

Equality and Quality Impact Assessment Tool - Coventry and Warwickshire ICB

The following assessment screening tool will require judgement against all listed areas of risk in relation to quality. Each proposal will need to be assessed whether it will impact adversely on patients / staff / organisations.

Insert your assessment as positive (P), negative (N) or neutral (N/A) for each area.

Record your reasons for arriving at that conclusion in the comments column. If the assessment is negative, you must also calculate the score for the impact and likelihood and multiply the two to provide the overall risk score. Insert the total in the appropriate box.

Quality Impact Assessment

Quality can be defined as embracing three key components:

- Patient Safety – there will be no avoidable harm to patients from the healthcare they receive. This means ensuring that the environment is clean and safe at all times and that harmful events never happen.
- Effectiveness of care – the most appropriate treatments, interventions, support, and services will be provided at the right time to those patients who will benefit.
- Patient Experience – the patient’s experience will be at the centre of the organisation’s approach to quality.

Scheme Title:	System Wide Palliative and End of Life Care Strategy		
Project Lead:	Kathryn Drysdale Deputy Director of Nursing & Clinical Transformation Kate Butler: Project Manager	Senior Responsible Officer:	Tracy Pilcher
		Quality Review:	20 th July 2023
		Equality Review:	20 th July 2023
Intended impact of scheme:	<p>Coventry and Warwickshire ICS are committed to developing a system wide All-Age Palliative End of Life Care (PEoLC) Commissioning Strategy. The aim of the strategy is to develop a vision for our system through identification of 5 priority areas to improve key strategic outcomes in equity and quality of PEoLC care.</p> <p>This strategy will provide an overview of how health and social care will work together with our communities across Coventry and Warwickshire to improve the lives of people with palliative and end of life care needs and those who look after them.</p> <p>A cohesive, integrated PEoLC offer across Coventry and Warwickshire, which reflects the diversity of place underpinned by a co-produced strategy will support the development of services based on the needs of our population.</p>		

	<p>PEoLC services can be delivered in any setting, and they include the following services:</p> <ul style="list-style-type: none"> • GP or primary care • Social care • Voluntary sector • Care homes • Specialist palliative care services • Community nursing including symptom control • Hospice at home • Hospice inpatient beds • Holistic and therapeutic support • Bereavement support • Care homes • Domiciliary care support
<p>How will it be achieved:</p>	<p>PEoLC strategy development, implementation and the engagement that supports this is likely to comprise of the following activities:</p> <ul style="list-style-type: none"> • Fully assess and understand population needs and current data sets for service utilisation. • Identify key stakeholders and partners to the strategy • Develop a communication plan to enable engagement across the system of the draft strategy • Review the outputs of our local systems self-assessment of the National Ambitions for PEoLC. • To ensure the strategy vision and priorities are co-produced with our people and supported through rigorous stakeholder engagement. • To ensure the engagement incorporated the all-age nature of the strategy with involvement of children’s, Young People’s, and Transitional service leads. • To identify a clear Delivery Plan of how and when strategic priorities will be achieved and measured. • Enable robust governance structures to be implemented to support delivery of the Strategy.

<p>Name of person completing assessment:</p>	<p>ICB: Kathryn Drysdale & Kate Butler Input from:</p> <ul style="list-style-type: none"> • Katie Herbert Integrated Lead Commissioner (SWFT and WCC), • Kate Hoddell PEOLC Clinical Lead, • Jon Reading Head of Commissioning and Quality Coventry City Council • Tracey Sheridan Shakespeare Hospice
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Position:	Deputy Director of Nursing & PEO LC Project Manager
Date of Assessment:	4/07/2023

Quality Review by:	Mary Mansfield
Position:	Deputy Director of Nursing
Date of Review:	19/07/2023

Equality Review by:	Laura Whiteley
Position:	Governance and Corporate Affairs Manager
Date of Review:	27/07/2023

High level Quality and Equality Questions

The risk rating is only to be done for the potential negative outcomes. We are looking to assess the likelihood of the negative outcome occurring and the level of negative impact. We are also seeking detail of mitigation actions that may help reduce this likelihood and potential impact.

AREA OF ASSESSMENT		OUTCOME ASSESSMENT (Please tick one)			Evidence/Comments for answers	Risk rating (For negative outcomes)			Mitigating actions
		Positive	Negative	Neutral		Risk impact (I)	Risk likelihood (L)	Risk Score (IxL)	
Duty of Quality Could the scheme impact positively or negatively on any of the following:	Effectiveness – clinical outcome	✓			Integrated and collaborative approach to delivery of systemwide PEO LC pathways with NHS, social care and third sector colleagues working together to improve				

					personalised care and support planning.				
	Patient experience	✓			Experience of the PEOLC patient and those important to them is essential as we only get one chance to get this right. The strategy highlights the core foundations of building trust with the people of Coventry and Warwickshire and on-going co-production with people and stakeholder to enable robust and effective feedback loops to be developed and to enable patient experience to be gathered, through a range of mechanisms and enabling this feedback to be developed into constructive, meaningful service development.				
	Patient safety	✓			In the development of any strategic approach, patient safety must be paramount in the development of services connected through an integrated and collaborative system approach to personalised care and support planning. The strategy will enable a systemwide approach and response to identify patient safety and safeguarding issues and to disseminate the learning from these situations across the				

					system.				
	Parity of esteem	✓			Identification of our under-served communities will be undertaken through an Equality Impact Assessment, which will in turn work with communities across the system to build trust and work toward co-production of service development to support equity of service provision.				
	Safeguarding children or adults			✓	Maintenance of current safeguarding arrangements as per ICB Local Authority and/or Provider safeguarding policies and procedures. A systemwide approach to care with a collaborative, integrated approach, will enable learning from incidents to be shared across the system.				
NHS Outcomes Framework Could the scheme impact positively or negatively on the delivery of the five domains:	Enhancing quality of life	✓			<p>Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 document will be used as the basis for the strategy.</p> <p>“We know that access to good and early palliative care can improve outcomes for life expectancy as well as improve the quality of life”. Temel, J.S, Greer, J.A,</p>				

					Muzikansky, M.A, Gallagher, E.R, Admane, M.B, et al (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. N Engl J Med 2010;363:733-42				
	Ensuring people have a positive experience of care	✓			The Programme will ensure equity of service delivery, working together with partners across the system to develop effective, inclusive personalised care pathways, which collate feedback in tandem to audit tools such as NACEL (National Audit for Care at the End of Life) and the OACC (Outcome Assessment and Complexity Collaborative) suite of outcome measurements. Complaints, compliments, and feedback will be sought through on-going engagement with the people and stakeholders of our system.				
	Preventing people from dying prematurely	✓			The Strategy and supporting Delivery Plan will prioritise identification of those thought to be in the last 12 months of life, to support pro-active personalised care and support planning to improve access to services and				

					support to ensure that people in need of PEoLC and those who are important to them and / or care for them. Pro-active enablement of treatment and support will reduce the risk of uncontrolled palliative care which should reduce premature death although death will be expected for all patients on an PEoLC journey. LeDeR reviews will be used to learn from premature and avoidable deaths for people with Learning Disability and Autism.				
	Helping people recover from episodes of ill health or following injury	✓			The programme includes developing equity of access to pro-active palliative care e.g., community support services; Day Hospice Therapy Services e.g., Breathlessness Management support				
	Treating and caring for people in a safe environment and protecting them from avoidable harm	✓			Wrap around care at home – coordinated via an identified care coordinator depending on the patient's preferred place of care. Remote monitoring and consultations for housebound patients and those residing in a care home setting to support assessment and expedite the provision of timely end				

					<p>of life care.</p> <p>All PEoLC services will adhere to up-to-date IPC guidance and policies.</p> <p>Support with admission avoidance and discharge enablement to support those thought to be in the last 12 months of life to be cared for and die in their preferred place.</p>				
<p>Patient services Could the proposal impact positively or negatively on any of the following:</p>	<p>A modern model of integrated care, with key focus on multiple long-term conditions and clinical risk factors</p>	✓			<p>This strategy has at its heart an integrated care approach with partners and key stakeholder collaborating across organisational boundaries to improve the lives of people with life limiting conditions and multiple clinical risk factors who are approaching the end of their lives.</p> <p>Resources to support the strategy are integrated across the system and we are working with other frailty work programs to ensure a consistent and integrated model of care.</p>				
	<p>Access to the highest quality urgent and emergency care</p>	✓			<p>Timely access to urgent and emergency care services which can direct palliative patients and their carers to the most appropriate service,</p>				

					whether community or secondary care based, to support the patient with symptom management and the patient's preferred place of care to be maintained if clinically appropriate. Escalation of care to MDTs and/or specialist teams for timely review can be enabled through an integrated approach to support proactive care and support planning, when clinically required.				
	Convenient access for everyone	✓			A key theme for the strategy is access, currently there is inequity of access to services, the strategy will raise the profile of inequity and support active review of services from the lens of our under-served communities and support service development and redesign with co-production with under-served communities.				
	Ensuring that citizens are fully included in all aspects of service design and change	✓			The Strategy development process has already increased the opportunities for engagement and co-production with the people of Coventry and Warwickshire and this is planned as the beginning of on-going engagement to support the Strategy's				

					<p>delivery plan over the next 5 years.</p> <p>Patients will be fully involved in their care planning.</p> <p>Friends and Family feedback will inform service development.</p> <p>Compassionate Communities development work will support with an integrated approach to co-production and community led approach to care.</p>				
	Patient Choice	✓			<p>The 5 priority areas identified within the strategy include:</p> <p>1. Information: to enable people to better understand the care pathways available to them and support options within our current system to increase patient choice. This information will also be available to health and social care professionals to increase the range of services made available to patients and those important to them.</p> <p>3.Support – mapping and reviewing options for those who are unpaid carers, increasing knowledge of health and social care professionals as to</p>				

				<p>currently available support offers in increase choice.</p> <p>Where feasible and clinically appropriate remote, digital, and self-management options will be offered</p> <p>Currently we are mapping data sets which can be utilised to support this programme of work. Preferred place of care and death are included within advance care planning and will be included within the proposed PEOLC data set, which can then be utilised to review the delivery of patient choice, whilst other data sets are reviewed, and monitoring options expanded.</p>				
	Patients are fully empowered in their own care	✓		<p>The strategy will seek to build upon the personalisation and shared decision-making work which has been on-going through our system. In relation to PEOLC, we already have established work around advance care plans including the ReSPECT form and standardised end of life care plans. (EPaCCS (Electronic Palliative Care Coordinating Systems))</p>				

	Wider primary care, provided at scale			✓	Primary care is a key partner in PEOLC and the implementation of the strategy.				
Access Could the proposal impact positively or negatively on any of the following:	Patient choice	✓			The 5 priority areas identified within the strategy include: 2. Access – review of current pathways to enable inequity for our under-served communities to be better understood and addressed and therefore increasing patient choice. Where feasible and clinically appropriate remote, digital, and self-management options will be offered. The aim of universal personalised care planning through shared-decision making will improve patient choice.				
	Access	✓			Mapping of services PEoLC including timely access and place-based service access issues will be incorporated into the Strategy's delivery plan. People known to have inequity of access to services will be identified and service design developed to reflect the				

					<p>need for personalised care and support planning for all our diverse communities.</p> <p>In patient bed access</p> <p>Access to digital technology will be considered</p>				
	Integration	✓			<p>This strategy has at its heart an integrated care approach with partners and key stakeholders collaborating across organisational boundaries to improve the lives of people with life limiting conditions and multiple clinical risk factors who are approaching the end of their lives.</p>				
Compliance with NHS Constitution	Quality of care and environment	✓			<p>We will seek to understand the current position and set priorities and aims to improve the current integrated pathway offer for people with end of life / palliative needs. The extent to which this improves individual outcomes will be subject to the extent to which the strategy priorities and outcomes are delivered and embedded through care collaboratives and place.</p>				

	Nationally approved treatment/drugs			✓	NICE guidance and local guidance will be followed. Current working group set up to review access to PEO LC anticipatory medication.				
	Respect, consent, and confidentiality			✓	All usual ICB and/or Provider respect, consent and confidentiality policies and mechanisms will apply.				
	Informed choice and involvement	✓			<p>Patients will be fully involved in their care planning through shared decision-making, personalised care, and support planning.</p> <p>Those who matter to the patients will also be involved in shared care decision making and advance care planning where appropriate.</p>				
	Complain and redress			✓	Usual ICB and/or Provider compliment, complaint and redress policies and mechanisms will apply				

Equality Impact Assessment

All public authorities are required to have due regard to the aims of the Public Sector Equality Duty (PSED) of the Equality Act 2010 in exercising their functions, such as when making decisions and when setting policies.

Publishing guidance or policies or making decisions without demonstrating how you have paid due regard to the PSED leaves the organisation open to legal challenge.

