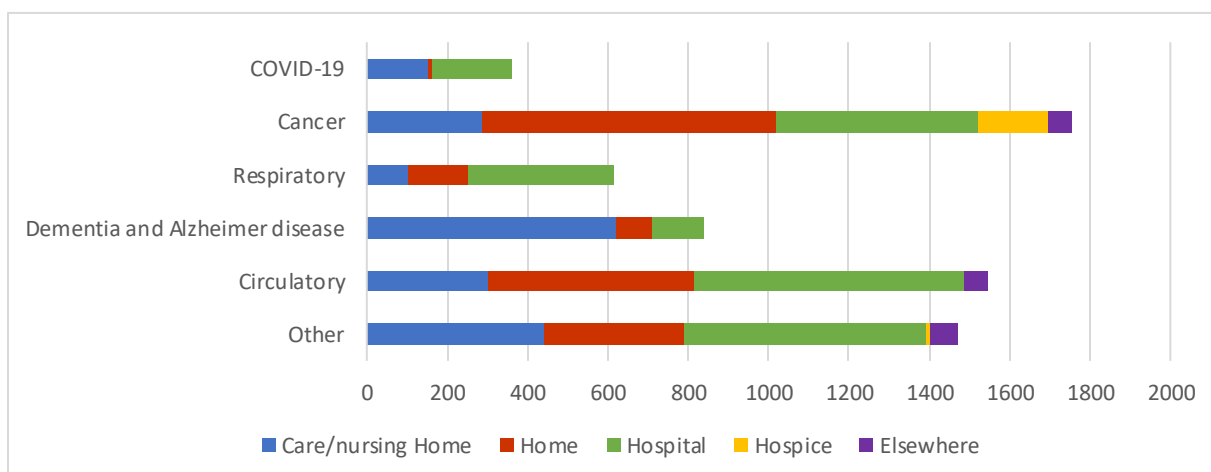


Figure 8: Place of death by cause of death, 2020

The place of death by condition is shown in Figure 8. The two most striking differences from the average are for dementia/Alzheimer's, where a significantly larger proportion of deaths are in care or nursing homes, and for cancer, where hospices make up about 10% of deaths. Whilst evidence suggests that a majority of people want to die at home, this is a sensitive issue and many can change their minds as their disease progresses. However, responding to patient wishes is important, requiring them to be discussed with patients and to be recorded (in Advance Care Plans or Treatment Escalation Plans), and the place of death recorded and the data linked to the plan.

