Coventry City Council

Agenda

Health and Social Care Scrutiny Board (5)

Time and Date
11.00 am on Wednesday, 25th February, 2026

Place
Diamond Rooms 1 and 2 - Council House

Public Business

1. **Apologies and Substitutions**

2. **Declarations of Interest**

3. **Minutes** (Pages 3 - 18)

    a) Minutes of the Meeting held on 21st January 2026

    b) Briefing note - proposed amendments to the minutes of the Meeting held on 17th September 2025:

        i) Appendix 1 – Minutes of Meeting held on 17th September 2025
        ii) Appendix 2 – Alzheimer's Society Response

    (a) Matters Arising

4. **Healthwatch Update** (Pages 19 - 70)

    Briefing Note of L-A Howat, Service Manager, Healthwatch Coventry

    a. Housing with Care – Enter and Views report
    b. NHS Survey report

5. **End of Life Strategy and Hospices** (Pages 71 - 180)

    Briefing Note of the Head of Communications and Public Affairs – Coventry & Warwickshire ICB, R Uwins and the Director of Public Health & Wellbeing, Coventry City Council, A Duggal

6. **Work Programme and Outstanding Issues** (Pages 181 - 190)

    Report of the Scrutiny Co-ordinator

7. **Any other items of Public Business**

    Any other items of public business which the Chair decides to take as matters of urgency because of the special circumstances involved

Private Business

Nil

Julie Newman, Director of Law and Governance, Council House, Coventry

Tuesday, 17 February 2026

Note: The person to contact about the agenda and documents for this meeting is Caroline Taylor, Governance Services caroline.taylor@coventry.gov.uk

Membership: Councillors F Abbott, S Agboola, S Gray, L Harvard, A Hopkins, L-A Howat, S Jobbar, M Lapsa, C Miks (Chair) and B Mosterman

By invitation Councillors L Bigham, K Caan, G Hayre and D Toulson

Public Access

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Caroline Taylor, Governance Services
caroline.taylor@coventry.gov.uk

Coventry City Council
Minutes of the Meeting of Health and Social Care Scrutiny Board (5) held at 11.00 am on Wednesday, 21 January 2026

Present:

Members:	Councillor C Miks (Chair) Councillor S Agboola Councillor S Gray Councillor L Harvard Councillor A Hopkins Councillor S Jobbar Councillor M Lapsa Councillor B Mosterman
Other Members:	Councillor L Bigham (Cabinet Member for Adult Services), K Caan (Cabinet Member for Public Health, Sport and Wellbeing)
Co-Opted Members:	L-A Howat, Healthwatch Coventry

Employees (by Directorate)

Adult Social Care	G Borro, N Byrne
Law and Governance	E Jones, C Taylor
Public Health	A Duggal
Apologies:	Councillors F Abbott and G Hayre
Others Present:	A Cartwright, ICB

Public Business

28. **Declarations of Interest**

There were no Declarations of Interest.

29. **To agree the minutes of the meeting held on 17th December 2025**

The minutes of the meeting held on 17th December 2025 were agreed and signed as a true record.

There were no matters arising.

30. **Matters Arising**

Further to Minute 25 – UHCW Performance, the Board noted a Briefing Note which included recommendations was sent to the Cabinet Member for Public Health, Sport and Wellbeing.

31. **Access to Dentistry and All Age Oral Health**

The Board received a Briefing note and verbal presentation of the Chief Integration Officer, Integrated Care Board (ICB) and the Director of Public Health and Wellbeing, Coventry City Council, which provided an update on the current state, performance and strategic direction of dental services in Coventry and Warwickshire. It outlined the types and distribution of dental services, highlighted strong contract performance and recovery to pre-pandemic activity levels, and detailed recent initiatives such as increased urgent care appointments, incentive schemes for urgent dental care, targeted investments to address inequalities, and workforce support measures.

Dental health surveys had been carried out in the UK since 1968. Every 2 years an Adult Oral Survey was carried out in England. The latest survey was carried out in 2023 and was published in December 2025. The survey was carried out in addition to the Child Dental Health Survey and ad hock surveys such as oral health in care homes. The survey used a representative sample of adults in England aged 16 and over and used a questionnaire and oral examination in the participant’s own home to evaluate their oral health. The examination included condition of teeth, condition of root surfaces, erosion of teeth, signs of decay, enamel defects, signs of gum disease and type and condition of any dentures.

The findings were as follows:

- Over 21% of adults had at least one tooth with obvious decay.
- A total of 93% of dentate adults had one or more signs of gum disease.
- 7% of dentate adults were experiencing current dental problems including pain, which was more likely in people that last visited the dentist more than 5 years ago. Nearly 21% of adults had one or more potentially urgent conditions
- 51% of the respondents reported that the usual reason for dentist attendance was for a check-up and almost 65% of adults reported going to the dentist at least once in a 2 year period.
- 35% of adults reported going to the dentist less frequently or only when they had problems with teeth or dentures. This had increased in recent years.
- The most common reasons for infrequent attendance were:
- Being unable to find a dentist (40%)
- Unable to afford the charges (31%)
- Not perceiving a need to do so (27%)

Health inequalities impact

Dental access in Coventry was uneven, with areas like Central and East facing the greatest deprivation and highest rates of dental disease. Targeted investments and programs were being directed to these priority areas to improve access and reduce oral health inequalities.

The planned reforms to the NHS dental contract were expected to further reduce barriers to care, improve workforce retention and ultimately help decrease oral health inequalities. Despite strong overall performance, the Coventry &

Warwickshire ICB acknowledged that further work was needed to address and reduce inequalities in access to dental services.

From the Adult Oral Health Survey, the number of people with 21 or more natural teeth was lower among those who were older, had lower household incomes and lived in more deprived areas.

The proportion of adults in England reporting no natural teeth was 2.5% and this was more likely in older people, people with lower household income and those living in more deprived areas.

The Cabinet Member for Public Health, Sport and Wellbeing, Councillor K Caan, welcomed the update regarding dental services in Coventry, which he said had become a challenging due to years of underinvestment which had caused a decline in oral health of the population. It was noted some treatments offered abroad were cheaper than parts of the dentistry service in the UK and he called for further transparency of the treatments offered abroad. The Cabinet Member advised inequalities continued to be driven forward with ongoing work with GP's and dentists to ensure the most vulnerable communities received support so they did not require greater intervention later on. The Cabinet Member referred to communities who may not routinely visit the dentist, praising health professionals who support and encourage these communities to visit the dentist.

The Cabinet Member for Adults, Councillor L Bigham, welcomed the information regarding dentistry, suggesting more emphasis should be placed on other health issues when oral health is poor, in particular, in areas of inequality in the city.