This means ICB (Integrated Care Board), and NHS England should understand the potential effect of policies and practices on people with characteristics that have been given protection under the Equality Act, especially in relation to their health outcomes and the experiences of patients. This will help the organisation to consider whether the policy or practice will be effective for all people

Project / Policy Details

What is the aim of the project / policy?

To develop a Coventry and Warwickshire system wide strategy for PEOLC services for the next 5 years and a supporting initial 2-year delivery plan, with the development of a further 3-year delivery plan during the first 2 years of the strategy.

This strategy will aim to improve the quality of PEOLC services across the local system, through collaboration and integration, whilst aligning to the National Ambitions for PEOLC whilst complimenting other interdependent system strategies and work programmes.

The strategy will layout the vision and priorities for PEOLC care from a system perspective.

The strategy and delivery plan development will:

- Build on the co-production which has already been undertaken with the people and Coventry & Warwickshire and stakeholders from across the system.
- Prioritise a “patient and those important to them” approach, from across our diverse communities through co-production and engagement which feeds into the strategy and delivery plans throughout the 5 years.
- Identify inequity of access to services and wider inequalities to support the development of the strategy, the launch, and the delivery.
- Utilise intelligence and feedback from PEOLC place groups and other committees, boards, and work programmes from throughout the system to improve collaborative working and the development of an integrated, personalised approach to care pathways.

The identification of our under-served communities and the health inequity which is present in our system is vital to drive forward improvement of access to PEOLC services for all our diverse communities, which we are keen to do through continued engagement and co-production.

Ensuring the strategy reflects and addresses the needs of all local communities, our workforce and other stakeholders is essential to the successful development of PEOLC across the system.

Who will be affected by this work? e.g staff, patients, service users, partner organisations etc.

Our System in numbers



Palliative care is about improving the quality of life of anyone facing a life-limiting condition. It includes physical, emotional, social, spiritual care and practical support. We want our people of Coventry and Warwickshire to live as well as possible for as long as possible.

End-of-life care is the treatment, care and support for people who are nearing the end of their lives. It is an important part of palliative care and aims to help people live as comfortably as possible in their last months, weeks, or days of life and to die with dignity.

Palliative and End of Life Care involves a range of healthcare, social care, third sector and communities working together, to provide physical, emotional, and spiritual support for the individual and those who matter to them.

Palliative and End of Life Care is one of the few areas which will impact on everyone during their life and is a key thread throughout the delivery of all areas of healthcare, but also in social care and community support.

Through understanding the experiences of people and the barriers they experience, we can listen and learn in order to embed equity, inclusion, and improved patient experience for all in the development of a collaborative and integrated approach to care.

Through engagement with our stakeholders, through developing services and pathways with a collaborative, integrated approach, we can achieve systemwide, patient-centered pathways which support individuals and those important to them at the most difficult time in their lives and so improving the quality of care.

Our people

The Coventry and Warwickshire Integrated Care System provides health, care and wellbeing services and support to a diverse registered GP population of over 1 million people, and that population is growing.

The footprint covers several diverse patient populations:

- Coventry has a population of approx. 345,300:
 - high level of ethnic diversity, with a Black and Minority Ethnic population of 34.5% (2021 census)
 - a younger population age profile than England in general (due to 2 universities) with only 14.6% aged over 65 years.

- 3% of the Coventry population cannot speak English well or at all and for approximately 14% of Coventry residents, English is a second language.
- 72.1% of people in Coventry were born in the UK (United Kingdom)
- Warwickshire has a population of approx. 596,800:
 - in contrast to Coventry, is less ethnically diverse with 11.5% identifying as Black and Minority Ethnic.
 - Warwickshire has an older population with 20.8% aged 65 years and over, which is higher than both the West midlands and National averages.
 - More rurality, and in some places greater levels of deprivation.
 - Of the Warwickshire population, 0.8% cannot speak English well or at all.

Our stakeholders



Key collaborators and individuals and groups impacted by the PEOLC Strategy have been identified via a stakeholder analysis as:

- People using PEOLC and Palliative care services
- Those who matter to the patient
- People of Coventry & Warwickshire
- Integrated Care Board
- Integrated Care Collaboratives
- Local Authorities in Coventry and Warwickshire
- Expert Advisory Groups
- PEOLC Place Groups
- Community Providers (CYP & Adult)
- Secondary Care Providers (CYP & Adult)
- Primary Care Providers (CYP & Adult)
- Hospice Providers (CYP & Adult)
- Independent Service Providers e.g. Domiciliary Care, Care Homes, Independent Hospitals
- Voluntary Sector Services
- West Midlands Ambulance Service
- Faith Groups
- Coroner's Office
- Chaplaincy Service
- Community Groups
- H.M.Prisons

- LD Representative organisations
 - LGBT representative groups
 - Homelessness Support Providers
 - Schools
 - Carers Trust
 - Healthwatch
 - HEE & Training Lead orgs
 - AGE UK
 - Compassionate Communities/City
- The above is not an exhaustive list and is regularly reviewed.

Is a full Equality Analysis Required for this project?			
Yes	Proceed to complete this form.		Explain why further equality analysis is not required.
If no, explain below why further equality analysis is not required. For example, the decision concerned may not have been made by the ICB or it is very clear that it will not have any impact on patients or staff.			
N/A (EQIA / Equality Plan requirement from NHSE (NHS England))			

Equality Analysis Form

1. Evidence used
<p>What evidence have you identified and considered? This can include national research, surveys, reports, NICE guidelines, focus groups, pilot activity evaluations, clinical experts or working groups, JSNA or other equality analyses.</p> <p>In determining the equity of access to and quality of PEOLC services which our communities in Coventry and Warwickshire have, a wide range of evidence has been considered. Co-production of the strategy has been at the forefront of driving the understanding of how we can support our underserved communities better and improve quality of care for all.</p> <p>Links have been made through to other organisations and focus groups to utilise recently undertaken engagement, e.g. Carer’s Survey and in tandem to this, an 8-week systemwide PEOLC engagement has been run in June and July 2023.</p> <p>Links have been made to stakeholders across the system to ensure that on-going work is being mapped and utilised where appropriate, e.g. Integrated Care System (ICS) Strategy; Local Authority (LA) Joint Needs Assessments; ICS Health Inequalities Strategy; Coventry and Warwickshire Personalisation Strategy; The University of Warwick: Palliative and End of Life Care Research Hub; NHSE Palliative and End of Life care Strategic Clinical Network both regional & national in addition to others in order to ensure we are building on a strong foundation of the learning which has already taken place within our system and wider region.</p> <p>A review of currently available research and clinical evidence has also been undertaken to ensure we have a clear and consistent approach to reducing the unfair and avoidable differences in palliative and end of life care across our population and between different groups within our society, through identification of our under-served communities.</p>

Review of this research¹ has evidenced that certain groups of people receive inequitable access to palliative and end of life care than others with a comparable need. These identified groups include:

- people over the age of 85,
- people from a black, asian or minority ethnic background,
- people who identify as lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ+),
- people from more deprived areas,
- people who are socially isolated or live alone,
- people who are homeless,
- people who have mental health needs,
- people who are living in prisons.

Local review² and engagement has also included the following groups for Coventry & Warwickshire:

- People from the asylum and migrant communities
- People from the gypsy, Roma, and traveller communities
- People from boater communities
- People with a learning disability

Over-arching evidence considered in this review:

- [NHS Long Term Plan 2019](#)
- Department of Health & Social Care (2021) [Integration & Innovation: working together to improve health and social care for all.](#)

Over-arching PEOLC evidence considered in this review:

- The Kings Fund (2023) [Dying well at home: commissioning quality end-of-life care](#)
- BMC (2023) [How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease? A mixed methods systematic review](#)
- BMJ (2023) [Communication about sexual orientation and gender between clinicians, LGBTQ+ people facing serious illness and their significant others: a qualitative interview study of experience, preferences and recommendations.](#)
- Palliative medicine (2023) [Palliative and end of life care needs, experiences and preferences of LGBTQ+ individuals with serious illness; A systematic mixed-methods review.](#)
- BMJ (2022) [Ethnicity and palliative care: we need better data – five key considerations](#)
- BMC Palliative Care (2022) [The end of life experiences of people living with socio-economic deprivation in the developed world: an integrated review](#)
- EAPC (2022) [Understanding parent experiences of end of life care for children: a systematic review and qualitative evidence synthesis](#)
- NHSE (2021) [Ambitions for Palliative and End of Life Care](#)
- Age UK (2021) [Breaking down the barriers of ethnic inequalities in health](#)
- Hospice UK (2021) [Equality in hospice and end of life care: challenges and change](#)
- BMC Palliative (2021) [Exploring socio-economic inequities in access to palliative and end of life care in the UK: a narrative synthesis](#)
- Cancers (2021) [Socio-economic deprivation and symptom burden in UK Hospice patients with advanced cancer – findings from a longitudinal study.](#)
- NIHR Evidence (2021) [Most children with life-limiting conditions still die in hospital, not home or hospice - Informative and accessible health and care research.](#)

¹ [Palliative and End of Life Care Profiles - Inequalities - OHID \(phe.org.uk\)](#)

² [Coventry & Warwickshire ICS Health Inequalities Strategy](#)

- Palliative Medicine (2021) [End of life care for people with severe mental illness: Mixed methods systematic review and thematic analysis.](#)
- Cureus (2021) [Challenges of Providing Palliative Care to a Patient with Learning Disability: A Case Study from UK general practice](#)
- BMJ (2021) [Specialist palliative care services response to ethnic minority groups with Covid-19: equal but inequitable – an observational study.](#)
- The Strategy Unit (2020) [Palliative and End of Life Care in the West Midlands](#)
- British Geriatrics Society (2020) [End of Life Care in Frailty](#)
- Journal of Advanced Nursing (2020) [A systematic review exploring palliative care for families who are forced migrants](#)
- BMJ (2020) [Hospice care access inequalities: a systematic review and narrative synthesis](#)
- European Association for Palliative Care (2020) [The palliative care needs of adults with intellectual disabilities and their access to palliative care services: systematic review](#)
- Manchester Metropolitan University and Community Fund (2019) [Good Practice Guidance. Supporting people with substance abuse problems at end of life](#)
- Manchester Metropolitan University (2019) [Palliative end of life care for people with alcohol and drug problems](#)
- NHSE (2019) [Achieving more for people with severe mental illness](#)
- NHSE (2018) [Care committed to me – delivering high quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.](#)
- NHSE (2018) [Dying Well in Custody Charter.](#)
- NHSE (2018) [My future wishes: Advance Care Planning \(ACP\) for people with dementia in all care settings.](#)
- Seminars in Oncology Nursing (2018) [Palliative and End of Life care for Lesbian, Gay, Bisexual and Transgender \(LGBT\) Cancer Patients and their caregivers](#)
- BMC Palliative Care (2018) [Palliative care for homeless people: a systematic review of the concerns, care needs and preferences and the barriers and facilitators for providing palliative care](#)
- Macmillan (2017) [The final injustice: Variations in end-of-life care in England](#)
- BMJ (2017) [Healthcare on the water](#)
- Care Quality Commission (2016) [A different ending: end of life care review](#)
- Marie Curie (2015) [Why do older people get less palliative care than younger people?](#)
- Clinical medicine (2014) [Palliative care for frail older people](#)
- Understanding patterns of health and social care at the end of life - This report details the key findings from a study of over 73,000 people in England during the last 12 months of their lives. October 2012 <https://www.nuffieldtrust.org.uk/research/understanding-patterns-of-health-and-social-care-at-the-end-of-life>
- Department of Health (2008) [End of Life Care Strategy](#)
- International Journal of Palliative Nursing (2007) [The Challenges of providing palliative care to terminally ill prison inmates in the UK.](#)

Data sources:

- Office for Health Improvement & Disparities. (2022) [ICS Data Pack: Palliative and end of life care. Coventry & Warwickshire.](#)
- Office for National Statistics. [Census 2021.](#)
- [Coventry City Council Joint Strategic Needs Assessment \(JSNA\)](#)
- [Warwickshire City Council Joint Strategic Needs Assessment \(JSNA\)](#)
- Coventry and Warwickshire ICS available PEoLC data

Specific focus has been given to the 2020 Strategy Unit Report as outlined below:

Health service usage in the last 2 years of life – a report for Coventry and Warwickshire STP³

This report published in October 2020, provides a summary of death and dying within our local system, how services are used and how they may be utilised in the future (if nothing changes). Drawing on local datasets, the conclusions from this report are as follows:

- 66% of people say they would like to **die at home**. In Coventry and Warwickshire just 22% do so.
- People from **deprived areas** are more likely to die in hospital than people from affluent areas. The reverse is true for deaths in care homes.
- 39% of people in Coventry and Warwickshire who die do so after being admitted to hospital as an **emergency**. Their length of stay in hospital is often short. The most common experience is a terminal episode of two days.
- If patterns of care follow those observed nationally, then as many as a third of palliative patients (around 2,000 people) in Coventry and Warwickshire may have **died with their pain not properly controlled**.
- Over 90% attend **A&E** at least once in the two years prior to their death. 86% have at least one emergency admission. Around two-thirds call 111.
- 19% of those dying are in contact with **mental health services**. This is lower than for the Midlands region (25%).
- **Frailty** is the single largest underlying cause of death, accounting for close to half of all deaths. Frailty has the largest proportion of deaths in a care home setting;
- **Cancer** is the cause of death for around a fifth of the population. 22% of cancer patients die in a hospice setting. This is considerably higher than other causes;
- People's use of **urgent care** starts low and increases slowly for much of the last two years of life. There is a **rapid increase** a few months prior to death. The same is true for the use of hospital beds.
- Use of emergency admissions and A&E attendances does not differ greatly by age at death. What drives use of these services is not age, but proximity to death.
- In the last two years of life around **£115 million is spent on hospital services for decedents in Coventry and Warwickshire**. Urgent service events account for around two-thirds of this.
- The spend per decedent on hospital services was around **£17,000; this was significantly higher** than Midland's average of £15,800. The range between STPs in the Midlands was £13,600 to £17,400.
- Having declined for decades, the number of **deaths has begun to rise and is set to continue**. The greatest number of deaths is among those aged 85 and above. This is also the group with the largest expected increase.
- If patterns of care do not change, the current growth in deaths per annum suggests that **200 additional beds will be needed in the STP by 2040**.