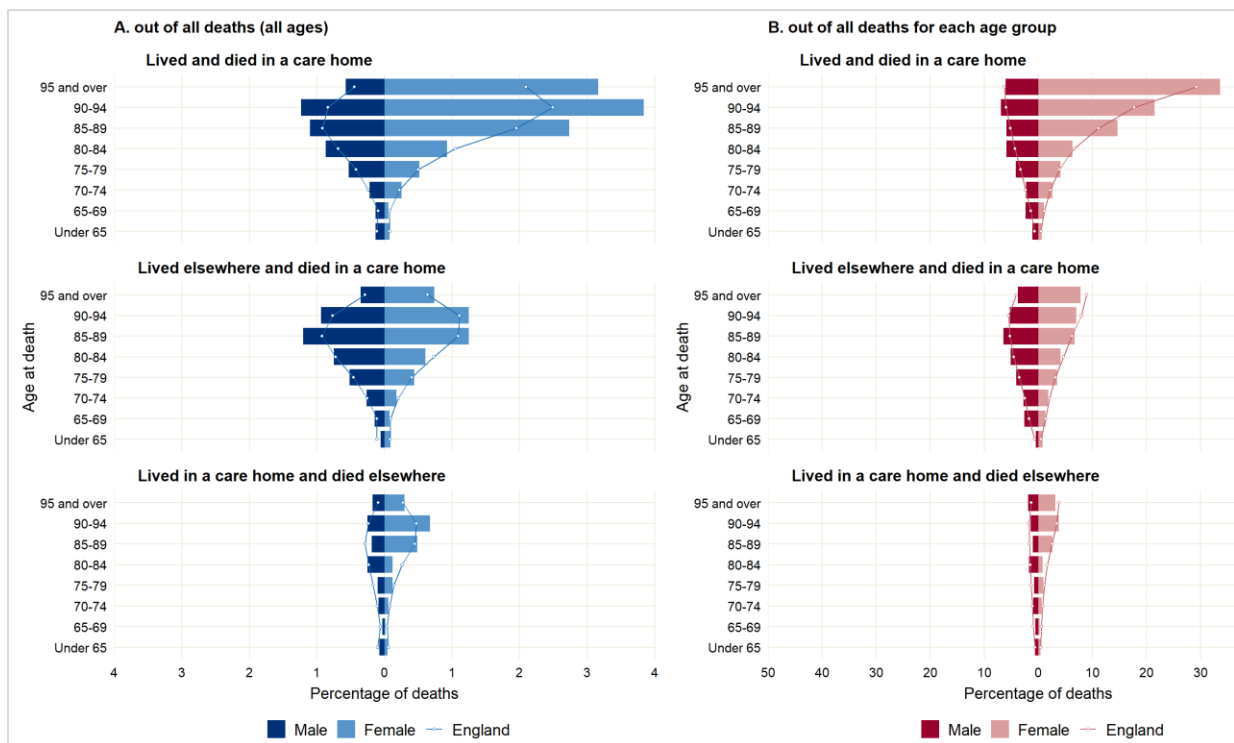


Figure 9: Percentage deaths by 'cared for' group - Somerset  
[fingertips.phe.org.uk/static-reports/end-of-life-care-home-factsheet/June2023/E1000027.html?area-name=Somerset Cty](https://fingertips.phe.org.uk/static-reports/end-of-life-care-home-factsheet/June2023/E1000027.html?area-name=Somerset%20Cty)

Figure 9 shows how the majority of care home deaths are of women over the age of 80. The likelihood of death being in a care home, whether normally resident or not, increases steadily with age.

**In order for as many as people to die in the place of their choosing, their wishes need to be recorded as much as possible in ACPs and reflected in TEPs. The actual place of death then needs to be linked to monitor effectiveness.**

**The dashboards developed in Suffolk and NE Essex, and by Hospice UK shown in Figure 10, offer the potential to monitor effectiveness.**