Members of the Board, having considered the Briefing Note and presentation, asked questions and received information from officers on the following matters:

- An additional 30,000 units of dental activity had been commissioned in the priority areas of Coventry east and an additional 6,000 in Coventry west.
- There were limits as to what could be commissioned as some dentistry was a contractual requirement and the ICB were reliant on providers accepting and undertaking NHS work over private work.
- The ICB was currently funded to provide dentistry to 56% of the population.
- Patients travelling abroad for dentistry treatments either undertook services not provided on the NHS or undertook standard dental work, which the ICB were investigating.
- The ICB were undertaking work on population health data regarding how health conditions linked to each other.
- A number of local schemes to retain the dentistry workforce including a workforce training hub, a dental golden hello scheme and learnings from exit interviews, were in place.
- A team from the ICB was in place to work with newly arrived communities in the city to encourage dental visits.
- Practices could choose whether or not to take on additional units of dental activity. In some cases, in order to increase their dental activity, additional staff would be required.

- A degree in dentistry is carried out at university and paid for by the student. Post graduate qualifications were paid for by the NHS depending upon speciality.
- Dental cosmetic procedures were not covered by the ICB.
- Practices could set their own prices for any dental work which fell outside of the national contract.
- NHS dentistry could be accessed anywhere and patients were able to change dentist at any point if they wished.
- The ICB commissioned standard NHS dental care from practices along with more specialist dental services and secondary care services where patients would see a consultant.
- The NHS no longer provides dentistry in mobile units at schools. Some school work was undertaken eg. toothbrushing schemes, but not in mobile units. Family Hubs and health visitors provided oral health advice to parents.
- The ICB had communication plans to promote different services including how to access emergency dental services.

The Cabinet Member for Public Health, Sport and Wellbeing, Councillor K Caan, welcomed the valuable discussion, suggesting writing to the Health Minister relaying the Boards concerns.

The Board requested:

- Further information on the knock effect of poor oral health issues.
- Ways in which health visitor support and intervention could be expanded.
- Production of a newsletter explaining dentistry in Coventry to newly arrived residents from abroad.
- Information on the rising costs of dentistry.

RESOLVED that the Health and Social Care Scrutiny Board (5):

1. **Note the findings of the report in Appendices 1 and 2.**

2. **The Cabinet Member for Public Health, Sport and Wellbeing to write to the Minister for Health explaining SB5's concerns, seeking answers to the Board's suggested changes in access to dentistry and all age oral health and requesting a meeting to discuss the Boards concerns prior to May 2026.**

32. Carers Strategy - Engagement and Planning Overview

The Board received a Briefing Note and presentation providing an update of Coventry's development of a 5 year Carers Strategy (2026-2031) and Carers Action Plan progress, which aims to improve support for over 27,000 local carers by focusing on co-production with carers and stakeholders, broad engagement – especially with underrepresented groups – and sustainable services, building on recent achievements and ensuring statutory duties are met as some funding ends in 2026, with the overall goal of improving outcomes for carers and those they support.

The Cabinet Member for Adult Services, Councillor L Bigham, in thanking officers for the strategy, congratulated the Adult Social Care teams on their enthusiasm and determination, in particular by providing as much support to carers as possible. Councillor Bigham also welcomed advancements in technology which allowed isolated carers to get online and belong to a carers network.

The Deputy Cabinet Member for Adult Services, Councillor D Toulson welcomed the Strategy and the support provided for carers across the city.

Members of the Board, having considered the Briefing Note and presentation, asked questions and received information from officers on the following matters:

- The importance of carers voice being essential for ensuring unpaid carers felt valued.
- Adopting a ‘soft approach’ to caring responsibilities involving language that emphasises human connection.
- Engaging with partners for the early identification of unpaid carers, who often do not recognise themselves as such.
- The importance of influencing all partners to support carers before they reach carer breakdown.
- Support mechanisms for carers in newly arrived communities.
- Ward based engagement with people who don’t realise they are carers.

The Board requested the following information:

- Inclusion and impact of carer voice and case studies when the Carers Strategy returns to SB5.
- Ward Councillors to be utilised to communicate the Carers Strategy.
- Officers to work with certain communities in Coventry to focus on the description of a carer to ensure caring responsibility support.

RESOLVED that the Health and Social Care Scrutiny Board (5):

1. **Endorse the engagement and delivery plan to inform a new Carers Strategy 2026-2031**

2. **Provide any feedback as part of the development of the new Carers Strategy that is currently being developed.**

33. Work Programme and Outstanding Issues

RESOLVED that the Health and Social Care Scrutiny Board (5):

1) **The Work Programme 2025/26 was noted with the amendments below:**

   - Healthwatch Annual Report – February 2026 meeting.

   - Emergency Services Partnerships relating to Health – Ambulance Service/Fire Service/Police – March 2026 meeting.

34. Any other items of Public Business

There were no other items of public business.

(Meeting closed at 12.45 pm)

Coventry City Council

Briefing note

To: Health and Care Scrutiny Board

Date: 25th February 2026

Subject: Proposed Amendment to Minutes from the Meeting held on 17th September 2025

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1 Purpose of the Note

1.1 The Health and Care Scrutiny Board are asked to consider a proposed amendment to the Minutes of their meeting held on 17 September 2025 relating to the item “Training of Care Staff Supporting Patients with Dementia” (Minute 4/25 refers) following the clarification of information received from the Alzheimer’s Society.

2 Recommendations

2.1 Health and Social Care Scrutiny Board are recommended to

2.2 Review Minute 4 from the meeting held on 17 September, 2025 (attached as Appendix 1) relating to “Training of Care Staff Supporting Patients with Dementia” and review the clarification of information received from the Alzheimer’s Society (attached as Appendix 2)

2.3 Approve the following amendment to Minute 4 which reflects the Alzheimer’s Society’s clarification and the distinction between national recommendations and Coventry’s local approach:-

That the following paragraph be inserted into Minute 4:-

> “For clarity, the Scrutiny Board subsequently noted that the Alzheimer’s Society’s ‘Because We are Human Too’ report sets out national recommendations aimed at improving consistency and quality in dementia training across the social care workforce. The Alzheimer’s Society does not obligate care providers to deliver its own dementia training programme, and the examples within the report are included purely as illustrative case studies. The reference to £2,000 relates to an estimated annual cost saving demonstrated through evidence-based training approaches, not a cost or fee for undertaking Alzheimer’s Society training. Coventry’s local approach to dementia training—delivered through a range of models—remains robust,

appropriate to local resources, and aligned with improving workforce capability."

3 Information and Background

3.1 At the meeting on 17 September, 2025, the Scrutiny Board considered a Briefing Note relating to "Training of Care Staff Supporting Patients with Dementia" which included information relating to the Alzheimer's Society's recently published national report entitled 'Because We are Human Too: Why dementia training for care workers matters and how to deliver it'

3.2 Since the meeting, the Alzheimer's Society has provided clarification in relation to the national report and how it was reflected in the Briefing Note and Minutes. They have emphasised that the 'Because We Are Human Too' report's purpose is to highlight the importance of high-quality dementia training and make the case for national consistency. It focuses on quality and impact of training, not a specific programme. Examples included are illustrative only. (Their clarification is attached as Appendix 2)

3.3 The Alzheimer's Society have also confirmed that the reference to £2,000 within their report is an estimated annual cost saving per care home associated with evidence-based dementia training—not a training fee or cost charged to providers.