Considering this report, a review of the impact which the COVID-19 pandemic has had on the system has been undertaken so we can have a clear understanding of the current position.

The Office for Health Improvements and Disparities [collates statistics](#) to provide a more up to date review regarding palliative and end of life care. The monthly percentage and count of people who died in England, from January 2019 to September 2022 is shown by place of death (hospital, home, care home, hospice, and other places) in Figure 1. The effect of the COVID-19 pandemic is evident in the distribution of deaths by place of death, most notably:

- the percentage of people dying in care homes showed a marked increase in April and May 2020, during the first wave of COVID-19

³ Health Services in the last 2 years of life – Coventry and Warwickshire STP, A report by The Strategy Unit, 1 October 2020

- the percentage of people dying in their home increased in April 2020 and has remained higher than previous years
- the percentage of people dying in hospital fell from January to May 2020, then started to rise again in September and peaked in January 2021

Figure 1: Monthly trends in % of deaths and count of deaths by place of death: England (all ages, 2019 to 2022)

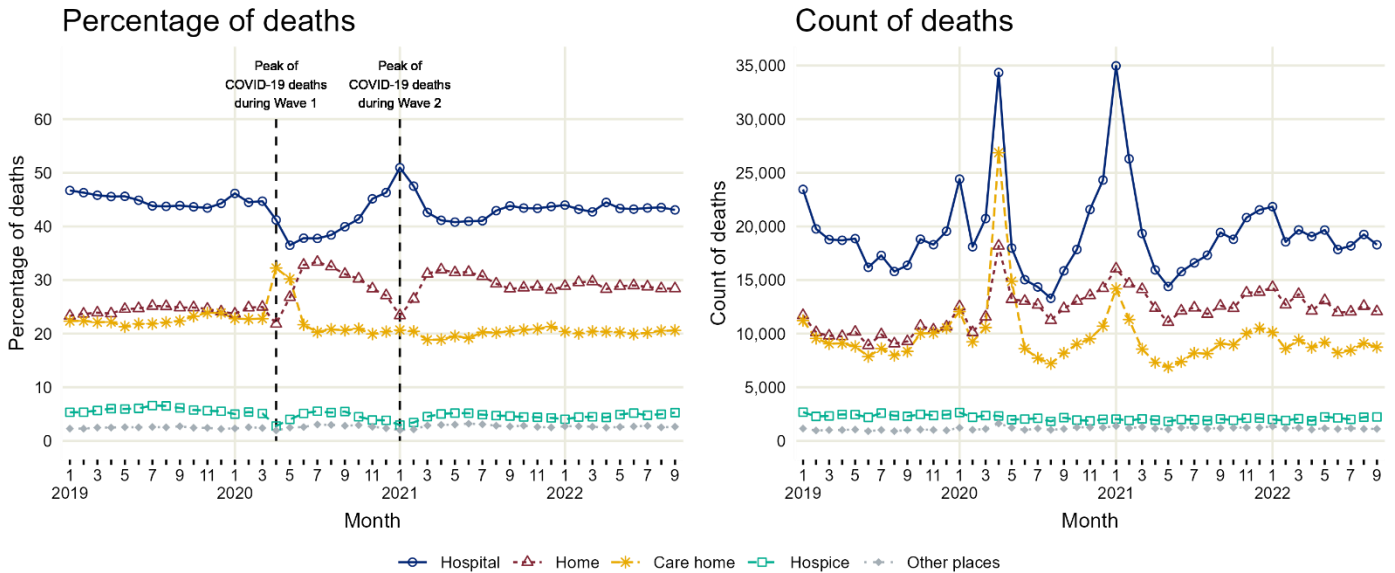
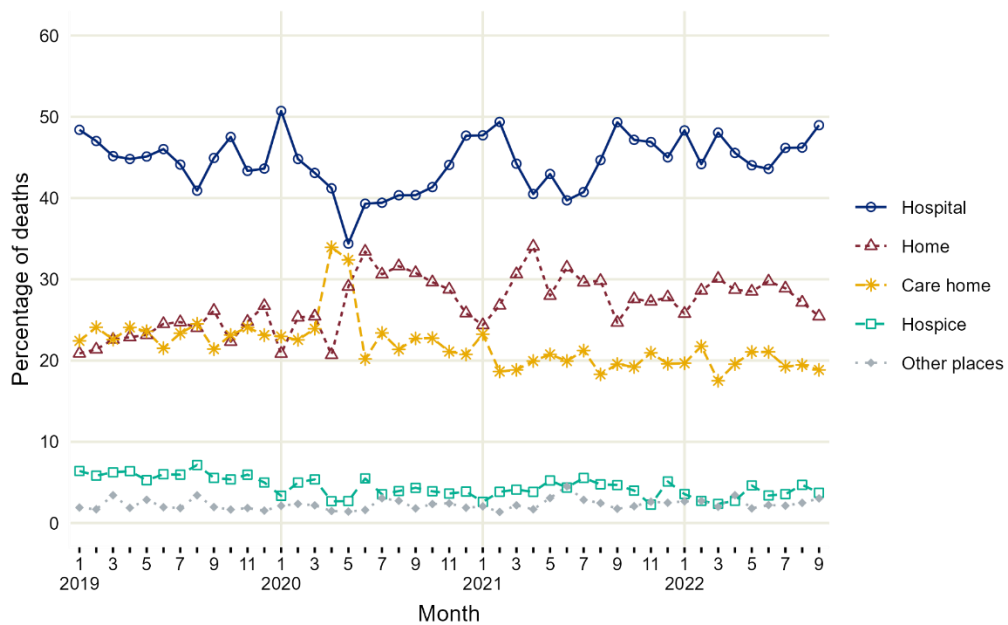


Figure 2: Monthly trend (%) in deaths (all ages) by place of death: NHS Coventry and Warwickshire CCG (2019 to 2022)



Data from Public Health England Palliative and End of Life Care Profiles 2021⁴:

- The percentage of deaths that occurred in hospital in Warwickshire as a whole in 2021 was 44.0%

⁴ [Public Health England, Palliative and End of Life Care Profiles.](#)

and in Coventry were 49.1%. They were 50.8% in Nuneaton and Bedworth, and 45.7% in North Warwickshire, this is higher than England at 44% and higher than Stratford on Avon 37.8%, Warwick 42.4%, and Rugby 39.8%.

- Percentage of deaths in Warwickshire that occur in care homes 21.8% and for Coventry 16.7%, for Nuneaton and Bedworth 14.7%, North Warwickshire 23.9%, Rugby 25.5%, Stratford upon Avon 24.5, Warwick 22.5%
- The percentage of deaths in Warwickshire that occur in hospices was 3.9% and 4.5% in Coventry. 3.2% of people die within a Hospice bed in Stratford upon Avon, 5.8% in Warwick, and 4.8% Rugby and 3.1% in Nuneaton and Bedworth 1.8% in North Warwickshire.

2. Impact and Evidence:

In the following boxes detail the findings and impact identified (positive or negative) within the research detailed above; this should also include any identified health inequalities which exist in relation to this work.

Age: A person belonging to a particular age (e.g. 32 year olds) or a range of ages (e.g. 18-30 year olds)

Describe age related impact and evidence. This can include safeguarding, consent and welfare issues:

- Warwickshire has a growing and ageing population, with an average life expectancy of 79.9 years for males and 83.6 years for females.
- Coventry's population has an average life expectancy of 78.7 for males and 82.2 for females.



- The greatest number of deaths is among those aged 85 and above. This is also the group with the largest expected increase.
- Use of emergency admissions and A&E attendances does not differ greatly by age at death. What drives use of these services is not age, but proximity to death.
- Whilst end of life/palliative care can cover all ages articles such as [Palliative care for frail older people \(nih.gov\)](#)⁵ published by the Royal College of Physicians state that “the palliative care needs of older patients are often under assessed and undertreated” and that “Pain is widely underassessed and undertreated in older patients, especially those with cognitive impairment”.

The Marie Curie Report ⁶ identified the following findings:

- Older people had more unmet pain, less access to generalist and specialist palliative care and greater information needs than younger people with clearer illnesses. However, physicians were more likely

⁵ [Palliative care for frail older people - PMC \(nih.gov\)](#)

⁶ [Age Disparities Report \(mariecurie.org.uk\)](#)

to discuss the end of life with older people compared to younger people where there was a clear terminal diagnosis and death appeared imminent.

- There were clearly disparities in consideration of a palliative approach or specialist palliative services between those in the frail study and those diagnosed with clear terminal conditions. The issue would appear to relate to the diagnosing of a terminal illness and the lack of triggers for recognising the end-of-life in frailty compared to other conditions.
- Poor symptom control was an issue described by some in the frail group and related to patients' experience of negative side effects, physicians' concerns about the potential exacerbation of other difficulties and normalisation of pain in older people leading to delays in recognising and addressing treatable problems.

Children

Health & Social Care Research⁷, analysed the issue of a higher number of deaths in hospital amongst children in comparison to adults in the UK.

The following areas were identified:

- Some deaths are unexpected but around half of these children have life-limiting conditions and could benefit from palliative care.
- Previous research has suggested that parents cope better, even years later, when their child has been able to die at home.
- Not all families prefer this, but another study found that those with access to palliative services were eight times as likely to die somewhere other than in hospital. It could be that death at home or in a hospice indicates that good palliative care services were available.
- Researchers looked at the records of more than 39,000 children and young people (aged up to 25) who died with life-limiting conditions in England. Between 2003 and 2017, most of the children (73%) died in hospital. Far fewer died at home (16%), or in a hospice (6%).

The place of death was affected by various factors.

- **The child's age.** Older children were more likely than younger children to die in a hospice or at home. Most infants died in hospital (97% of those in the first month; 71% aged 1-12 months). This fell to just over half (57%) of children aged 6-10 years.
- **Deprivation.** Children living in more deprived areas were more likely to die in hospital than children from better-off areas. 78% of children from the most deprived areas died in hospital, compared to 66% of those from the least deprived areas.
- **Ethnic group.** Those from some ethnic minority communities were also more likely to die in hospital. Most children from Chinese, Mixed or Other backgrounds (78%) and from Bangladeshi communities (85%) died in hospital. This is higher than the two in three (69%) of White children.
- **Diagnosis.** Children with cancer were less likely than others to die in hospital. Less than half of those with cancer (44%) died in hospital. These children had the highest rates of deaths at home (41%), or in a hospice

The study confirms that most children with life-limiting conditions die in hospital. The research therefore raises questions whether children's and families' needs are being met, and whether services are sufficiently flexible. The results need to be interpreted carefully as not all children with life-limiting conditions will choose to die in a hospice or at home. There is insufficient information about children and families' preferences. The finding that children with cancer were much more likely than others to die at

⁷ [NIHR Evidence - Most children with life-limiting conditions still die in hospital, not home or hospice - Informative and accessible health and care research](#),

home or in a hospice could reflect the different model of care in place. Children with cancer typically receive palliative care from specialists, including teams of paediatric oncology nurses working in most major treatment centers. These nurses are involved throughout their treatment and can provide palliative care.

Warwickshire JSNA 2022 Childrens 0-5 needs assessment states⁸ when examining the type of death by age of the child, neonatal deaths within Warwickshire are mainly attributable to either 'Chromosomal, genetic, and congenital anomalies' or a 'Perinatal/neonatal event'. This noticeably alters for children who are in the age group of up to one year where categories of death become most pertinent in the category of 'Unexplained or SIDS'. The latter ages stages all illustrate a higher category context within 'Chromosomal, genetic, and congenital anomalies'.