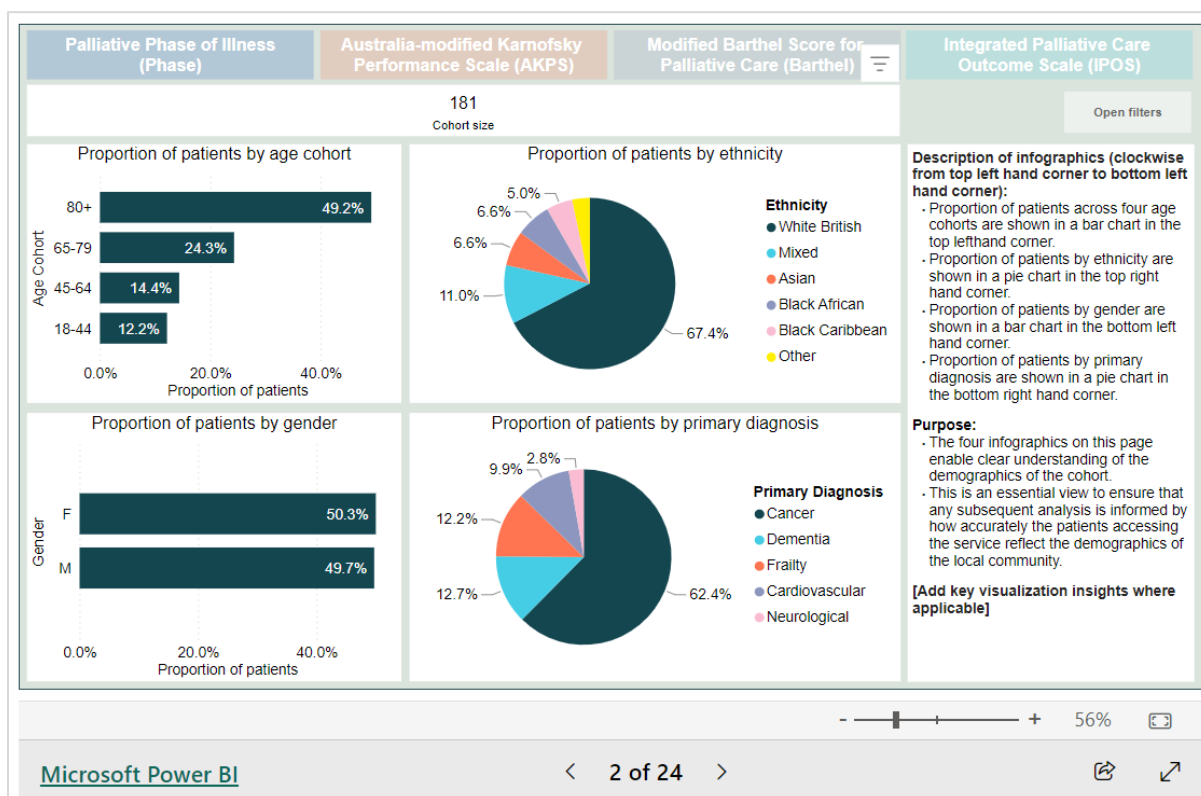


Figure 10: Hospice UK example Dashboard<sup>2</sup>

## 2.5 Population Groups

The potential disparity between those approaching end of life with different conditions has already been referred to, and is an EoLC-specific element of inequality.

People with Learning Disabilities have particular challenges when it comes to the difficult conversations necessary in preparing ACPs and TEPs. Somerset has already developed 'easy read' material to help.

Elsewhere, there is significant evidence that members of minority ethnic groups or in deprived communities do not receive the same level of care that is available to more prosperous, White British patients and their families ([Research - No Barriers Here](#)<sup>©</sup>). This can be seen in the accessibility of hospice care, with hospices playing a major role in coordinating patient-centred care, including services not available on the NHS, such as aromatherapy.

Barriers to equal treatment include many that have an effect on all health services, such as language and perception of discrimination. Others are more prevalent in relation to EoLC, such as dementia leading to a disproportionate loss of a second language or different perceptions of such care, with many minority communities in Somerset prioritizing family support, or difficulty in understanding the complex organizational structure of EoLC, such as assuming that hospice treatment was not free because outside the NHS. Others may want to return to their original country to die or to be buried, affecting their choices of treatment.

<sup>2</sup> [Developing a dashboard for your hospice: good practice guide | Hospice UK](#)

It is important to note that minority ethnic populations in Somerset, which tend to have a younger population structure than the White British, are also ageing, and such minority groups are likely to become an increasing proportion of EoLC patients.

LGBT+ people may also feel [excluded from EoLC services](#). Many now coming to the end of life will have grown up in a period when (male) homosexuality was illegal in the UK, and still worry about facing discrimination. In 2008, the [English End of Life Care Strategy Quality Impact Assessment](#) noted that, in terms of access to quality palliative and end of life care, LGBT people were at the most risk of experiencing discrimination. The sector needs to be sensitive to LGBT+ needs in order to provide equitable care. All people at end of life who do not have children locally, or at all, may find themselves needing significantly more formal care than those with children and families available to help.

**Understanding the various needs and preferences of minority groups is necessary if EoLC is to be available equally to all. The Musgrove Park library service will undertake a literature review of research on equality of access to EoLC.**

**The data underlying the dashboards developed in Suffolk and NE Essex, and by Hospice UK, offer the potential to monitor effectiveness of addressing inequalities.**

### **3 Key data sources**

Contextual national data is available in the Office for Health Improvement and Disparities profiles, including specific reports on place of death and care homes.