3.4 To ensure clarity, it is proposed that that Minute 4 be amended by the insertion of the following paragraph:

3.5 "For clarity, the Scrutiny Board subsequently noted that the Alzheimer's Society's 'Because We Are Human Too' report sets out national recommendations aimed at improving consistency and quality in dementia training across the social care workforce. The Alzheimer's Society does not obligate care providers to deliver its own dementia training programme, and the examples within the report are included purely as illustrative case studies. The reference to £2,000 relates to an estimated annual cost saving demonstrated through evidence-based training approaches, not a cost or fee for undertaking Alzheimer's Society training. Coventry's local approach to dementia training—delivered through a range of models—remains robust, appropriate to local resources, and aligned with improving workforce capability."

4 Health Inequalities Impact

4.1 There are no health inequalities implications arising from this amendment to the Minutes.

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Appendix 1: *Minutes of the meeting of the Health and Social Care Scrutiny Board held on 17 September 2025*
Appendix 2: *Clarification received from the Alzheimer's Society on "Because We Are Human too": What the report is seeking to achieve.*

Coventry City Council
Minutes of the Meeting of Health and Social Care Scrutiny Board (5) held at 11.00 am on Wednesday, 17 September 2025

Present:

Members:	Councillor C Miks (Chair) Councillor S Agboola Councillor S Gray Councillor A Hopkins Councillor S Jobbar
Other Members:	Councillors L Bigham (Cabinet Member for Adults), K Caan, (Cabinet Member for Public Health, Sport and Wellbeing) and G Hayre, (Deputy Cabinet Member for Public Health, Sport and Wellbeing)
Employees (by Directorate)	
Adult Care, Health & Housing	S Atkins, N Byrne, K Clarke, P Fahy, L Hay
Law and Governance	G Holmes, C Taylor
Public Health	A Duggal
Regeneration & Economy	J Hunt, D Nuttall
Apologies:	Councillor F Abbott, L Harvard, M Lapsa, B Mosterman and D Toulson (Deputy Cabinet Member for Adult Services)

Public Business

1. Declarations of Interest

There were no Declarations of Interest

2. Minutes

The minutes of the meeting held on 2nd April 2025 were agreed and signed as a true record.

There were no Matters Arising.

3. Adult Social Care Performance - Self-Assessment and Annual Report (Local Account) 2024/25

The Board considered a report and presentation of the Director of Care, Health and Housing, regarding the Adult Social Care Performance – Self-Assessment and Annual Report (Local Account) 2024/25.

The Annual Report covered performance and activity for the previous year along with examples and case studies of where a positive impact to people's lives had been made.

Since the introduction of the Local Authority Assessment Framework by the Care Quality Commission, the format of the Annual Report had followed each of the four CQC themes for inspection and the quality statements associated with these themes.

An accompanying Self-Assessment had also been produced to provide operational detail and Adult Social Care produced and published its first Self-Assessment in 2024 and both the Annual Report and Self-Assessment would be updated annually.

The approach taken to both the Self-Assessment and Annual Report demonstrated an open approach to success, challenges and where further development would take place to improve outcomes for people with care and support needs and their unpaid carers within Coventry. The Self-Assessment also provided the opportunity to present the context within which CQC would be inspecting Adult Social Care in Coventry.

The production of the 2024/25 report had drawn on the pool of feedback and information gathered over the year from a range of sources including social care staff, Partnership Boards, Adult Social Care Stakeholder Group, providers, partner organisations and people who had been in contact with Adult Social Care, along with their families and carers.

The Cabinet Member for Adult Services, Councillor L Bigham introduced the item, thanking the team and advising of the importance of the personal stories within the Annual Report.

The Cabinet Member for Public Health, Wellbeing and Sport, Councillor K Caan, commended the strategic partnerships in sport which worked with care homes and supported mental health.

The Director of Public Health and Wellbeing, A Duggal advised the Board that relationships were strengthening between Public Health and Adult Social Care to prioritise prevention and wellbeing.

Members of the Scrutiny Board, having considered the report and presentation, asked questions and received information from officers on the following matters:

- Changes to the front door responses and the early help team, with a better focus on signposting and prevention had affected the numbers using low-level support and short-term support.
- Spend had increased mainly due to the increase in the minimum wage as well as an increase in the complexity of care needs. However, the Council's costs were generally in line with the average of other local authorities.

- How elected members could promote the work of Adult Social Care and tell the positive story that there is to tell, to support the visibility and transparency of the service.
- The uptake of Bridgit Care for carers had been really positive and nearly 16,000 contacts had been made since February 2025. Highest access was at weekends when other services weren't accessible.
- There were positive relationships with all public sector partners, including the Fire Service.
- The biggest challenge to address for the service was one of hearing the voice of the most disenfranchised of society who don't access services. This was an area that Members could help the service with.

Members also requested:

- A further item on how Adult Social Care and Public Health were working together on prevention, prioritising wellbeing.
- The most recent LGA data showing spend comparison with other local authorities in the West Midlands.
- Data regarding the number of migrants delivering Adult Social Care in Coventry.
- Communications on key facts – how Council Tax is spent etc, so Members could sell the story to communities.
- A summary report regarding the uptake and impact of Bridgit Care.

RESOLVED that the Health and Social Care Scrutiny Board (5):

1. **Consider the Adult Social Care Self-Assessment and Annual Report (Local Account) 2024-25 and submit any comments to Cabinet for their consideration on the context of the assessment and report.**

4. Training of Care Staff supporting patients with Dementia

The Board considered a Briefing note and presentation of the Joint Commissioning Manager – Dementia and Mental Health, regarding training and development for Care Staff Supporting People with Dementia.

The Alzheimer's Society recently published a report *'Because We're Human Too: Why dementia training for care workers matters and how to deliver it'*, which expresses concern at low levels of dementia training amongst care staff – 29% nationally.

The report recommended local authorities, when commissioning adult social care services, included a contractual obligation for care providers to ensure staff undertook the Alzheimer's Society's dementia training programme at an annual cost of £2,000 per care home.

This briefing gave assurance to the Scrutiny Board that current training protocols for care homes were robust and appropriate within available resources. While some training delivered or procured by providers may differ in scope from that recommended by the Alzheimer's Society, it nonetheless contributed to enhancing staff knowledge and the overall quality of dementia care.

The Cabinet Member for Adult Services, Councillor L Bigham commended the supportive partnership working in this growing and ever evolving area, where the importance of research and regular training of care staff was paramount.