Disability: A person has a disability if he/she has a physical, hearing, visual or mental impairment, which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities

Describe disability related impact and evidence. This can include attitudinal, physical, communication and social barriers as well as mental health/ learning disabilities, cognitive impairments:

People with a disability, particularly those with learning disabilities are vulnerable, and are likely to need greater support and increased advocacy in end-of-life care. (DoH: EOL (End of Life) strategy).

National data collected through the Family Resources Survey (Family Resources Survey: financial year 2020 to 2021 - GOV.UK (www.gov.uk))

In 2020 to 2021 the number of people who reported a disability was 14.6 million, an increase of 3 million since 2010 to 2011, where disability was reported by 11.6 million people. The percentage of people who reported a disability in 2020 to 2021 has increased to 22%, a change of three percentage points over the period since 2010 to 2011, when the percentage was 19%. One in five people reported a disability. West Midlands had one per cent more people reporting a disability than the UK national average, with 23% of people within the region reporting a disability.

Learning disability

A learning disability affects the way someone understands information, and how they communicate. They may need support to:

- understand new or complicated information
- learn new skills
- interact with other people
- manage daily activities.

A learning disability is sometimes called an intellectual disability.

National research suggests that 2 – 2.5% of the population in the UK are believed to have a learning disability (Mencap, 2019). We know that the population of people with a learning disability is growing, and that people are living longer with more complex health and support needs.

Population estimates suggest that in 2020, 14,400 adults with a learning disability were residing in Coventry and Warwickshire (PANSI, 2021) and about 6000 autistic people were living in Coventry and Warwickshire in 2020.

The difference in life expectancy and age of death amongst people with learning disabilities and those without is significant. Across the UK, life expectancy in 2018 to 2020 was estimated to be 79.3 years for

⁸ [WCCC-135001118-3095 \(warwickshire.gov.uk\)](http://WCCC-135001118-3095.warwickshire.gov.uk)

males and 83.1 years for females in England. On average, the life expectancy of women with a learning disability is 18 years shorter than the general population and for men 14 years shorter. The national LeDeR report published in 2021 showed the average age of death for people with learning disabilities was 62.

For Coventry & Warwickshire, the age range at death for the 62 adults notified to the LeDeR programme during 2022/23 was 19 to 92. Of the people for whom notifications were received, the median age of death was 61.5 years for men, a slight increase from 60 last year, and remains in line with the most recent national LeDeR data. The median age of death for women was 62.7 which is an increase from 53 in the previous year and higher than the national average.

Of those who died, 59% died in hospital compared to estimates for general population of around 48%.

There are known inequalities of access to palliative and end of life care services for people living with Learning Disability. Research indicates that people with a learning disability may find it hard to communicate or to understand what is being told to them. This may lead to people enduring pain for longer than they need to or missing medication because they have not understood how to take it. Consideration will need to be given to accessibility of information and support required for individuals e.g. Easy read literature, support, and advocacy consideration

Emerging research cites the need for accessible advance care planning and courageous conversations, breaking down stigma, earlier diagnosis, advocacy, and partnership working with Learning Disability and Mental Health organisations.

Information provided by Marie Curie, in the document: **Caring for people with learning disabilities at the end of life** (mariecurie.org.uk) explains that whilst people with learning disabilities have the same palliative care needs as the general population, including symptom management, coming to terms with illness and dying, and making decisions about their wishes. But they may also have additional needs due to their disability.

There are lots of issues that can be challenging for people with learning disabilities towards the end of their life. People with learning disabilities:

- have more physical and mental health problems and these can be complex
- are more likely to be vulnerable and socially isolated
- have difficulty accessing healthcare systems
- are more likely to be diagnosed with cancer later which means they have a poorer prognosis
- have a higher risk of dementia – people with Down's syndrome may also have dementia at a much younger age than average
- may have communication difficulties which make it harder to express their symptoms
- may find it harder to express their wishes about their care.
- communication difficulties which affect all aspects of palliative care provision
- difficulties around insight and the ability to participate in decision-making
- unconventional ways of expressing signs and symptoms of ill health and distress
- multiple co-morbidities
- complex family and social circumstances
- higher levels of behavioural or psychiatric problems.

Providing the best person-centered care involves identifying and addressing these additional needs and challenges.

Equity of access ([Palliative Care and Intellectual Disabilities | Intellectual Disability and Health](#))

There is growing evidence that people with intellectual disabilities face significant barriers in accessing

health services, including palliative care services (Emerson & Hatton 2013).

In 2016, the Care Quality Commission (CQC) carried out a review of inequalities in end of life care https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf and concluded that people with intellectual disabilities can experience poorer quality of care at the end of their lives because providers do not always understand or fully consider their needs (Care Quality Commission 2016).

A CQC briefing on end of life care for people with intellectual disabilities https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_LearningDisabilities_FINAL_2.pdf highlighted lack of staff knowledge, poor understanding of the Mental Capacity Act, and communication problems as significant barriers to good care.

There is a risk of professionals attributing the signs and symptoms of ill health (which may take uncharacteristic forms of expression) to the intellectual disability itself rather than to the underlying illness – a phenomenon known as ‘diagnostic overshadowing’ (Reiss & Syzszko 1983).

Poor access to palliative care services may be due to the difficulties in recognising that palliative care is needed. When someone has intellectual disabilities, predicting the need for palliative care can be particularly challenging (Vrijmoeth et al. 2016). This is complicated by the fact that many people with intellectual disabilities have a number of comorbidities, such as epilepsy. Those with congenital conditions may have had complex health problems throughout their lives, so it can be hard to know when life-long and ongoing management of these problems turns into a need for palliative and end of life care.

To ensure equitable access to palliative care services, it is important to make ‘reasonable adjustments’ <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities> to healthcare services, in order to make them accessible to people with disabilities. In the UK, this requirement is law (Equality Act 2010). Examples of reasonable adjustments for people with intellectual disabilities include:

- Giving people information that is tailored to their communication needs (for example, providing easy-read materials and pictures, or opportunities to see clinical areas or equipment beforehand)
- Allowing more time
- Involving family and other care givers
- Providing staff training about the needs of people with intellectual disabilities
- Accessing expertise about intellectual disability when needed (for example, by engaging with intellectual disability nurses)

Life expectancy

The life expectancy of people with intellectual disabilities has increased significantly during the last century (Patja et al. 2000). The increase in life expectancy for people with Down’s syndrome has been particularly marked, from 12 in 1949 to nearly 60 in 2004 (Bittles & Glasson 2004). Reasons for this dramatic shift include reduced childhood mortality and better knowledge, healthcare, advocacy, and services (Yang et al. 2002) (Haveman et al. 2009).

Despite this positive news, life expectancy is still significantly below that of the general population. A government inquiry in England investigated the deaths of 247 people with learning disabilities between 2010 and 2012, the CIPOLD study (Heslop et al. 2013) <http://www.bristol.ac.uk/media->

library/sites/cipold/migrated/documents/fullfinalreport.pdf They found that the average age of death was 65 years for men with learning disabilities, and 63 years for women. That is, on average, 16 years younger than the general population. It could be that the shorter life expectancy is due to something related to the learning disability itself. For example, some conditions that cause learning disabilities can also cause significant physical health issues, which may be life-limiting. However, there is mounting evidence that the shorter life expectancy of people with learning disabilities is also due to substantial health inequalities, leading to poorer outcomes (Emerson & Hatton 2013). This includes poorer access to palliative care services. The CIPOLD study found that people with learning disabilities are at risk of premature death that could be prevented by better healthcare provision. For example, the investigations that were needed to diagnose the problem were often not done or posed difficulties. Physicians were more likely to take a 'wait and see' approach. In a quarter of those who went to the doctor or to hospital, the concerns of the person with intellectual disabilities, their family or paid care staff said they were not taken seriously enough by medical professionals. Families of people with intellectual disabilities were significantly more likely than those of people without intellectual disabilities to not feel listened to (Heslop et al. 2013). This finding echoed earlier reports (Michael 2008).

Causes of death

The main causes of death for people with intellectual disabilities are respiratory disease, heart disease and cancer. In the CIPOLD study, cancer accounted for 20% of deaths among people with intellectual disabilities. (In the general population, 29% of deaths are caused by cancer. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality>)

There is a higher incidence of dementia among people with intellectual disabilities (Strydom et al. 2010). The incidence of Alzheimer's disease is very high among people with Down's syndrome, with around 40% of people with Down's syndrome aged 60 and over suffering from the condition (although exact prevalence estimates vary).

The cancer profile for people with intellectual disabilities is slightly different from the general population, with a higher-than-average incidence of gastrointestinal cancers (Hogg & Tuffrey-Wijne 2008). People with Down's syndrome have a significantly increased risk of leukaemia and a lower risk of many solid tumours, including a lower risk of breast cancer (Satgé & Vekemans 2011).

Palliative care

The palliative care needs of people with intellectual disabilities are, in essence, the same as those of the general population. Who would not want to die a death that is free of pain and other symptoms, or spend time with their family or friends, or be listened to and involved when choices and decisions are made about their care and treatment? However, people with intellectual disabilities often have unique issues, challenges and circumstances that make it much more difficult to meet those needs.

This includes, for example:

- communication difficulties which affect all aspects of palliative care provision
- difficulties around insight and the ability to participate in decision-making
- unconventional ways of expressing signs and symptoms of ill health and distress
- multiple co-morbidities
- complex family and social circumstances
- higher levels of behavioural or psychiatric problems.

The Palliative Care for People with Learning Disabilities (PCPLD) Network was set up in the UK in 1998 to bring together professionals, family carers and paid carers to share best practice and learn

from each other. The PCPLD Network website <http://www.pcpld.org/> has invaluable information, links to useful resources and relevant academic articles, to help improve end of life and palliative care provision for people with intellectual disabilities. In 2017, NHS England and the PCPLD Network worked together to produce a useful guidance document for best practice. [PCPLD Network and NHS England \(2017\) Delivering high quality end of life care for people who have a learning disability. Resources and tips for commissioners, service providers and health and social care staff](#)

In 2015, the European Association for Palliative Care published a White Paper <http://www.eapcnet.eu/LinkClick.aspx?fileticket=lym7SMB78cw%3D> in order to promote best practice in supporting people with intellectual disabilities at the end of life, setting out 13 important areas of practice and service delivery that are relevant in a wide range of settings, including the family home, independent living arrangements, residential care settings, nursing homes, hospitals and specialist palliative care settings. The White Paper is a useful document which contains aspirational norms, as well as best practice examples and links to useful resources. Some of the key areas are expanded below.

Equity of access

There is growing evidence that people with intellectual disabilities face significant barriers in accessing health services, including palliative care services (Emerson & Hatton 2013). In 2016, the Care Quality Commission (CQC) carried out a review of inequalities in end of life care https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf and concluded that people with intellectual disabilities can experience poorer quality of care at the end of their lives because providers do not always understand or fully consider their needs (Care Quality Commission 2016). A CQC briefing on end of life care for people with intellectual disabilities https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_LearningDisabilities_FINAL_2.pdf highlighted lack of staff knowledge, poor understanding of the Mental Capacity Act, and communication problems as significant barriers to good care.

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Poor access to palliative care services may be due to the difficulties in recognising that palliative care is needed. When someone has intellectual disabilities, predicting the need for palliative care can be particularly challenging (Vrijmoeth et al. 2016). This is complicated by the fact that many people with intellectual disabilities have a number of comorbidities, such as epilepsy. Those with congenital conditions may have had complex health problems throughout their lives, so it can be hard to know when life-long and ongoing management of these problems turns into a need for palliative and end of life care.

From talking to many professionals over the years, I have discovered that those working in palliative care services often do not know the population of people with intellectual disabilities in their catchment areas and are therefore unlikely to reach out to them. Among those working with people with intellectual disabilities, there may be a misconception about hospice and palliative care services as being concerned only with the final stages of dying, rather than with helping people to live and cope with the life they have left. It may not be known to families and support staff that palliative care can be provided within people’s own homes.

To ensure equitable access to palliative care services, it is important to make ‘reasonable adjustments’ <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities> to healthcare services, in order to make them accessible to people with disabilities. In the UK, this requirement is enshrined in law (Disability Discrimination Act 2005). Examples of reasonable adjustments for people with intellectual disabilities include:

- Giving people information that is tailored to their communication needs (for example, providing easy-read materials and pictures, or opportunities to see clinical areas or equipment beforehand)
- Allowing more time
- Involving family and other care givers
- Providing staff training about the needs of people with intellectual disabilities
- Accessing expertise about intellectual disability when needed (for example, by engaging with intellectual disability nurses)

Assessment and control of pain and other symptoms

Pain is often the first indicator of injury and illness, but in a person with intellectual disabilities this warning sign could be easily missed. If a person is unable to communicate with words, pain, and other symptoms (such as nausea, dysphagia, fatigue) may be communicated in different ways. Specific skills of observation, together with a close knowledge of what is normal behaviour for an individual with intellectual disabilities, are needed to pick up signs and symptoms related to the illness. This can only be achieved by close co-operation between health professionals and the person's carers.