These reports provide factual information about numbers, type and place of care. However (as discussed later), end of life care typically involves a range of agencies, and the sort of information required to understand how they work together can only be obtained locally; this does not necessarily happen in the most useful way. The dashboards described above are ways in which locally derived information for performance monitoring and strategy development can be held and presented.

## 4 Key policies

A full list of guidance, reviews and policy is available from the Office for Health Improvement and Disparities. The two discussed here – on the basis of currency, force and breadth are the statutory requirements for ICBs from the Department of Health and guidance from the National Institute of Health and Care Excellence.

### 4.1 Palliative and End of Life Care - Statutory Guidance for Integrated Care Boards (ICBs) 2022: Key considerations to meet ICB legal duties

1. *People with palliative and end of life care needs should be supported by a whole system approach. This means that care and support should be provided by the right professional, at the right time. This includes access to out of hours palliative and end of life care.*

At a strategic level the coordination is provided by the Somerset End of Life Care Board and represented on the Somerset End of Care website (<https://someset.eolcare.uk>). Palliative care consultants work in acute, hospice and community settings; GPs also work in St Promotion of TEP and ACP by Margaret's hospice ([St Margaret's Hospice | 24-hour adviceline \(st-margarets-hospice.org.uk\)](http://StMargaretsHospice.org.uk)). Multiple agencies are typically involved in care of individuals and bereaved families. Information is shared through SIDeR (SIDeR - NHS Somerset <https://nhssomerset.nhs.uk/about-us/digital-projects/sider/>).

Somerset ICB has a responsibility in relation to NHS Continuing Health care Fast Track funding which provides an urgent package of care in the last days or weeks of life. A healthcare professional will assess the care needs of an individual and identify, with them and their family, the immediate level of care required within their own home or in a care home or other setting with the exception of 24 hour care. Fast track will commission providers who have the necessary skills to deliver the end of life (EoL) care that is assessed as required.

Providers, such as nursing homes, will be expected to be able to demonstrate, upon request that they have taken into account the overall dependency of all service users by considering the complexity of their needs and have sufficient levels of staffing and skills to support the needs of the individuals residing in their provisions.

The ICB will have oversight of these provisions and actively work to identify any gaps to providing adequate EoL care in these settings and the community and work with providers to improve where indicated and possible.

2. *People's palliative and end of life care needs, and complexity of their needs, will fluctuate throughout their journey, and this means that a flexible model of care is required. No single provider can provide for all needs and people will require access to a wide variety of non-specialist palliative care delivered by primary, community, acute and urgent care services, as well as specialist-level palliative care services to enable the system to provide personalised care to the person.*

A wide and diverse range of agencies is involved in Somerset end of life care, as described in the next section. The complexity<sup>3</sup> of patients' conditions – widely seen to have increased in recent years – adds to the range of agencies who may need to be involved.

- 3. The consideration of commissioned palliative and end of life care services applies to people of all ages. There are important differences between adults and children's palliative and end of life needs, including at the transition between childhood and adulthood, which must be taken into account in the commissioning and design of services.*

Thankfully the numbers of children dying each year is small – only 8 children between 28 days and 18 years died in 2021/22, for instance. The numbers amenable to palliative care even smaller; and even more rarely does a child reach the transition to adult care whilst close to end of life. This means that broad conclusions are difficult to draw. For children, and young people at the transition to adult services, the importance of a patient-centred approach – already identified as essential in EoL care – cannot be overstated<sup>4</sup>.

There is no children's hospice in the Somerset Council/Integrated Care System boundary, although patients have access to the hospice at Charlton Farm in North Somerset. St Margaret's hospice has also worked with Little Bridge (children's) Hospice in Barnstaple, and St Peter's Hospice in Bristol, on transition.

- 4. ICBs should have a clear vision of how the package of services they commission locally deliver against the Ambitions Framework and should actively seek out commissioning resources to achieve this.*

See below (Ambitions Framework).