The Cabinet Member for Public Health, Wellbeing and Sport, Councillor K Caan, referred to the importance of close partnership working with health partners, advising of current programmes and with a focus on prevention, in particular, early intervention.

Members of the Scrutiny Board, having considered the report and presentation, asked questions and received information from officers on the following matters:

- Engaging with faith groups to create awareness and identify early symptoms of dementia may help overcome stigmas from different communities to enable access to services.
- The Dementia Partnership Hub was an important partner in the provision of dementia support to the different communities within the city.
- Numbers of care home staff receiving dementia training fluctuated dependent on staffing numbers.
- Quality assurance visits to care homes helped to provide feedback on their care from staff, residents and their families. Officers worked closely with social care teams working with dementia patients in the community who provide feedback on their care.

Members also requested:

- The proportion of staff working directly with patients with dementia who have received Level 3 or higher qualification.

The Cabinet Member for Adults, Councillor L Bigham, endorsed that 50% of care home staff in Coventry had received formal dementia training which exceeded national performance by a wide margin and that the Dementia Hub and Forget-me-Not Café in the city had received national recognition.

RESOLVED that the Health and Social Care Scrutiny Board (5):

1. **Consider the information provided in the Briefing Note and appendices.**

2. **Identify any further comments or recommendations for the Cabinet Member.**

5. Cabinet Members' Portfolio Priorities and Work Programme 2025 - 2026

The Health and Social Care Scrutiny Board (5) noted the work programme and requested the inclusion of the following items:

- Play Zones – impact on the city
- Impact of climate change on health across the city

- UHCW performance
- Public Health and Adult Social Care working together on Prevention (2026-27 Work Programme)

The Board received a presentation of the Cabinet Member for Public Health, Wellbeing and Sport, Councillor K Caan's portfolio priorities for 2025-26, which included:

- To deliver a new Partnership Sport, Physical Activity and Movement Strategy (Community Conversations)
- Sport England Place Based Expansion funding bid submitted and secured
- To deliver the action plan for Playing Pitch and Outdoor sports strategy and Indoor Facilities Strategy
- To deliver the capital infrastructure for Playzones in 6 local communities
- To continue to grow Go CV for all residents inclusive of access
- Engaging community events for all, such as Childrens Mile, Sports Fest etc.

Members of the Scrutiny Board, having considered the report and presentation, asked questions and received information from officers on the following matters:

- All schools in Coventry had received invitations to the Children's Mile. Officers worked with all schools in the city to encourage and promote regular activity.
- Home educated children were encouraged to access sports activities.

The Cabinet Member for Adults, Councillor L Bigham, advised the Board of her portfolio priorities for 2025-26, which were:

- A focus on diversity of workforce - recruit for diversity and develop skills to meet the diversity challenge
- Digital challenge - updating technology - replacing Care Director - more accurate capturing of conversations with users and carers
- Embed strength-based work – building on team support and peer learning to develop strength-based practice of staff and people support
- Workforce resilience and supporting the wellbeing of the existing workforce.

RESOLVED that the Health and Social Care Scrutiny Board (5):

1. **Consider the information shared regarding Cabinet Member priorities.**

2. **Consider the draft Work Programme and include the following on the Work Programme 2025-26:**

    - **Play Zones – impact on the city**
    - **Impact of climate change on health across the city**
    - **Performance at UHCW**
    - **Public Health and Adult Social Care working together on Prevention – to be placed on the 2026/27 Work Programme**

6. **Any other items of Public Business**

There were no other items of public business.

(Meeting closed at 12.50 pm)

Alzheimer's Society
Together we are help & hope
for everyone living with dementia

Because we are human too report

Briefing paper: What the report is seeking to achieve.

This report highlights the importance of high-quality dementia training for the social care workforce and makes the case for this to be mandated nationally. It shows that while there are pockets of good and even outstanding practice, access to quality dementia training is currently uneven and inconsistent. The report's purpose is to set out why this matters and to highlight the benefits of effective dementia training.

The focus of the report is on the quality and impact of training, rather than on any single programme. It explains why dementia training matters not only for people living with dementia, but also for unpaid carers, the workforce, and the wider health and care system. The report sets out recommendations for training that are mapped to the relevant national dementia training frameworks and identifies five key components that should be present to ensure training is impactful.

The report refers to WHELD/iWHELD and NIDUS-Professional as examples of evidence-based dementia training that have been trialled in the UK. These are included as illustrative, costed case studies, to demonstrate what can be achieved when training is well designed, properly supported and based on evidence. They are not presented as preferred or required programmes. For example, evidence from iWHELD is used to show that, after accounting for delivery costs, effective dementia training can be associated with an estimated £2,000 saving per care home per year to the wider health and social care system.

Overall, the report shows that guidance alone has not been sufficient to ensure consistent access to high-quality dementia training. It concludes that national government action, supported by appropriate funding, is needed to ensure people living with dementia receive high-quality social care wherever they live, with a statutory duty seen as the only way to achieve consistency. At the same time, local authorities and care providers are urged to act now by commissioning and delivering high-quality dementia training that meets the standards set out in the report.

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Coventry City Council

Briefing note

To: Health and Social Care Scrutiny Board

Date: 25 February 2026

Subject: Healthwatch Coventry: Enter & View Overview Report & NHS App Survey Report

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1 Purpose of the Note

1.1 To inform Members of Health and Social Care Scrutiny Board of updates from HealthWatch Coventry regarding their recent reports:

a) Overview of Enter & views that was completed in October-December 2025 (Appendix 1)

b) NHS survey results presentation (Appendix 2)

1.2 Representatives from HealthWatch Coventry will be sharing a presentation at the meeting.

2 Recommendations

2.1 The Health and Social Care Scrutiny Board is recommended to:

a) Note the update by HealthWatch Coventry relating to Overview of Enter & Views and NHS App Survey Report.

b) Support the recommendations identified by HealthWatch

3 Information and Background

Overview of Enter and Views Report – Appendix 1

3.1 Healthwatch Coventry carried out Enter & View visits across 11 Housing with Care schemes in Coventry during late 2024–early 2025. The aim was to understand residents’ experiences of living in Housing with Care—focusing on independence, safety, communication, wellbeing and the quality of care and environment.

3.2 Healthwatch Coventry undertook Enter & View visits across 11 Housing with Care schemes to understand residents’ experiences and identify strengths and improvement areas. Overall, residents reported feeling safe, supported and able to maintain their independence, with many describing positive relationships with staff and a strong sense of home within their flats.

3.3 However, several system-wide issues emerged. Communication remains inconsistent, with some residents unable to access information easily or lacking accessible formats. Staffing continuity also affects confidence, particularly at night, and some residents are unsure how to express concerns or preferences. While many enjoy activities, the current offer does not consistently meet varied needs, contributing to isolation for residents with limited mobility.