Capacity, consent to treatment, and end of life decision-making

The issue of consent to tests and treatments can cause anxiety and confusion among clinicians and carers alike. Clinicians may be reluctant to consider and provide the same range of treatment options for people with intellectual disabilities as for the rest of the population, because of perceived difficulty obtaining informed consent, or for fear of litigation. This is a complicated issue. People with intellectual disabilities may have difficulties with understanding risks and possible treatment outcomes, which require abstract thinking. This can lead to being denied opportunities to give consent.

It is important to understand the law, which is different in different countries. In England and Wales, the Mental Capacity Act (Department for Constitutional Affairs 2005) makes it clear that no-one, not even parents or medical staff, can consent on behalf of an adult who is not competent to give consent. The guiding principle should be that doctors must act in the patients' best interest if they cannot choose for themselves. It may be negligent to withhold treatment because the patient cannot give consent. It is also important to remember that capacity is decision- and situation-specific; in other words, it is possible for someone to have capacity to decide on one aspect of care or treatment at one moment but lack capacity on another occasion or for another decision. It is therefore important to assess capacity for each decision. It is crucial to ensure that the person with intellectual disabilities has access to information in a format he or she can understand.

Communicating about illness, death and dying

Carers and health professionals are often unsure whether they should talk to a person with an intellectual disability about his or her illness, or the illness and impending death of someone close to them. There is a danger of creating a 'conspiracy of silence', where professionals, family and friends all know about the illness and impending death but will not talk about it in the presence of the patient. Reasons for such protection from bad news include "he won't understand", "the truth is too upsetting", "I will get too upset", or "others don't want him to be told". However, there is also growing recognition of people's "right to know"; of the fact that many people with intellectual disabilities cope better if they understand what is happening; and of the need for people to be involved in decision-making about their treatment and care (Tuffrey-Wijne et al. 2013) (Wiese et al. 2013). When it comes to bereavement, staff who work with people with intellectual disabilities tend to talk to them about death *after* the death of someone close to them has occurred, but not beforehand (Ryan et al. 2011).

Talking about illness and dying is never easy – but *not* talking about it does not make the bad news go

away! Comprehensive guidelines on breaking bad news to people with intellectual disabilities can be found here. <http://www.breakingbadnews.org/> It is important to consider the person's understanding and capacity; look at all the people involved in the situation; and think about the support everyone needs to help the person with intellectual disabilities understand what is happening.

Families and carers

People with intellectual disabilities themselves have indicated how important it is for them to have familiar people around at the end of life (Tuffrey-Wijne et al. 2007; McLaughlin et al. 2015). It has been shown that a lack of effective carer involvement leads to poorer outcomes for people with intellectual disabilities (Heslop et al. 2013; Tuffrey-Wijne, Abraham, et al. 2016).

Health professionals need to understand the nature of the relationships that the individual with intellectual disabilities has with his or her family, carers, and close friends. Many people who have a life-threatening illness (whether they have intellectual disabilities or not) and their families have a strong need to have some deep and meaningful communication together. People with intellectual disabilities often have a very firm and important place in their social environment, and the impending death will mean a profound loss and a complete change in the family dynamics. In addition, if the person has left the family home to live in another care setting, carers may also have difficulty coming to terms with the impending loss. Health professionals need to be aware of these issues; they may be needed to provide sensitive support and aid honest communication.

Collaboration and support services *

Research and case reports to date clearly indicate that people with intellectual disabilities receive the best end of life support if palliative care services and intellectual disability services collaborate. It is also important to establish who co-ordinates the care of the patient. Effective, pro-active facilities and support services are needed to help everyone manage the situation. It is important to look carefully at staff training needs. Involving palliative care staff to provide training for intellectual disabilities staff, and vice versa, can be very beneficial.

Learning disabilities

NHS England National end of life care programme: [The route to success in end of life care - achieving quality for people with learning disabilities](#)

PEoLC Programme

With a clear understanding as outlined above of the impact of uncoordinated palliative care for those with disabilities, the programme will focus on the development of a collaborative, integrated approach to service delivery which enables a holistic approach for individuals personalised to their needs.

Mental Health

People with severe Mental Illness on average have 15 to 20 years shorter life expectancy than the general population⁹. Most of this reduced life expectancy is due to a higher rate of physical conditions such as cardiovascular disease. Some of the drugs used to treat SMI can cause obesity and thus increase cardiovascular risk.

Also, health and care workers supporting people with SMI may not be aware of the associated risks of physical ill health or may not know how to provide support for such conditions and may focus only on

⁹ [Coffey at al \(2022\)](#)

an individual's mental health.

All people with SMI should be offered an annual physical health check. This should explore risk factors for CVD such as smoking, obesity and high blood pressure. And where such conditions are found, the person with SMI should be offered appropriate support and treatment.

Unless we deal with this systematically, we will perpetuate the inequality of care experienced by many people with SMI and which is associated with a significant reduction in life expectancy. Mental and physical health should be promoted and supported in a balanced way to achieve both quantity and quality of life for people with SMI¹⁰.

Collaborative, integrated working should be developed across the mental health and end-of-life systems, and ways found to support people to die where they choose. Staff caring for people with severe mental illness at the end-of-life need education, support, and supervision. End-of-life care for people with severe mental illness requires a team approach, including advocacy. Proactive physical health care for people with severe mental illness is needed to tackle problems of delayed diagnosis¹¹.

Physical Disability

The review of the specific needs and experiences of individuals with long-standing physical disability at the end of life was undertaken by Belperio et al in 2022¹², where five themes were identified:

- (1) The significance of place. All participants described how the end-of-life care experience was significantly impacted by the place in which dying occurred.
- (2) Knowing the person and their needs. Knowledge and familiarity with the individual with long-standing disability were seen as invaluable in terms of providing continued high-quality care.
- (3) Navigating a new care landscape. For disability support workers, struggling to adapt from providing disability support to end-of-life care was difficult.
- (4) Complexities of family involvement. Past experiences of families within the healthcare system had resultant impacts on care received by the individual with long-standing disability.
- (5) Being prepared. Participants felt more was needed in terms of end-of-life planning and discussions around end of life for this cohort.

This research highlights a significant lack of continuity of care and problems at the intersection of the disability and health systems when providing end-of-life care for this cohort. Suggested areas for improvement from the researchers included team approaches to enable continuity of care and dying in place, and a need for knowledge and skills in this area for all stakeholders.

PEoLC Programme

With a clear understanding as outlined above of the impact of uncoordinated palliative care for those with disabilities, this programme of work will have a key focus on the development of a collaborative, integrated approach to service delivery which enables a holistic approach for individuals personalised to their needs.

Gender reassignment (including transgender): Where a person has proposed, started or completed a process to change his or her sex.

Describe any impact and evidence on transgender people. This can include issues such as

¹⁰ [Powis \(2019\)](#)

¹¹ [Edwards et al. \(2021\) End of life care for people with severe mental illness: Mixed methods systematic review and thematic analysis.](#)

¹² [Belperio et al \(2022\)](#)

privacy of data and harassment.

The Equality Act 2010 states an individual must not be discriminated against because they are transsexual, when their gender identity is different from the sex assigned to the individual at birth.

People who are transgender or are caring for those who are, may experience barriers to PEOLC services related to assumptions and judgement.

Their experience of care has specific requirements particularly in relation to safe spaces, personalisation and gender identity before and after death. The programme will look at recommendations to ensure that the delivery of the strategy is gender inclusive.

Those working with transgender people at the end of life may be unaware the person life experience and additional experiences because of their transitioned status, and this could impact on their willingness to be open. Transgender people may also have been ostracised by families of origin and rely on other networks of support.

[The Last Outing](#): exploring end of life experiences and care needs in the lives of older LGBT people, found that LGBT people had several concerns related to end of life experiences and care needs. Trans people were concerned that they would be buried under the gender they were assigned at birth.

2021 Census for Coventry and Warwickshire outlined the following for our population:

- Gender identity the same as sex registered at birth = 93.5%
- Gender identity different from sex registered at birth but no specific identity given = 0.2%
- Trans woman = 0.09%
- Trans man = 0.09%
- Non-binary = 0.06%
- All other gender identities = 0.03%
- Question not answered = 6%

According to the recent report by Hospice UK – '[I just want to be me: Trans and gender diverse communities' access to and experiences of palliative and end of life care](#)' staff in the research felt there was a lack of training and understanding on LGBTQ+ issues, and a lack of access to information on providing medical and clinical care to trans people.

Trans and gender diverse people who had accessed palliative and end of life care at times experienced insensitivity from staff, misgendering and confusion over their identity and instances of poor physical care.

It is particularly important when thinking about end-of-life care for trans and gender diverse communities to remember how much of end-of-life care is about supporting the individual and understanding what is important to them.

PEoLC Programme

The importance of education and training for our staff and communities to enable an improvement in care quality for trans people and to increase access to information to support equity of care.

Marriage and civil partnership: A person who is married or in a civil partnership.

Describe any impact and evidence in relation to marriage and civil partnership. This can include working arrangements, part-time working, and caring responsibilities:

In the Equality Act marriage and civil partnership means someone who is legally married or in a civil partnership. Marriage can either be between a man and a woman, or between partners of the same sex. Civil partnership is between partners of the same sex.

People do not have this characteristic if they are:

- Single
- living with someone as a couple neither married nor civil partners
- engaged to be married but not married
- divorced or a person whose civil partnership has been dissolved

No significant evidence or expectation of current or future inequitable access to, or delivery of, PEoLC at this time.

Pregnancy and maternity: A woman is protected against discrimination on the grounds of pregnancy and maternity. With regard to employment, the woman is protected during the period of her pregnancy and any statutory maternity leave to which she is entitled. Also, it is unlawful to discriminate against women breastfeeding in a public place.

Describe any impact and evidence on pregnancy and maternity. This can include working arrangements, part-time working, and caring responsibilities:

In the Equality Act this is described as:

Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.

PEoLC staff and services will take full account of the additional health and care challenges faced by:

- Mothers with a PEoLC diagnosis
- Babies that are born with life threatening illnesses, who may need end-of-life care in their early years of life.

A key theme of the strategy is to support the collaborative working and integrated approach of health and social care providers within our system and across the region if tertiary care is required.

Race: A group of people defined by their race, colour, and nationality (including citizenship), ethnic or national origins.

Describe race related impact and evidence. This can include information on different ethnic groups, Roma gypsies, Irish travellers, nationalities, cultures, and language barriers:

Ethnicity

BASW [Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK](#)

Care Quality Commission (CQC) (2016) [People from black and ethnic minority communities. A different ending: addressing inequalities in end of life care](#)

Public Health England, King's College London, Marie Curie Cancer Care (2013) [Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK Demographic profile and the current state of palliative and end of life care provision](#)

Public Health England, National End of Life Care Intelligence Network (2017) [Place of death by ethnic group for people who died from cancer, England 2008 to 2017](#)

Race Equality Foundation (2018) [Dementia and end of life care for black, asian and minority ethnic communities](#)

In the Equality Act, this characteristic is described as:

Referring to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.

Coventry: (2011 Census data)

65.5% White,

18.5% Asian, Asian British or Asian Welsh

8.9% Black or Black British, Black Welsh, Caribbean or African

3.4% Mixed or Multiple ethnic group

and

3.7% of other ethnic groups.

Warwickshire: (2011 Census data)

Stratford on Avon

95.5% White,

1.9% Asian, Asian British or Asian Welsh

0.4% Black or Black British, Black Welsh, Caribbean or African

1.7% Mixed or Multiple ethnic group

and

0.5% other ethnic group.

Warwick

84.6% White,

9.7% Asian, Asian British or Asian Welsh

1.1% Black or Black British, Black Welsh, Caribbean or African

3.0% Mixed or Multiple ethnic group

and

1.6% of other ethnic groups.

North Warwickshire

96.1% White,

1.3% Asian, Asian British or Asian Welsh

0.6% Black or Black British, Black Welsh, Caribbean or African

1.7% Mixed or Multiple ethnic group

and
0.3% of other ethnic groups.

Nuneaton & Bedworth

87.1% White,
8.0% Asian, Asian British or Asian Welsh
1.8% Black or Black British, Black Welsh, Caribbean or African
1.8% Mixed or Multiple ethnic group
and
1.2% of other ethnic groups.

Rugby

85.7% White,
7.6% Asian, Asian British or Asian Welsh
2.7% Black or Black British, Black Welsh, Caribbean or African
2.8% Mixed or Multiple ethnic group
and
1.1% other ethnic group.

There are known inequalities of access to PEOLC services based on race and ethnicity. Evidence indicates barriers include understanding of cultural need, understanding of hospice, perception of palliative care, access to information which is culturally relevant, access to translation and language appropriate.