- 5. There must be sufficient workforce in place across all settings, with the knowledge to deliver the care required. Regard should be given to supporting general clinicians to build knowledge, skills and confidence to deliver high quality, personalised EoLC, supported by specialist palliative care clinicians and services where appropriate.*

Workforce issues exist across the health and care sector – and indeed in many sectors of the wider economy. This has just been addressed nationally in the workforce plan<sup>5</sup>. In the meantime, all agencies are engaged in recruitment of necessary staff. Strategic development of staffing has to include effective pathways for career development, for current and future staff<sup>6</sup>.

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<sup>3</sup> Multiple, usually long-term, conditions have an exponential effect on the efforts needed to treat patients, as medicines may be incompatible, or dementia, say, may make compliance with the medicines' regime more challenging.

<sup>4</sup> [Somerset ICB Child Death Annual Report 2021/22.](#)

<sup>5</sup> [NHS England » NHS Long Term Workforce Plan](#)

<sup>6</sup> [Variations in the delivery of palliative care services to adults — HSIB](#)

## 4.2 Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026<sup>7</sup>

### 1. 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.*

The EoLC Board seeks to promote genuinely person-centred care at the end of life, with medical, personal, social and spiritual needs. It also recognizes the needs of families and carers, and the bereaved after death. It recognizes, though, that with finite resources this may involve compromises.

The Canadian model of Occupational Performance, used in St Margaret's Hospice and shown in **Error! Reference source not found.**, describes how these 'domains' are related to each other, with spirituality – which does not need to be religious – at the centre. This is the core of the person, where they decide on the meaning of everything, their likes and dislikes, their priorities, how they interpret the world. Around the core of the person is their mood or affect, physical state and cognitive abilities. This completes the person. A person performs a variety of occupations relating to self care, productivity and leisure. Spirituality is expressed and shaped through their occupations. The person exists within their environment. Occupation is the link between the person and their environment. Occupations are the way a person interacts with their environment. The physical, institutional, cultural and social environment influences both the person and their occupations. The environment presents the person with occupational opportunities. A change in one domain affects all the other domains.

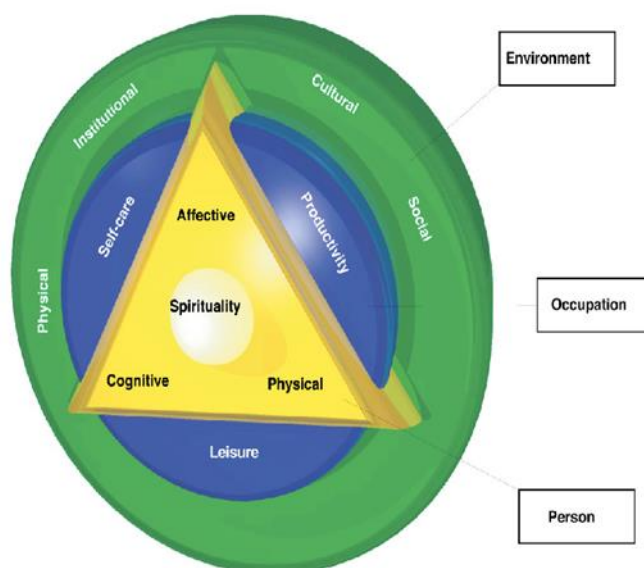


Figure 11: Canadian Model of Personal Performance

<sup>7</sup> National Palliative and End of Life Care Partnership May 2021, [ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf](https://www.england.nhs.uk/publications/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf) (england.nhs.uk)



## **2. 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.*

Services are open to all on the basis of need. However, the EoLC Board acknowledges that truly equitable access requires active engagement with those individuals and communities who are more easily overlooked. Those with learning disabilities, members of minority ethnic communities, people living in more deprived communities and those with life-limiting conditions other than cancer are all recognized as needing attention. Research is planned into the barriers to people in these groups.

The LeDeR Programme in Somerset - Learning from Lives and Deaths of people with learning disabilities and autistic people – has found that people in this population group can experience additional challenges in accessing EoLC. In particular this can relate to difficulties accessing appropriate medication, communication between services and a lack of training and support in providing EoLC for care and support staff<sup>8</sup>.