3.4 Environmental challenges were noted, including reliance on single lifts, inconsistent building condition, and variation in the usability of communal and dining spaces. Food quality, availability, and affordability also varied significantly across schemes. Staff and managers highlighted increasing numbers of younger residents and people with complex mental health needs, which is placing new pressures on service models and staff capability.

3.5 Despite these challenges, the majority of residents remain broadly positive about their care. The findings point to important opportunities to strengthen communication, accessibility, activity provision, staff continuity, and support for mental health. Healthwatch will review progress at 3 and 6 months and seek provider responses to recommendations.

NHS App Report – Appendix 2

3.6 The *NHS App Report 2025* presents the findings of a community-focused survey undertaken to understand how residents across Coventry use – or struggle to use – the NHS App. The App, available to anyone aged 13+ and registered with a GP, is promoted nationally as an easy way to manage healthcare tasks such as appointments, prescriptions, and health records. However, local experiences can vary significantly, especially depending on GP practice systems and digital confidence.

3.7 The NHS App Report 2025 summarises feedback from Coventry residents on their experiences using the NHS App. The survey explored how widely the app is used, how easy people find it, and what barriers or improvements are needed.

3.8 Data was collected between October and December 2025, using an online survey and extensive face-to-face outreach at community centres and foodbanks across Coventry. In total, 246 responses were gathered, with many participants receiving support to download or navigate the app.

3.9 The report highlights the growing importance of the NHS App in accessing healthcare and identifies key issues around usability, accessibility, digital confidence, and inconsistent features across GP practices. It aims to inform improvements and ensure residents can access digital healthcare fairly and effectively.

3.10 The survey aimed to explore several key questions:

- Whether people in Coventry are using the NHS App
- How easy they find it to use
- Whether it helps them manage their healthcare needs
- What improvements they feel are needed

- Why some residents may not use the app or struggle to access it

3.11 The goal is to better understand digital access to health services and highlight barriers that may prevent residents—particularly those in more disadvantaged communities—from fully benefiting from the App.

4 Health Inequalities Impact

Overview of Enter and Views Report (Appendix 1):

4.1 Findings from the Enter & View visits indicate that several groups of residents may be disproportionately affected by health inequalities within Housing with Care settings. Residents with limited mobility, visual impairment, or limited English face barriers in accessing information, participating in activities, and communicating their needs, due to inaccessible noticeboards, lack of large-print materials, and reliance on staff or family for translation. Differences in activity provision, inconsistent staff continuity, and variable access to social spaces increase the risk of isolation, particularly for those unable to leave their flats.

4.2 Younger residents and those with complex mental health needs are an emerging group whose support requirements are not always fully met, with staff reporting limited time and training to respond effectively. Variability in food affordability and availability may further disadvantage residents on lower incomes, affecting nutrition and wellbeing. Together, these factors highlight areas where current service arrangements may unintentionally widen inequalities and where targeted improvements could help ensure more equitable access to care, information, and opportunities for wellbeing.

NHS App report (Appendix 2):

4.3 The report shows that the NHS App can unintentionally widen health inequalities in Coventry. While most people are aware of the app and have a device, many still struggle due to low digital confidence, lack of photo ID, and limited support, particularly among residents reached through foodbanks and community centres.

4.4 Differences between GP practices mean that some patients can book appointments or access records while others cannot, creating unequal access based on practice systems. The app also lacks accessibility features needed by disabled users, people with low literacy, and carers managing dependants.

4.5 Families, carers and those with complex health needs face extra barriers because proxy access is inconsistent and hospital or maternity records are not always visible, leading to fragmented care.

4.6 Overall, the findings highlight that without improvements in accessibility, consistency, and support, digital healthcare risks excluding those already experiencing poorer health outcomes. The report provides clear evidence to guide changes that could help reduce, rather than deepen, local health inequalities.

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Appendix 1

Healthwatch Coventry

Overview Housing with care report Winter 2025

Introduction and Background

healthwatch
Coventry

What is housing with Care

Housing with care is a term that reflects Coventry City Council Adult Social Care and Housing Providers delivery of housing for vulnerable people who need additional support. “In a housing with care setting “you Housing with Care offers residents their own home alongside on-site care and support.

Our Enter & View visits aimed to understand:

- How residents experience day-to-day life in their schemes
- What is working well
- Where improvements could be made
- How care, support, activities and communication contribute to resident wellbeing

Themes presented here are high-level and non-identifiable. Full findings will be published after provider responses are received.

Introduction and Background cont

Background

We visited housing with care schemes in Autumn 2024, to speak to people about their experiences of NHS services, their GP, dentists and community care, we were aware that we weren't speaking to residents about their views and opinions of care received within the scheme, we were also aware that we hadn't explored the views of people using Adult social care to find out what they felt and how they benefited or not, from their care. The Steering Group earlier in 2025 agreed that we could carry out an enter and view to housing with care, so we briefed our Authorised Representatives accordingly.

We were interested in how people experienced their care, and how it met their needs. We were also interested to understand more about Adult Social Care and how it works for the people of Coventry who need additional support and care.

> **We wanted to explore the services on offer to help schemes to understand the issues and improve them.**

Methodology (how we carried out the Enter & View)

Visits to multiple Housing with Care schemes across Coventry

Surveys completed with residents, staff and family members

Informal conversations and observations in communal settings

Review of the environment and accessibility features

Findings grouped into **themes**, avoiding scheme-specific detail

In a nutshell

healthwatch
Coventry

We spoke to 109 residents

We spoke to 36 staff and 5 family or friends

We visited 11 housing with care schemes

Age of residents we spoke to was between 49 and 104 years

We focused on the following areas: -

- Personalisation dignity & respect
- Care and support
- Activities, Mental Health and isolation
- Food and nutrition
- Building and environment

Housing with care scheme we visited.

We visited multiple Housing with Care schemes across Coventry, delivered by a range of providers.

Specific scheme names and details are not included at this stage in line with the 20-day provider response period

** Full disclosure in main report**

Personalisation

The range of people with different physical and mental ability, means it is difficult to organise activities, services and communication that meet everybody's needs all of the time.

Residents generally reported:

- Feeling able to maintain independence
- Having their own routines and preferences respected
- Feeling that their flat is "their home"
- Positive relationships with staff and other residents

Some residents expressed a desire for more flexibility in day-to-day arrangements

Good Practice displayed - Personal care plans are in place i.e. people have their plans on boards at an accessible height in their rooms.

** Full disclosure in main report**

> **Freedom to do what you want, go out. I come down for company if and when wanted. I have my own home in the flat."**

healthwatch Coventry

What the residents told us about their experiences of care and support as individuals

> **“The whole idea of Housing with Care is the reason why it is good.**
> **I still get to keep my independence.**
> **Staff get to know us, and it is wonderful being listened to”**

Many residents spoke of the schemes as being “their home” and the staff and some of the other residents are like family. Important in terms of connection and mental wellness. These relationships are positive parts of resident’s lives, but some feel that some of the practices prevent them being independent, for example the locking up of medications, and having to ask staff to get them, when they were self-medicating before.