The PEOLC strategy and programme will include development of service and pathway design to support personalised care and support planning, including cultural needs

It has already been identified that there is a lack of understanding, knowledge, and information about the end-of-life care

- Local communities have limited understanding of available services and pathways
- Some communities feel that end of life care services is 'not for them'
- Concerns held on whether cultural needs will be met.
- Health and social care professionals are often frightened to approach conversations around advanced care planning with someone from a different community as they are worried, they will offend an individual¹³.

Language Barriers

Where there is a language barrier, care providers can be more apprehensive and in fear of 'offending' someone and may not convey information they normally would do to a patient with no language barrier.

¹³ [Monette et al 2021](#)

Access to interpreters is limited and, in many cases, very slow, so this too plays a key part in the barriers that exist for the population and end-of-life care¹⁴.

Religion or belief: A group of people defined by their religious and philosophical beliefs including lack of belief (e.g. atheism). Generally, a belief should affect an individual's life choices or the way in which they live.

Describe any religion, belief or no belief impact and evidence. This can include dietary needs, consent and end of life issues:

Some people may be less likely to access end of life care services due to lack of knowledge of available resources and their beliefs.

Evidence suggests that religious needs are another barrier for access to end of life care. There is a lack of understanding about the religious/cultural rituals associated with end-of-life care and the necessary funeral arrangement requirements that are part of religious/cultural beliefs when a patient is cared for in a health care setting. As a result of this many individuals opt for end-of-life care to be continued at home. Accessing community groups and faith leaders will be an important way to develop further engagement and understanding.

Issues include understanding dietary requirements, religious prayer (and access to the appropriate chaplaincy), release of the deceased body in time for cultural or religious rituals to commence. All these factors contribute to individuals making decisions on end-of-life care. It has been suggested that cultural competency is paramount in helping individuals to make an informed decision and where there is a lack of cultural competency amongst care providers, service users will not access services available¹⁵.

Evidence suggests British Muslims experience unmet needs towards the end of life. Challenges can include limited training of healthcare professionals regarding faith and cultural values and their implications on care plans. In addition, there is a lack of awareness of palliative care services among British Muslims¹⁶.

Providing accessible and culturally appropriate information to the diverse communities of Coventry and Warwickshire and reviewing the education and training needs of our staff are both priority areas within the strategy.

Sex: A man or a woman

Describe any impact and evidence on men and women. This could include access to services and employment:

There is a bias on women to support informal care giving which is a consideration for both carer support needs and compassionate communities workstreams. The strategy delivery plan will reflect appropriate support to family carers

Sexual orientation: Whether a person feels generally attracted to people of the same gender, people of a different gender, or to more than one gender (whether someone is heterosexual, lesbian, gay or bisexual).

Describe any impact and evidence on heterosexual people as well as lesbian, gay and bisexual people. This could include access to services and employment, attitudinal and social barriers:

Most documents and literature combine issues around End-of-Life Care and Palliative Care for people who are lesbian, gay, bisexual and trans (LGBT).

¹⁴ [D. Silva et al \(2016\)](#)

¹⁵ [Mayeda et al \(2019\)](#)

¹⁶ [j437-muslim-council-report_en.pdf \(mariecurie.org.uk\)](#)

LGBTQ+

Marie Curie (2016) [“Hiding who I am” The reality of end of life care for LGBT people](#)

Marie Curie [Palliative and end of life care for LGBTQ+ people](#)

LGBT Foundation [End of life care](#)

Sexual orientation for Coventry and Warwickshire population from 2021 Census

- Straight or Heterosexual = 89.8%
- Gay or Lesbian = 1.2%
- Bisexual = 1.3%
- Pansexual = 0.2%
- Asexual = 0.07%
- Queer = 0.02%
- All other sexual orientations = 0.02%
- Not answered = 7.2%

Barriers to palliative cancer care for the LGBTQ+ community include discrimination, criminalisation, persecution, fear, distress, social isolation, disenfranchised grief, bereavement, tacit acknowledgment, homophobia, and mistrust of healthcare providers. All these factors should be considered through any work in delivering the strategy.

Overview of issues, barriers, and experiences

Being lesbian, gay, bisexual, or transgender (LGBT) is not just about sexual preferences and/or identity. This means that when end of life care is delivered, it must be delivered in a way that embraces the individual's culture and social interests and in a way that does not make assumptions about the individual solely based on their sexual orientation or gender identity.

According to the NHS National End of Life Care Programme report “The route to success in end-of-life care – achieving quality for lesbian, gay, bisexual and transgender people” there is a background of wider social processes that shape the experiences of a person who is LGB or T. While LGBT people and their lives vary enormously, they share a history of oppression and cultural bias in favour of opposite sex relationships (heteronormativity). In other words, health and social care workers may assume a person is heterosexual unless proven otherwise.

The ‘unless proven otherwise’ aspect often relies on the individual having the confidence to contradict the assumption that the care professional may have made, for example the assumption of asking husband or wife details as opposed to partner.

LGBT people are more likely to have poorer physical and mental health than heterosexual people. The Marie Curie (Hiding who I am, 2016) report points to research suggesting that LGBT people have a higher incidence of life-limiting and life-threatening disease than people who are not LGBT. The risk of smoking and alcohol abuse is higher among LGBT people, and is attributed to stress from homophobia, discrimination, transphobia, and marginalisation.

Discrimination has a significant impact on health and wellbeing outcomes for LGBT people. Williams et al (2013) points out that LGBT people are less likely to engage with health interventions and screening programmes if they are not explicitly recognised by the service.

LGBT people may also experience barriers to palliative care because they are:

- Three times more likely to be single.

- Far more likely to be estranged from their birth families
- Less likely to have children.
- Significantly more likely to experience damaging mental health problems.

Issue: Anticipating discrimination

People access palliative care services later or not at all, either because they anticipate stigma or discrimination, or they think the service is not for them. Stonewall reports that three in five older gay people are not confident that social care and support services will be able to understand and meet their needs.

People approaching the end of life are among the most vulnerable in our communities. This vulnerability can be made worse if people fear that services might not understand their needs related to their sexual orientation or gender identity. These fears are based on real experience.

Older LGBT people have lived through times when identifying openly as lesbian, gay, bisexual, or trans could mean, for example, being arrested, being defined as mentally ill and in need of treatment, or losing one’s job, family, or children.

It should be noted that lesbian, gay, bisexual and trans people do not all experience the same kinds of discrimination; a ‘one size fits all’ approach will not work; for example, some bi-sexual people report encountering discrimination within lesbian and gay support networks and communities; trans people face significant difficulties when accessing services where staff lack an understanding and lack of cultural competency around trans issues.

[hiding-who-i-am-the-reality-of-end-of-life-care-for-lgbt-people.pdf \(mariecurie.org.uk\)](#) in this 2016 report by Marie Curie evidence was published that concluded “LGBT people access palliative care services later than non-LGBT people because they anticipated discrimination”. Palliative care services and end of life care improves quality and length of life, reduces emergency admissions to hospital and the likelihood of dying in hospital.

Issue: Carers - Increased pressure on LGBT carers

Marie Curie report (Hiding who I am) concluded “that it is likely that LGBT people have a significantly worse experience of dying than non-LGBT people. It is also likely that this reluctance to access palliative care means there is increased pressure on the informal carers of LGBT people.”

If LGBT people are delaying or refusing access to health and social care support at home at the end of life, it may also mean they are relying heavily on family and friends to provide informal care. Whilst such care is a vital part of palliative and end of life care, informal care without adequate support from health and social care professionals can put immense strain on people. 82% of carers say that caring has a negative impact on their health and 55% say their caring role has contributed to depression.

Issue: Assumptions

Most of the research and publications reviewed cited that health and social care staff often make assumptions of heteronormativity (an assumption of heterosexuality unless otherwise stated) or gender identity (Trans people report that they are often referred to by the pronouns of their birth gender, asked insensitive questions about being trans or even outed as trans in front of other patients and staff). These assumptions will have an impact on their experience of palliative and end of life care.

A survey by Stonewall revealed that 57% of health and social care professionals said a person’s sexuality had nothing to do with their healthcare. This can lead to an avoidance of conversations about sexual orientation and gender identity or assuming heterosexuality.

If LGBT people are under-represented in images and language in information leaflets and posters this

can make LGBT people feel excluded and may contribute towards perpetuating stereotypes that hospices are only for white middle-class families.

Issue: 'Coming out'

Coming out is the process of telling people you are lesbian, gay, bisexual and/or transgender. This is something that LGBT people must make choices and decisions about on a regular basis.

For older LGBT people it is important to understand that they lived through a time when same-sex relationships were pathologized and, for gay and bisexual men, illegal. LGBT people will have experienced prejudice, harassment, and negative attitudes, which contributes to the fear and potential reluctance to disclosing their sexual orientation or gender identity, particularly if they are not assured of a 'safe space'.

All too often the experience of LGBT people has been that health and care settings are not safe spaces within which to disclose important aspects of their identity nor a place to demonstrate affection towards their partner as a time when they may feel more vulnerable.

It is important that those staff involved in providing care understand not simply that people might have different sexual orientation or gender identity, but also that with sexual orientation/gender identity comes different historical experiences. Past experiences will inform expectations of how they might be treated which affects the coming out conversations.

Issue: Support/family network

As a result of disclosure or coming out, relationships with family may have become strained and distant. Significant research content was found on the support network that LGBT people might choose to surround themselves with (close friends and support groups). However, there is a risk that the significance of 'friend' relationships is not recognised before and after death. This could result in a person or group, their relationship with the dying person and their grief going unrecognised. Service providers need to understand and support LGBT people by acknowledging, respecting, and involving those most important to the individual, and this may or may not include the family of origin.

A survey carried out by Stonewall (2011) found that LGBT people over 55 were more likely to live alone and less likely to have regular contact with biological family members. The results of the survey went on to comment that whilst this is likely to mean that there is a need for formal support and care services in later life, that this same cohort lacked confidence that public services would meet their needs.

Staff training should include understanding how to support conditional family relationships, such as might be experienced by trans people. For example, a trans woman who wants to maintain contact with her daughters and grandchildren is only able to do so if she reverts to being their 'Dad' and 'Granddad' in their company.

Continued access to LGBT networks and links it was identified as of important by LGBT people if/when they were dependent on others for daily assistance.

Issue: Next of Kin/Partners and Unsupported Grief and Bereavement

This is an important aspect identified by many LGBT people; in *The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people* srcc-project-report-last-outing.pdf (nottingham.ac.uk) A 2015 study found that LGBT people had a number of concerns related to end of life experiences and care needs:

- Respondents felt advance care planning and being able to nominate 'important others' as next of kin was particularly important for many LGBT people.
- Some issues distinct to LGBT people were highlighted such as providing protection to partners who might not otherwise be recognised.
- 82% agreed that it was particularly important for LGBT people to make and record plans for future care.

Respondents also raised concerns that they did not know who to nominate in decision making roles due to the people closest to them being the same age as them or due to the fact they were socially isolated. LGBT people were concerned that someone close to them could be denied visiting rights and information because they might not be seen as the next of kin. It needs to be made clear that nominating a next of

kin, can include same-sex partners or significant friends.

Service providers should understand that LGBT people might experience both the same barriers to completing advance care plans and Lasting Powers of Attorney reported for the general population - such as feeling daunted by the paperwork or costs involved and not wanting to think about or plan for the end of life. Additional issues include not knowing who to nominate in decision making roles due to their personal networks comprising people of the same age or ongoing social isolation.

The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people [srcc-project-report-last-outing.pdf \(nottingham.ac.uk\)](https://www.nottingham.ac.uk/research/centres/healthcare-research-centres/healthcare-research-centre-for-older-people/projects/last-outing/) A 2015 study found that LGBT people had a number of concerns related to end of life experiences and care needs:

- A particular concern that was raised was people were concerned that their wishes were not going to be respected after their death, for example having their partners / friends excluded from their funerals.
- Survey and interview respondents report that advance care planning is important for LGBT people. Motivations to complete advance care plans include some issues similar to those reported for the general population such as not placing burdens on others but also distinct issues such as providing protection for partners and significant others who might otherwise not be recognised.
- Having one's wishes respected after death was a particular concern. Respondents gave many anecdotal stories of LGBT people they knew who had died and whose partners and/or friends had been excluded from the funerals by families of origin. For trans people, particular concerns are expressed about being buried by family of origin under their birth gender, despite knowledge of legal protection of one's acquired gender identity – concerns here are not only about being cared for and dying where one wishes but to be buried as one wishes

Issue: The Mental Capacity Act (2005)

Service providers should pay particular attention to the Mental Capacity Act for LGBT people, as this allows a person to make decisions in advance of losing capacity.