## **3. 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.*

Patient well-being is assessed by engagement with patients and families, and using tools such as Integrated Palliative Outcomes Score. The range of agencies involved, and types of care offered, reflects the diverse ways in which patient needs are addressed. 'Reasonable adjustments', as defined in equalities legislation, must be made to ensure that access is fair. These can include, for example, providing Easy Read versions of documents for people with learning disabilities<sup>9</sup>.

## **4. 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.*

At a strategic level the coordination is provided by the Somerset End of Life Care Board and represented on the Somerset End of Care website (See: <https://somerset.eolcare.uk>). In practice, professionals serve in a range of settings: for instance, palliative care consultants work in acute, hospice and community settings; GPs also work in St Margaret's hospice ([St Margaret's Hospice | 24-hour advice line \(st-margarets-hospice.org.uk\)](http://StMargaretsHospice.org.uk)). Multiple agencies are typically involved in care of individuals and bereaved families. Information is shared through SIDeR (SIDeR, NHS Somerset <https://nhssomerset.nhs.uk/about-us/digital-projects/sider/>)<sup>11</sup>. As well as receiving support, of course, families are often the primary providers of care to patients at the end of life.

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<sup>8</sup> See <https://www.tandfonline.com/doi/full/10.1080/13576275.2022.2044299>

<sup>9</sup> [https://www.ndti.org.uk/assets/files/RA-End\\_of\\_Life.pdf](https://www.ndti.org.uk/assets/files/RA-End_of_Life.pdf)

<sup>11</sup> This commentary replicates that for question one of the ICB statutory guidance.

## **5. 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.*

Feedback from patients and family regularly shows the great appreciation given to staff across the EoLC system in Somerset. When care does not reach the standards expected then complaints are investigated and learnt from, at an organizational and system level.

## **6. 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.*

The EoLC Board is very aware of the importance of Advance Care Planning, and supports efforts to have early conversations about living and dying well. This is led by Marie Curie in the community. We realize that there is still much to be done to make these conversations 'normal', and to bring together all the support that is potentially available. Inconsistency of Voluntary, Community and Social Enterprise (VCSE) support for patients and carers was identified by the Healthcare Safety Investigation Branch report into end of life care<sup>12</sup>.

### 4.3 NICE guidance 2021<sup>13</sup>

#### **1. Adults who are likely to be approaching the end of their life are identified using a systematic approach.**

Identification is normally by GPs, who hold this information. Patients are put onto a palliative care register, which is accessible through SIdER. However, there may be differences between GPs' decisions, and providing consistent decisions between different conditions is especially problematic. It has already been stated that cancer patients have a well-established procedure and are very likely to be identified as being close to death. The greater difficulty of doing so for conditions such as circulatory disease may be a source of inequality in the provision of palliative care<sup>14</sup>.

**The 'Vital Signs' project is seeking to improve consistency. A consistent register of palliative care patients, linked to treatment and demographic data, is a necessary denominator if an effective dashboard of EoLC is to be established. Artificial Intelligence, such as Brave AI in Axbridge and elsewhere, may help in identification.**

Evidence from Bristol, North Somerset and South Gloucestershire ICB suggests, unsurprisingly, that patients identified and included on the palliative care register have better outcomes than those who do not.

<sup>12</sup> [Variations in the delivery of palliative care services to adults — HSIB](#)

<sup>13</sup> [Published at Overview | End of life care for adults | Quality standards | NICE](#)

<sup>14</sup> [Variations in the delivery of palliative care services to adults — HSIB](#)

## **2. Adults approaching the end of their life have opportunities to discuss advance care planning**

There are well-established procedures for Treatment Escalation Plans (Somerset TEP :Somerset Treatment Escalation Plan (STEP) - NHS Somerset; <https://nhssomerset.nhs.uk/new-project-launches-in-somerset-to-help-families-have-important-end-of-life-conversations/>). Advance Care Planning, which covers wider considerations than the simply medical, is similarly established. However, this can be of greatest value if it is started for patients before a terminal diagnosis, making links with the frailty specialty and care homes particularly valuable. Those GP practices that have the highest number of ACPs (

Patients with Advance Care Plans by GP practice from SIDeR, July 202

Table 4) have strong links with care homes. ACPs are part of a quality improvement plan led by Musgrove Park Hospital.