> **Freedom to do what you want, go out. I come down for company if and when wanted. I have my own home in the flat.”**

- ** Full disclosure in main report **

Personalisation continued

Staff commonly described:

- Commitment to supporting residents’ wellbeing
- Enjoying helping people maintain independence
- Challenges linked to increasing complexity of needs
- Limited time for meaningful conversations due to workload

When asked what they most liked about their role staff members said:

“Being able to help people live a productive happy life where they feel supported and safe.”

All staff were clear about their role to support tenants and make sure they were looked after.

- ** Full disclosure in main report**

Our observation included

- **Warm and respectful interactions between staff and residents**
- **Staff focusing on residents' preferences and interests**
- **Variation between schemes in communal spaces and activity levels**
- **Different approaches to displaying or sharing information**

Observations are reported at a thematic level only

Care and Support

.

Residents generally described:

- Feeling safe
- Receiving help with personal care, medication, or daily tasks when needed
- Appreciation for consistent and supportive staff

Most felt their care needs were met, though a few noted concerns around communication or unfamiliar staff

Some residents expressed:

- Anxiety when supported by staff they did not know
- Hesitation to raise concerns
- Difficulty communicating preferences at times

These themes were not linked to specific schemes

** Full disclosure in main report**

Care and Support cont.

Reflecting the positive impact of living in the housing with care scheme, not all reflections were positive, and people had concerns about staff they did not know or some of their feelings were negative. **Some of these less positive comments are:**

- **"Some carers are ok and some are not. Want to have happy, cheery people. Sometimes it feels like they don't want to be here."**

Some of the issues identified, were not knowing some of their care support workers, especially at night and, finding it difficult to communicate with carers. There is a juxtaposition between what residents want and their concerns/ reticence/reluctance about how they can communicate it with carers to ensure that they have their care needs met in the way they want.

** Full disclosure in main report**

Activities

Isolation, and Mental Health

Over **75 %** said they do take part in activities, although it can depend on their availability or whether the activities were of interest to them.

Residents told us:

- Many take part in activities and enjoy them
- Activities help reduce loneliness and support mental health
- Some would like more choice or more frequent activities

Isolation was a concern for those who struggle to leave their flats.

Insights included:

- Some activities were well-attended and enjoyed
- Residents valued opportunities to socialise
- A small number said the activity programme didn't meet their personal interests

We observed:

- Engaged residents participating in communal activities
- Differences in how frequently activities were offered
- Residents expressing interest in more structured or varied options
- Staff wanting more time or resources to support activities

Communication and Inclusion

Majority of residents said they received enough information, which is positive, however for some communications are not always effective and with small improvements they could make a difference to the information people have access to.

Not all residents receive information or are able to access it easily e.g. if it is on a noticeboard pinned too high to read, if you are on a scooter or wheelchair. Residents also told us more about

- "Sometimes staff tell me what is happening and sometimes they don't" showing communication can for some people be hit and miss.
- "I don't get anything in large print, which would help.

- **Full comments in main report**

Language and translation

A small number of residents with limited English relied on carers or family for communication. This sometimes affected:

Their understanding of what was happening in the scheme

Their ability to raise concerns.

Resident's meetings

Residents who participate in their residents' meetings, have a greater knowledge of what is happening in the scheme and notes/minutes of these meetings are displayed on the wall if anyone wishes to read them.

Health Care and Independence

Residents reported mixed understanding of:

What support staff could provide in relation to healthcare

Processes for first aid, falls, or emergency responses

Some felt these could be explained more clearly

> “One person said, “if I fall, they will come and pick me up.”

** Full disclosure in main report**

Food and Nutrition

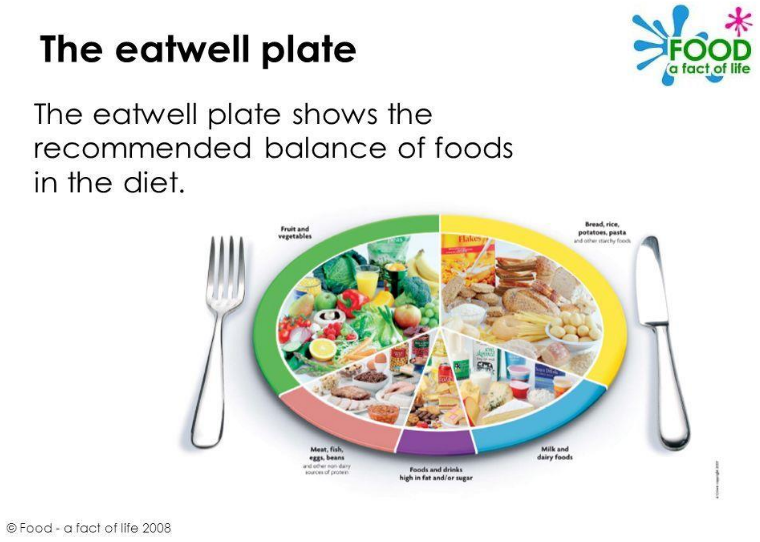
Healthy food and nutrition are essential for mental and physical health -our findings showed a wide variation in people’s exp3434657-eriences of the food provided in the schemes which might impact on their mental health.

https://www.mind.org.uk/information-support/tips-for-everyday-living/food-and-mental-health/

https://www.nutrition.org.uk/nutrition-for/food-and-the-brain/

A high percentage of residents said that they eat or have eaten in the past in the restaurant, but not everyone eats there all the time unless they pay for it as part of their package.

There is a variety of different experiences of the food served and also it has an impact on the benefits or money people have in order to purchase it.



The eatwell plate

The eatwell plate shows the recommended balance of foods in the diet.

© Food - a fact of life 2008

What residents say about their food

- “Cafe is expensive and food not always good.”
- “Only have access to cafe on Tuesday and Friday now - due to chef being off, was meant to be back in September, still not back”.
- “Use microwave in flat to make meals, not allowed to use the oven. Brother helps with meals sometimes”.
- “My relative brings food in for me, and the carers heat it up”.
- Pay all week for meals, too expensive, they changed what I ordered, not telling me.”

- **Full comments in main report**

We observed

We observed at one scheme home cooked lamb curry and rice, they also made homemade biscuits and cakes. The prices looked a bit expensive.

We observed a client asking for support from staff to help cut up their food. We saw staff check on clients to see if they needed any help.

There was a range of different experiences of food, for some schemes they seemed successful, while others were more challenging.

Some residents pay for their food at the canteen through their package.

The residents seemed to be enjoying eating their food.

Some of the canteens' food is not particularly good and is quite expensive, some are not open all the time, which means that people need to have ready meals or other straightforward way to make dishes.

We observed residents having pie, mash, and vegetables. One scheme had fish, chips, and mushy peas.