This can include nominating someone as a Lasting Power of Attorney, identifying who they want to share information with and who they want involved in their care. The Mental Capacity Act also provides legal redress where this does not take place. Such decisions about wishes and preferences for care are best recorded in writing in an advance statement. Equally, decisions need to be made throughout the end-of-life care pathway.

Issue: Religion

Like heterosexual people, LGBT people may have religious or spiritual needs. There is anecdotal evidence that suggests that palliative and end of life care services may not always ensure that these are addressed for LGBT people at end of life as they are for other patients. Gay men may be concerned that they will be treated with hostility by church affiliated providers of hospice care. Service providers should seek to:

- Demonstrate that they are a welcoming and safe place for all patients.
- Enable LGBT people access to spiritual and religious support as required.

Issue: Dementia and LGBT people

Whilst there is no comprehensive evidence about the rates of LGBT people and dementia, the Alzheimer's Society suggests that some typical symptoms of dementia may be experienced differently for those who are LGBT. For example, as dementia progresses, older memories are likely to stay with someone longer than newer memories, meaning that some people, particularly those who are older, may recall many memories from a time before they were out. Some LGBT people with dementia may also experience memory problems, making it harder to recall who they have or have not disclosed their sexual orientation or trans status to. Some people can also become confused about their sexuality or gender, just as people of any sexuality or gender may be about other matters such as recognising partners or children. Some carers can use this confusion as a reason to ignore LGBT patients' gender identity or sexual orientation.

Some further challenges identified by the Alzheimer's Society include:

- LGBT+ people with dementia who have faced discrimination or stigma may feel forced back into the closet, or their dementia could mean they feel they are still living in those times.
- Trans people with dementia may go back to a time before they transitioned, which can be distressing and confusing.
- Some LGBT+ people may feel isolated as they may have no long-term partner or family to support them.

Advance care planning is particularly important to LGBT people to ensure their relationship with their loved one(s) is recognised and their identities and wishes are respected.

These identified areas will be reflected in the development of the strategy, delivery plans and in particular the review of education and training available within the system.

Carers: A person who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support

Describe any impact and evidence on part-time working, shift-patterns, general caring responsibilities:

A PEO LC diagnosis will often place an extra burden on the role of friends and family as informal carers. The Strategy's Delivery Plan will aim to better support carers by working with communities in the Compassionate Communities Workstream and focusing on Carer Support

- Earlier, more comprehensive care and crisis planning
- Involving carers more in the care planning process
- Signposting/referring carers to relevant support services e.g. Carer's Trust, respite care, VCSE (Voluntary, Community and Social Enterprise) support organisations
- Bereavement Support

Other disadvantaged groups:

Describe any impact and evidence on groups experiencing disadvantage and barriers to access and outcomes. This can include lower socio-economic status, resident status (migrants, asylum seekers), homeless, looked after children, single parent households, victims of domestic abuse, victims of drugs / alcohol abuse: (This list is not exhaustive)

- lower socio-economic status,
- resident status (migrants, asylum seekers),
- looked after children,
- single parent households,
- victims of domestic abuse,
- victims of drugs / alcohol abuse
- Boater community
- Traveler community

Homelessness

Care Quality Commission (CQC) and Faculty for Homeless and Inclusion Health (2017) [A second class ending. Exploring the barriers and championing outstanding end of life care for people who are homeless](#)

Frontline Network St Mungo's [How to support individuals and end of life care needs](#)

Government Statistical Service [UK official statistics on homelessness: Comparisons, definitions, and processes](#)

Hospice UK (2018) [Care committed to me](#)

Office for National Statistics (2020) [Deaths of homeless people in England and Wales](#)

St Ann's Hospice [Homelessness and palliative care – the film](#)

St Ann's Hospice [Homelessness and palliative care: how can we improve equity of care?](#)

St Mungos & Marie Curie Cancer Care (2017) [Homelessness and end of life care. Practical information and tools to support the needs of homeless people who are approaching the end of life and those who are bereaved](#)

The University of Sheffield and Crisis (2012) [Homelessness kills](#)

Homelessness Statistics

Between April to June 2022:

- 72,210 households were initially assessed as homeless or threatened with homelessness and owed a statutory homelessness duty, up 1.3% from April to June 2021.
- 33,570 households were assessed as being threatened with homelessness, and therefore owed a prevention duty which is up 5.1% from the same quarter last year. This includes 5,940 households threatened with homelessness due to the service of a Section 21 notice to end an Assured Shorthold Tenancy – an increase of 75.7% from the same quarter last year. This may partially reflect the removal of restrictions on private rented sector evictions from May 2021 that were in place the same quarter last year.
- 35,610 households were initially assessed as homeless and therefore owed a relief duty, down 0.9% from the same quarter last year. Households with children owed a relief duty increased 14.1% from the same quarter last year to 9,820 households in April to June 2022.
- 11,810 households were accepted as owed a main homelessness duty, up 16.5% from April to June 2021. This reflects the increase in households with children owed a relief duty this quarter (14.1%) and last quarter (24.7%) compared to previous year.
- On 30 June 2022, 94,870 households were in temporary accommodation, which is a fall of 1.0% from 30 June 2021. Households with children fell by 0.8% to 59,500, and single households fell by 1.3% to 35,370. Compared to the previous quarter, the number of households in temporary accommodation fell 0.1%.¹⁷

Homeless people are reported to have more health problems than the general population. Many die young and records in England and Wales between 2013 and 2017 showed that the average age at death was 42 years for homeless women and 44 for homeless men. This was much lower for the general population. Homeless people are at a higher risk of multiple health problems – sometimes referred to as tri-morbidity and do not have access to a regular GP. As a result of this they often end up having a health problem treated in Accident and Emergency departments rather than receiving regular care and access to available services or building relationships with healthcare providers who may be able to help them access services and plan their long-term care needs.

Marie Curie provides information on some of the barriers that exist for **homeless people**, explaining how they do not have the opportunity to access end of life care when compared to those that are not homeless - [Caring for homeless people at the end of life \(mariecurie.org.uk\)](#).

¹⁷https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1119847/Statutory_Homelessness_Stats_Release_Apr-Jun_2022.pdf

The CQC also offers information on the barriers faced by homeless people and examples of good practice - [20160505 CQC EOLC Homeless FINAL 2.pdf](#).

Key barriers for Homeless people:

- Access to health care provisions and therefore access to identification of end-of-life care needs
- A lack of awareness of the number of homeless people locally
- Potentially, homeless people who are dying have complex health care needs, some maybe due to substance addiction and misuse, and complex mental health problems. These needs are difficult to meet in hospices and so individuals often end up being cared for in a hostel. Which is not ideally equipped for End-of-Life support

Prisoners

[Ambitions for Palliative and End of Life Care Partnership \(2018\) Dying well in custody charter. A national framework for local action](#)

[Centre for Policy on Ageing \(2016\) Diversity in older age – Older offenders](#)

[Hospice UK \(2021\) Dying behind bars. How can we better support people in prison at the end of life?](#)

[Ministry of Justice Safety in Custody quarterly](#)

[Prisons and Probation Ombudsman for England and Wales \(2013\) Learning from PPO Investigations: End of life care](#)

[Public Health England \(2017\) Health and social care needs assessments of the older prison population. A guidance document](#)

Key Barriers for prisoners

- [The following article explores barriers within prison systems - End of Life Care in Frailty: Prisons | British Geriatrics Society \(bgs.org.uk\)](#)
- A key issue is that a high proportion of older prisoners are convicted sex offenders, which is borne out in Warwickshire. Nationally this amounts to 45% of the over-50s and 87% of the over-80s prisoners. Because of the nature of their offences and often a lack of social support outside prison, early release on compassionate grounds is usually not an option for this group, so end of life care may have to be delivered in the prison setting

End of Life suites/cells have been created in our local Prison to support those prisoners at End of Life

Refugees /Asylum seekers /Migrant workers

For people whose first language is not English, there may be communication difficulties e.g. for refugees, asylum seekers, and migrant workers, who may need an interpreter.

Key barriers for Asylum seekers

As of June 2021, the total 'work in progress' asylum caseload consisted of 125,000 cases ([Source: Asylum statistics - House of Commons Library \(parliament.uk\)](#))

The key barriers for asylum seekers having access to end-of-life care are as follows:

- A lack of knowledge of services and how to access them
- A fear of being financially charged and feeling they will not be able to afford care
- Unaware of what they are entitled to
- The inability to communicate in English
- Not registered with a GP and so do not have a GP record or rapport with health care professionals to help plan end of life care in advance.

The following study looks at the perceptions of asylum seekers in accessing health care and exploring the barriers that exist for them. It considers barriers such as, language, socio economic status and paying for medication, their knowledge and understanding of what they are entitled to, and access to information - [Asylum seekers' and refugees' experiences of accessing health care: a qualitative study \(bjgpopen.org\)](http://bjgpopen.org).

For all the groups above consider challenge of access to GP, PEO LC and other health care services. Barriers related to place and ability to contact, history of trauma informing perception of health service, co-morbidities, and lack of joined up care, access to suitable carers or appropriate place of care

Digital Accessibility

Healthcare services are increasingly using digital methods for people to access care. This could create challenges for people with disabilities, low digital literacy, or people who do not have devices or connectivity to use these services. Online forms are an additional barrier to some people (for example those with communication or dexterity difficulties) in accessing healthcare. These factors may lead to some groups of people becoming less likely to seek help.

Actions

- Ensure there are always face-to-face and/or phone alternatives to digital options
- Other actions as relevant to the scheme/services involved

3. Human Rights		
FREDA Principles / Human Rights	Question	Response
Fairness – Fair and equal access to services	How will this respect a person's entitlement to access this service?	The PEO LC Strategy will help to ensure an increase in available information to our diverse communities regarding pathways, collaborative, integrated working, and service availability for health, social and third sector providers. This links to Ambition 2: each person gets fair access to care
Respect – right to have private and family life respected	How will the person's right to respect for private and family life, confidentiality and consent be upheld?	Usual ICB, Local Authority and or Provider Policies relating to respect and consent will be applied. Working with a systemwide vision in line with information governance leads and safeguarding policies to uphold these rights in palliative and end of life

		<p>care.</p> <p>This links to: Ambition 1: each person is seen as an individual; Ambition 2: each person gets fair access to care; Ambition 3: maximising comfort and wellbeing; Ambition 4: care is coordinated; Ambition 5: all staff are prepared to care</p>
<p>Equality – right not to be discriminated against based on your protected characteristics</p>	<p>How will this process ensure that people are not discriminated against and have their needs met and identified?</p>	<p>See section 2: we have identified our underserved communities through engagement, co-production and research and are working with communities towards equity of access to PEOLC and equity of care quality.</p> <p>This links to Ambition 1: each person is seen as an individual and Ambition 2: each person gets fair access to care.</p>
<p>Dignity – the right not to be treated in a degrading way</p>	<p>How will you ensure that individuals are not being treated in an inhuman or degrading way?</p>	<p>Usual ICB, Local Authority and or Provider Policies relating to respect and consent will be applied.</p> <p>We will work with safeguarding leads and the quality team as well as stakeholders across the system to ensure we have clear lines of feedback for complaints and compliments to support culturally appropriate personalised palliative and end of life care which promotes dignity.</p> <p>This links to Ambition 2: each person gets fair access to care; Ambition 3: maximising comfort and wellbeing</p>

<p>Autonomy – right to respect for private & family life; being able to make informed decisions and choices</p>	<p>How will individuals have the opportunity to be involved in discussions and decisions about their own healthcare?</p>	<p>Promote a shared decision-making approach to advance care planning to support those thought to be approaching the end of their life and those important to them to be making informed decision and choices for their care. DOLS (Deprivation of Liberty Safeguards) will also be considered in all areas and patient relatives/carers or advocates involved as appropriate.</p> <p>This links to: Ambition 1: each person is seen as an individual, in particular the building blocks of honest conversations, clear expectations and helping people take control.</p>
<p>Right to Life</p>	<p>Will or could it affect someone's right to life? How?</p>	<p>The PEoLC Strategy will not impede reasonable exploration of clinical options to treat an individual, this will be promoted with a shared decision-making discussion which is personalised to the individual and those important to them to improve the quality of care.</p>
<p>Right to Liberty</p>	<p>Will or could someone be deprived of their liberty? How?</p>	<p>Deprivation of liberty would only be sought in individual circumstances where this was clinically appropriate, the PEoLC Strategy would not impact on these pathways, but would seek to support early advanced care planning, so for example people diagnosed with dementia could be involved in their care planning whilst they still have capacity.</p>