Evidence from Essex suggests that preventative action can reduce hospital admissions – with a reduction of 46% linked to ACP, compared to 40% for a falls risk assessment and 28% from a structured medicines review.

The evidence for the effectiveness of ACPs is clear, but patients need to be able to express their desires and needs throughout their treatment. This can be direct, or through patient advocates who can speak on their behalf.

**End of Life Care should be integrated with approaches to long-term conditions and frailty, to assist early conversations on Advance Care Planning.**

Patients with Advance Care Plans by GP practice from SIDeR, July 202

*Table 4: Advance Care Plans - Leading GP practices*

Org code	Name	Count
L85004	Crewkerne Health Centre; Crewkerne	8
L85062	Lyngford Park	6
L85019	Minehead Medical Centre	5
L85023	St James Medical Centre	3
L85035	East Quay Medical Centre	3
L85009	Williton Surgery	3
L85010	Highbridge Medical Centre	3
L85033	Langport Surgery	3

**Marie Curie in particular has worked to promote ACPs, and this valuable activity should be encouraged further.**

**3. Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations**

At a strategic level the coordination is provided by the Somerset End of Life Care Board and represented on the Somerset End of Care website (<https://somerset.eolcare.uk>). Palliative care consultants work in acute, hospice and community settings; GPs also work in St Margaret's hospice ([St Margaret's Hospice | 24-hour adviceline \(st-margarets-hospice.org.uk\)](https://st-margarets-hospice.org.uk)). Multiple agencies are typically involved in care of individuals and bereaved families. Information is shared through SIDeR (SIDeR - NHS Somerset <https://nhssomerset.nhs.uk/about-us/digital-projects/sider/>).<sup>15</sup>

**Whilst most families are very complimentary about the care their relatives receive at end of life, the complaints that are made tend to involve poor communication or coordination between agencies, showing the importance of continuing to improve in this area. The newly-introduced PSIRF process for investigating issues should help learning from incidents in a patient-centred way across the system.**

**4. Adults approaching the end of their life and their carers have access to support 24 hours a day, 7 days a week**

The St Margaret's advice line provides such support, not exclusively for those under the care of the hospice ([St Margaret's Hospice | 24-hour adviceline \(st-margarets-hospice.org.uk\)](https://st-margarets-hospice.org.uk)).

**5. Carers providing end of life care to people at home are supported to access local services that can provide assistance**

Evidence from Carers' groups suggest that support is available, but stretched and with sometimes long waiting times. Health and care agencies may not always find it easy to identify the primary carer(s) for people at end of life.

Where there is a carer able to give JIC medications, training, assessment and support are provided to enable this to be undertaken safely.

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<sup>15</sup> This commentary replicates that for question one of the ICB statutory guidance.

## 5 Evidence reviews – Gaps in knowledge

It is clear from the review above that the main gaps in knowledge come in the difficulties of placing existing EoLC in its wider context. These take two forms:

- **Information about people not events**

The data that we have tend to be organized around care or health events, rather than people. Only by being able to track people through their pathways can we assess how well their needs and wishes are being met.

**SIDeR demonstrates that individual data can be joined up across ICT systems and agencies for operational purposes. Population Health Management approaches, and Business Intelligence, offer the potential for similarly integrated data to support strategic management and a whole system approach to care.**

- **Known unknowns**

We cannot be certain whether the people who receive integrated, patient-centred palliative care are all of those who could benefit, and if they are not, whether there are unacknowledged barriers to access for some groups, such as minority ethnic groups, those with learning difficulties or 'non-cancer' diagnoses.

**Integrated data may help point out where potential barriers exist, but understanding them properly – which includes learning how to remove them – will require constructive engagement with the communities in question.**

- **Services overview/funding**

The membership of the End of Life Care Board gives a good indication of the main agencies involved in care provision in Somerset.