To observe at lunch time was a good opportunity to watch staff members interacting with the residents and the residents with each other as they ate their food, on two occasions this was fun and light-hearted, remembering past songs and memories. In others it was a quiet time where residents focused on their food, and staff did not interact. Dinner times varied in different schemes and were a mix of quiet time and other schemes had music from a radio or cassette – that sparked conversations.

Security & Safety

For most people and their relatives knowing that they or their loved one had extra care and support was reassuring, knowing that they were safe and had help if they needed it.

One resident said

- "yes, always helpful when I need anything, I am happy, family are happy, I have an alert button on my necklace, to call for help, and they come quicker, in the day than at night, I think there are less staff, but [there is] always help if I need it"

In two of the housing with care schemes, people felt less secure on the ground floor because they had had equipment and people's scooters going missing from the sheds.

For some residents there are policies that don't make sense.

- "There are some policies that seem daft, that is; - can smoke in apartment but cannot have candles and sometimes if they are doing prizes, they have candles."

** Full disclosure in main report **

Building and Environment

Residents' views of the building and environment

As seen above over 75% of residents think the building is good or excellent/

Some of the resident we spoke to commented on how much they valued their environment,

- Excellent, clean tidy, I like the layout, it's like my own old place temperature is fine.

** Full disclosure in main report**

Issues

But there were some issues in terms of the equipment "If there is only one lift and it breaks down people can't access their apartments" if they are relying on scooters or wheelchairs and they live on the first or second floor.

- "Building is "good, but it only has one lift, if the lift goes down, we are totally stuck, happened one day, we were downstairs, they had to go out and get sandwiches – its design fault"

Residents told us of other issues with the buildings and apartments:

- "They are going to modernise the kitchen. We had a residents meeting and chose the kitchen."
- "One person said the scheme was "falling to bits".

** Full disclosure in main report**

Garden

All the housing with care schemes has outdoor areas that residents, their friends, and families can access. These had seating around tables and benches for people to sit on.

- “I go outside if it is warm and sit outside its nice in the garden, fund for people to put money into to make the garden nice, got daffodil bulbs recently.”
- “I will accept any conditions as long as I have got a home. Modest but clean, [I have no] no needs - occasional parking issues nothing that excludes me here.”
- ** Full disclosure in main report**

We observed residents walking up and down the paths, having chats with friends, or having a cigarette in the garden. There are places in the garden for residents to meet each other, although observed in one garden residents told us they were used in the summer when the weather is warmer and better.

Fixtures and fittings

General themes:

Variation in condition or usability of fittings and some accessibility challenges linked to layout or height of fixings. But despite this they had homely, warm, and calm feeling to them. We will look at this in more detail in the individual reports for groups of housing with care.

These themes were observed across multiple sites.

** Full disclosure in main report **

What staff and management said about Housing with care

Staff reflected on:

Being part of supportive teams, wanting more time for meaningful interaction:

- "Being part of a supportive environment, which contributes to individual's wellbeing.
- "Having more time to communicate with the tenants to give them time to talk."
- "At times need additional resources, It is a very fast-moving environment."
- ** Full disclosure in main report**

We Observed

Staff talking together and working well as a team, staff busy at their computers looking at records, staff being very busy, but gave time to talk to us and to residents

Future

What staff said

Managers highlighted that there is an increasing number of younger (i.e. in their 50s and 60s men in housing with care, what does this mean for future provision of housing with care services, including activities.

Alongside more younger men, there was concern about people with complex mental health issues, including.

“Managers don’t listen, more mental health tenants and not trained to deal with it.”

We spoke to ten people who said that their mental health was the reason that they were in housing with care.

Conclusion

We heard many positive experiences in housing with care, and many people feeling that their needs are met by the services provided, majority see the services and support as good or excellent, this shows the encouraging views of people using the service.

There is also a sense of pride in their scheme – people feel ownership and familial relationships with the staff and other residents and value the care they receive.

Activities are a positive part of people who want to engage with them, but sometimes there are not enough activities, and due to the changing resident demographics, these may not meet the needs of the people of all who are living in the scheme.

Provide a safe and homely environment where residents feel they are at home but have the safety and security if they need help or support.

Housing with care is able to change to meet people's needs as they get older or their physical needs change – so they are able to transition as part of their care.

Next Steps & Follow up

We will review progress at three and six months and consider further Enter & View or escalation to commissioners/CQC if significant concerns remain.

We will publish provider responses and a “You Said – We Did” update for residents in accessible formats.

We will send this report and recommendations to scheme owners/providers, requesting a written response within 20 working days.

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Facebook.com/HealthwatchCoventry

heaalthwatch coventry

NHS App Report 2025

healthwatch
Coventry

Purpose of the survey

The NHS App has been around for a while and is being more widely used across NHS care services. The app can be used by anyone registered with a GP aged 13 or over. It is promoted as an easy way to manage your healthcare. But while millions of people across the country use it, it might not work for everyone.

We wanted to find out how the app is working for the people of Coventry. We want to understand:

- If, and how they are using the NHS App
- Is it easy to use
- Does it help them manage their healthcare
- What improvements or changes would they like to see
- Or have they tried using it, but found it doesn't work for them?

How we collected the data

We created a digital form which was promoted on our website as well as across our social media platforms.

The survey was live from October to December 2025

We collected 246 responses

We took the survey along to outreach events:

- Community centres
- Foodbanks
- QR Code poster in community settings and GP Practices

Where we collected the data

Some of the data we collected was via online surveys, below we have listed the locations we visited to collect the data; we have broken them down by ward to target multiple areas around Coventry.

Place	**Area**
Holbrooks Social Supermarket	Holbrooks
Henley Food Hub	Henley
Canley Food Bank	Canley
John White Community Centre	Binley/Willenhall
Haggard Food Bank	Binley/Willenhall
Allesley Food Bank	Whoberley
Coventry's Girls & Boys Club	City Centre
St Francis Employability	Radford
Holbrooks Evangelica Church Food Bank	Holbrooks
Christ King Church Food Bank	Bablake

Place	**Area**
Walsgrave Baptist Church Food bank	Walsgrave/Henley
Coventry City Mission Food Bank	Woodend
Cheylesmore Food Bank	Cheylesmore
St Laurence Church Food Bank	Longford
Foleshill Baptist Church Food Bank	Foleshill
Christian Life Ministries Food Bank	St Michaels
Redeemed Church of God Food Bank	St Michaels
St Catherines Church of England Food Bank	Lower Stoke
St John Divine Church Food Bank	Binley/Willenhall
Queens Road Baptist Church Food Bank	St Michaels