4. Engagement, Involvement and Consultation

If relevant, please state what engagement activity has been undertaken and the date and with which protected groups:		
Engagement Activity	Protected Characteristic/ Group/ Community	Date
Coventry and Warwickshire LGBTQi support group - we met with this group to discuss the development of the ICP strategy, the group discussed and shared feedback about Palliative and End of Life Care and the importance of having cultural awareness included in as part of the strategy.	LGBTQi, race, religion, sex, gender	Thursday 8 th September 2022
Roots Connecting communities – a community group from the black African and Caribbean community took part in a discussion about the strategy and what this meant to their community.	Race, religion, sex, age, carers	Tuesday 27 th September 2022
Health Equity Group, Warwickshire - we spoke to people in Nuneaton about the strategy and one lady shared her story about her husband who was diagnosed with stage 4 cancer, she couldn't get hold of morphine, the nurses were only visiting once a week and now he is in End-of-Life care - staff were off sick with Covid, had to collect medication 5 miles away. She strongly recommended there needs to be a more joined up approach across services to support people and their families as the person approaches End-of-life care.	Race, religion, age, sex	Tuesday 25 th October 2022
The Lions Charity in Coventry held a partnership event with the ICB to raise awareness about diabetes, we took the opportunity to talk to people about the strategy and one person told us that her late husband who was at End-of-life care and all the services involved were very good.	Age, sex, religion, race, carers, disability, gender reassignment, maternity	Sunday 20 th November 2022
Coventry and Warwickshire Prostate Cancer Support group, this group was very positive about the strategy and have agreed to share a case study relating to Palliative and End of Life Care as well as be part of a Task and Finish group to review some patient stories which are to be	Race, religion, age, sex, disability	Tuesday 22 nd November 2022

included in the strategy.		
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For each engagement activity, please state the key feedback and how this will shape policy / service decisions (E.g. patient told us So, we will):

- Cultural awareness and training should be accessible for all staff involved in Palliative and End of life care.
 - We need a more joined up approach across services to support people and their families as the person approaches End of Life care.
 - Supporting information for families and relatives needs to be made easily accessible and in different languages
 - Set up a Task and Finish group to be involved in the development of the strategy from a patient and public perspective.
- Further 8-week engagement has been undertaken in 2023 June & July, the feedback collated, and links made during this engagement will enable strong foundations of collaboration and co-production with some of our underserved communities, for example we have worked with HMP Rye Hill and the Coventry Muslim Forum, among others. We plan for continued engagement and co-production with the people of Coventry and Warwickshire throughout the life of the strategy.

5. Mitigations and Changes

Please give an outline of what you are going to do, based on the gaps, challenges and opportunities you have identified in the summary of analysis section. This might include action(s) to mitigate against any actual or potential adverse impacts, reduce health inequalities, or promote social value. Identify the **recommendations** and any **changes** to the proposal arising from the equality analysis.

- General Actions:**
- Ensure communication content is inclusive
 - Review, and where appropriate, act on national evidence-based research and data
 - Not rely on family to deliver sensitive and important information about end-of-life care to a patient
 - Consider challenges in access to GP, PEO LC and other health care services, for all groups and communities
 - Ensure all staff equality training is up to date to facilitate cultural competency throughout the system
- Age:**
- Relevant data needs to be captured to understand the key areas for a service provision review to meet the needs of an ageing population.
 - Develop a stronger emphasis on identification of those thought to be in the last 12 months of life for adult patients, advanced planning and decision making with patients and those who matter to them.
 - Review service provisions for infants, children, and young people, including transition to adult services
 - Ensure paediatric as well as adult PEO LC services are clear to relevant groups
- Disability:**
- Ensure for people with a learning disability consideration is given to communication, facilitating decision making, access, multiple co-morbidities, and staff training

- Training and support should be available for all carers involved in end-of-life care
- Relevant data needs to be captured to understand the key areas for a service provision review to meet the needs of disabled population regardless of age
- Develop a stronger emphasis on advanced planning and decision making
- Explore how intersectionality can support/inform service improvements in the future moving forward
- Making reasonable adjustments
- Work closely with social care team and ensure there is flexibility in care packages so that patients can return home where possible (if desired)
- The programme will address the specific requirements for people living with these disabilities working closely with the LeDeR review team to ensure learning from reviews is shared and actioned
- Ensure all service locations are reasonably accessible for patients with mobility challenges
- Where reasonable, home visits, virtual contacts etc. taking account of patient's wishes
- Ensure appropriate home adaptations including use of Disabled Facilities Grants funding

Sexual Orientation/Trans:

- Ensure that **organisational commitment** to LGBT people extends to both employees and service users.
- Review religious practices and procedures through an LGBT lens.
- Review bereavement/grief support work through an LGBT lens.
- Consider the role of carers, and increased pressure on informal carers and how the service supports, communicates, and involves them.
- Ensure that the review covers and engages with full range of representatives (i.e., people who are Gay, Lesbian, Bi-sexual, Trans, and non-binary)
- Review promotional and advertising material for inclusivity.
- Review policies and procedures (for example, recruitment and other employment practices)
- Review content of staff training
- Communication and information – language used.
- Healthcare providers should have in place a clear policy on confidentiality. This should include details about how a situation should be handled if an individual decides to 'come out', for example finding out whether the person is happy for the information to be included in their care plan and whether they are comfortable with other people knowing they are 'out' and having access to the care plan.
- Respect individuals' preferences regarding disclosure of sexual identity or gender history.
- Service Delivery policies and procedures make specific reference to needs of LGBT people and how they will provide an inclusive service.
- Anticipating potential discrimination
- Have clear statements within policies and procedures on discrimination and 'anti' or zero tolerance approach, covering both role as employer and service provider.
- Policies should be developed to require staff to report any incidences of discrimination by staff or other residents.
- Having a clear policy on confidentiality which includes how a situation is handled if a person comes out and how / if the person wants this included in their care plan.
- Promoting a positive learning culture so that instances of care can be reflected on and learnt from.
- Closer partnership working among all stakeholders to ensure LGBT people are involved in service review and development and that models of good practice are shared.
- Under-representation or invisibility of LGBT people in the language and images used by a service provider in their leaflets, posters, marketing material can add to LGBT people feeling unacknowledged

or invisible. This fuels unhelpful perceptions – for example, that hospice care is for white, middle-class families.

- The 2018 LGBT Foundation Pride in Practice Patient Survey also found that LGBT patients were 24% more likely to share their sexual orientation with healthcare professionals and trans patients were 21% more likely to share their trans status when services displayed LGBT posters.
- Welcome packs should contain contact details of local LGBT organisations and support networks.
- Service providers should positively market themselves as being LGBT friendly places (through use of and displaying LGBT symbols and images) so that positive messages are given out and that LGBT people will feel that they will be welcomed in these environments. They should aim to promote themselves as a Safe Place – both for service users and staff.
- Provide staff with explicit markers of inclusion (such as rainbow lanyards/pin badges).
- There should be active engagement with the LGBT community by End-of-Life care services.
- It is important that LGBT people can access advice and advisors to make plans with someone who understands the diversity and issues they have/might face. Staff should be trained to understand LGBT issues; this should be regularly updated. The training content should include:
 - How to avoid heterosexually framed, assumption loaded questions – promoting inclusive language to not inadvertently make someone feel as if they must reveal their gender identity or sexual orientation.
 - How to sensitively explore identity, relationships and identify key important people in their life (next of kin, partners, friends, and wider networks).
 - Understanding of the historical and social context that older LGBT people will have lived through (to gain a better understanding of the fears and concerns they may have).
 - Exploring unconscious bias, stereotyping, attitudes and understanding of sexual orientation and gender identity.
 - How to provide sensitive, consciously inclusive, and appropriate care services which acknowledges and involves an individual's partner or chose family.
 - Confidentiality, Gender Recognition Certificates, and the Mental Capacity Act.
 - One crucial point made was that LGBT people needed access to advice and advisors to make plans, who would understand something about the diversity of LGBT lives.
 - Raising awareness of unique issues faced by LGBT people, their family, and carers and how these impact on end-of-life care. It should be recognised that the 'treat everybody the same' approach can sometimes exacerbate inequality.
 - Implement the NHS Sexual Orientation Monitoring standard.
 - People's sexual orientation with consent should be recorded and considered in any assessment given, and care provided if there are needs not addressed

Dementia:

- Encourage advanced care planning at the early stages of diagnosis
- Work closely with System Dementia leads to ensure due consideration is given
- Signposting to Alzheimer Society which has the specific publication [LGBTQ+: Living with dementia | Alzheimer's Society \(alzheimers.org.uk\)](#)

Race:

- Engage proactively with the whole of their local community to better understand and meet people's needs.
- Ensure access to interpreters is available when needed.

- Leaflets and information are not only handed out, but a verbal discussion from health care professionals to be given prior to this, as some cannot understand the content of leaflets – if need be, ask an interpreter to explain.
- Not rely on family to deliver sensitive and important information about end-of-life care to a patient
- Training for all staff delivering end of life care to become culturally competent.
- Interpreters provided so that language conversion is appropriate
- Ensure all staff equality training is up to date to facilitate cultural competency throughout the system
- Ensure cultural and religious needs for Minority Ethnic people are considered, addressed, and continue to develop work to address lack of knowledge and information about end-of-life care
- Ensure we have access to translation services at end-of-life care to address potential language barriers and consider the written word leaflet usage and website narrative.

Religion:

- Care providers to be aware of religious and cultural needs from the very beginning so that when information about end-of-life care is discussed, these factors are considered, and the best advice can be given for patients and families to make an informed decision throughout
- Provision of chaplaincy services appropriate for all religions
- Better community engagement between commissioners, local health care providers and community groups.
- Ensure all staff equality training is up to date to facilitate cultural competency throughout the system
- Religious rites, care of the body, burials etc. may vary across cultures and awareness and an empathic approach are essential

Homeless:

- Intervention by health care workers to be provided earlier on so that the necessary care plans can be accessed and provided.
- Better relationships between health care workers and homeless people
- A greater understanding and acknowledgement of the local homeless population by healthcare workers

Asylum Seekers:

- To improve access to literature in the preferred language so individuals understand what end of life services are available
- Interpreter services to be readily available as necessary
- Primary care providers to explain and inform asylum seekers what they are entitled to so that they have access to end of life care early on
- Better community engagement though local places of worship or community centers
- Identify those not registered with a GP
- Ensure all staff equality training is up to date to facilitate cultural competency throughout the system
- Ensure we have access to translation services at end-of-life care to address potential language barriers and consider the written word leaflet usage and website narrative.

Prisons:

- Continue to develop links with the Prison Service locally to establish ongoing needs around PEoLC care support

Digital Accessibility:

- Ensure there are always non-digital care options from those without internet access

- Adhere to the ICB policies around Digital inclusion
- Ensure there are always face-to-face and/or phone alternatives to digital options

6. How will you measure how the proposal impacts health inequalities?

e.g. Patients with a learning disability were accessing cancer screening in substantially lower numbers than other patients. By revising the pathway, the ICB is able to show increased take up from this group, this is a positive impact on health inequalities.

You can also detail how and when the service will be monitored and what key equality performance indicators or reporting requirements will be included within the contract.

What health inequalities already exist?

Collation of data in relation to palliative and end of life care and health inequalities is inconsistent across the country.

As part of the Strategy development, we have scoped the metrics which as a system we would like to collate so we can better understand issues of utilisation of services by our under-served communities and data quality.

Will your proposal have negative or positive implications on health inequalities?

We are working with system partners to drive towards a positive outcome, through highlighting the inequity which exists in our system and how we can design and deliver services to reduce health inequity, e.g. poverty proofing work programme

What can you do to mitigate any identified health inequalities?

We are looking at links through to health, social and community support and have already through the strategy development made links with Citizen's Advice Bureau and the Carer's Trust to review areas of need such as finances as well as reviewing the rural and fuel poverty for which we are an outlier in Warwickshire.

7. Is further work required to complete this assessment?

Please state what work is required and to what section. E.g. additional consultation or engagement is required to fully understand the impact on a particular protected group (e.g. disability).

No further work required on the assessment at this point


The EQIA will be reviewed again if/as necessary based on significant insight from the following:

- Next, and any further, rounds of communication and engagement activities
- Reviews of the PEoLC data
- Any feedback from Clinicians delivering PEoLC Services
- Changes to NHSE and/or NICE guidance on PEoLC Services

Work needed	Section	When	Date completed
e.g. Further engagement with disabled service users to identify key concerns about accessibility of the service.	2. Disability	June – July 2020	July 2020.

8. Sign off

The Equality Analysis will need to go through a process of **quality assurance** by a Senior Manager within the department responsible for the service concerned before being submitted to the Policy, Procedure and Strategy Assurance Group for approval. Committee approval of the policy / project can only be sought once approval has been received from the Policy, Procedure and Strategy Assurance Group.

Requirement	Name	Date
Senior Manager Signoff	 TRACY PILCHER	13/9/2023
Which committee will be considering the findings and signing off the EA?	Coventry and Warwickshire ICB: QSEC (Quality, Safety and Experience Committee) & Governing Board The PEOLC Partnership Board	
Approved by the Policy Procedure and Strategy Assurance Group.		

Minute number (to be inserted following presentation to the committee)	
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Once complete, please send to the ICB's Governance Team.