- Dorothy House Hospice
- Marie Curie
- NHS Somerset Integrated Care Board
- Out of Hours Doctors
- Primary Care
- Somerset Care (Care Homes)
- Somerset Council Public Health
- Somerset Council Social Care
- Somerset NHS Foundation Trust
- South West Ambulance Service Trust (SWAST)
- St Margaret's Hospice
- Weston Hospicecare

The End of Life Care Board co-ordinates the working of these agencies at a strategic level, and local working in multidisciplinary teams helps patients and their families care that best suits their needs.

## 6 Summary and Recommendations

### 6.1 Health need

End of Life Care is likely to increase in absolute and proportionate importance in the county's health needs.

Based on changes in the previous five years, it can be inferred that EoLC is unlikely to have to respond to significant changes in the proportion of different conditions in the near future, although dementia and Alzheimer's may become a greater element in deaths and complexity.

The main causes of death are typically conditions that develop over time, and most of those patients for whom EoLC is appropriate will also have had treatment for long term conditions, or identified as 'frail', or both. Joining up EoLC with these fields may mean that preparation for EoL, such as Advance Care Planning, can be made earlier in the patient journey.

### 6.2 Respecting Individual wishes

In order for as many as people to die in the place of their choosing, their wishes need to be recorded as much as possible in ACPs and reflected in TEPs. The actual place of death then needs to be linked to monitor effectiveness.

Marie Curie in particular has worked to promote ACPs, and this valuable activity should be encouraged further.

The Musgrove Park library service will undertake a literature review of research on equality of access to EoLC.

### 6.3 Integration

End of Life Care should be integrated with approaches to long-term conditions and frailty, to assist early conversations on Advance Care Planning.

Whilst most families are very complimentary about the care their relatives receive at end of life, the complaints that are made tend to involve poor communication or coordination between agencies, showing the importance of continuing to improve in this area. The newly-introduced PSIRF process for investigating issues should help learning from incidents in a patient-centred way across the system.

### 6.4 Data presentation and data gaps

The dashboards developed in Suffolk and NE Essex, and by Hospice UK, offer the potential to monitor effectiveness and equity of provision..

SIDeR demonstrates that individual data can be joined up across ICT systems and agencies for operational purposes. Population Health Management approaches, and Business Intelligence, offer the potential for similarly integrated data to support strategic management and a whole system approach to care.

Integrated data may help point out where potential barriers exist, but understanding them properly – which includes learning how to remove them – will require constructive engagement with the communities in question.

## 7 Glossary

<b>Advance Care Plan (ACP)</b>	This typically contains the patient's broader wishes in relation to the end of their life, such as care of pets and funeral arrangements. It may also contain medical considerations, which are more usually contained in a Treatment Escalation Plan (TEP).
<b>Continuing Health Care Fast Track</b>	This process allows a package of care to be put together quickly for a patient whose condition is deteriorating rapidly.
<b>End of Life (EoL)</b>	A period when a patient is incurably ill, and medical treatment needs to focus on palliative care, rather than dealing with the cause of illness directly.
<b>Frailty</b>	The condition of older people at highest risk of falls, disability, hospital admission or need for long term care. Severe frailty is usually close to End of Life.
<b>Gold Standards Framework (GSF)</b>	This is a charity that promotes best practice in End of Life Care.
<b>Integrated Palliative Outcomes Scale (IPOS)</b>	This is a measure of symptoms, concerns and feelings to identify and respond to what matters to patients.
<b>LeDeR</b>	A process for learning from the deaths of people with a learning disability and autistic people to find areas to improve.
<b>Office for Health Improvement and Disparities</b>	A successor body to Public Health England, OHID maintains repositories of data on population health.
<b>Somerset Integrated Digital e-Record (SIDeR)</b>	A mechanism for sharing patients' electronic records between health and care bodies in Somerset.
<b>Treatment Escalation Plan (TEP)</b>	The Somerset Treatment Escalation Plan (STEP) is a record of patients' wishes in relation to their medical treatment when their condition declines. It can overlap with the ACP, and the terms are sometimes used almost interchangeably.