What we found

90% of people we spoke to were already aware of the NHS App but only,

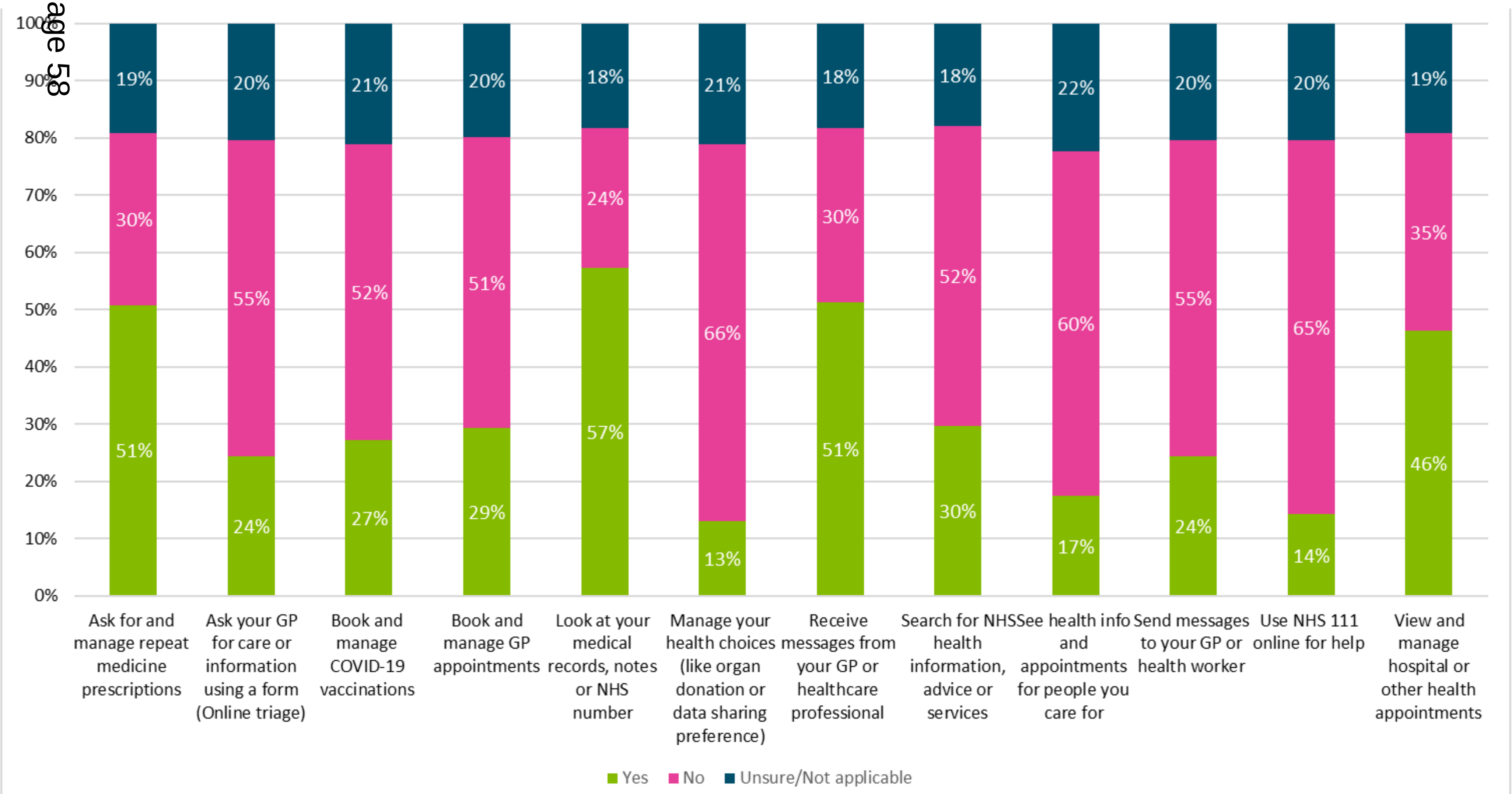
79% of people had used the NHS App

62% of people said they were 'somewhat satisfied to 'very satisfied' with the NHS App

People were more likely to complete the survey face to face. 80% of our surveys were completed face to face and 20% of our surveys were completed via online links.

At times, we assisted people with downloading and registering the NHS App as some found it difficult to navigate.

Services available on the NHS App



Did you know?

The services available on the App varied for everyone according to which GP practice you are registered with.

GP Practices

The tables shows how many surveys were completed by patients from each GP practice

GP PRACTICE	COUNT	GP PRACTICE	COUNT	GP PRACTICE	COUNT
Allesley Park Medical Centre	14	Henley Green Medical Centre	4	Quinton Park Medical Centre	3
Allesley Village Surgery	1	Hillfields - Dr Bano	0	Sky Blue Medical Group	7
Alliance Teaching Practice	7	Hillfields - Dr Sani	3	Springfield Medical Practice	7
Anchor Centre	3	Holbrooks Health Team	4	St Georges Road Surgery	0
Bredon Avenue Surgery	2	Jubilee Health Centre	6	Stoke Aldermoor Medical Centre	2
Broomfield Park Medical Centre	8	Jubilee Healthcare	4	The Gables Medicentre	4
Central Medical Centre	1	Kensington Road Surgery	4	Torcross Medical Centre	0
Cheylesmore Surgery	2	Kenyon Medical Centre	12	Walsgrave Health Centre	1
Clay Lane Medical Centre	8	Limbrick Wood Surgery	3	Westwood Medical Centre	0
Copsewood Medical Centre	1	Longford Primary Care Centre	4	Willenhall Oak Medical Centre	3
Edgwick Medical Centre	0	Mansfield Medical Centre	6	Willenhall Primary Care Centre 1	3
Engleton House Surgery	5	Meridian Practice	2	Windmill Surgery	1
Forrest Medical Centre	21	Moseley Avenue Surgery	2	Woodend Health Centre	9
Forum Health Centre	17	Paradise Medical Centre	14	Woodside Medical Centre	4
George Eliot Medical Centre	3	Park Leys Medical Centre	4	Woodway Medical Centre	6
Godiva Group - Stoney Stanton Site	5	Parkhouse Surgery	1	Out of Area	16
Govind Health Centre	0	Phoenix Family Care	2		
Harnall Lane Medical Centre	2	Priory Gate Practice	5		

What we heard

Really like it, easy to use and saves a lot of time

Easy for prescription ordering

Really useful and once you understand it's relatively easy to use

Would be better if it had pictures and/or a voice over for those who struggle with reading.

Cannot download the app as they don't have picture ID

Can't book blood test on App

Couldn't add parent onto NHS app as didn't have photo ID - won't accept bus pass

GP never answers messages through the App

Can't see referrals

What we heard

I would like to book GP appointments, but my surgery doesn't offer this facility

Useful information on drugs and medications

Really like it, easy to use and saves a lot of time

Use language that is understandable

GP never responds to messages sent through the App

It needs to be updated to meet the needs of all. You should be able to book appointments on it rather than everyone ring at 8am.

Yes, that you should be able to order ladies pill for periods without phoning up

It's not always clear where to find what you need - especially medical records

Only been using it for 4 months. Only thing that concerns me is the safety of it and making sure that no one else would be able to view

Support with NHS App

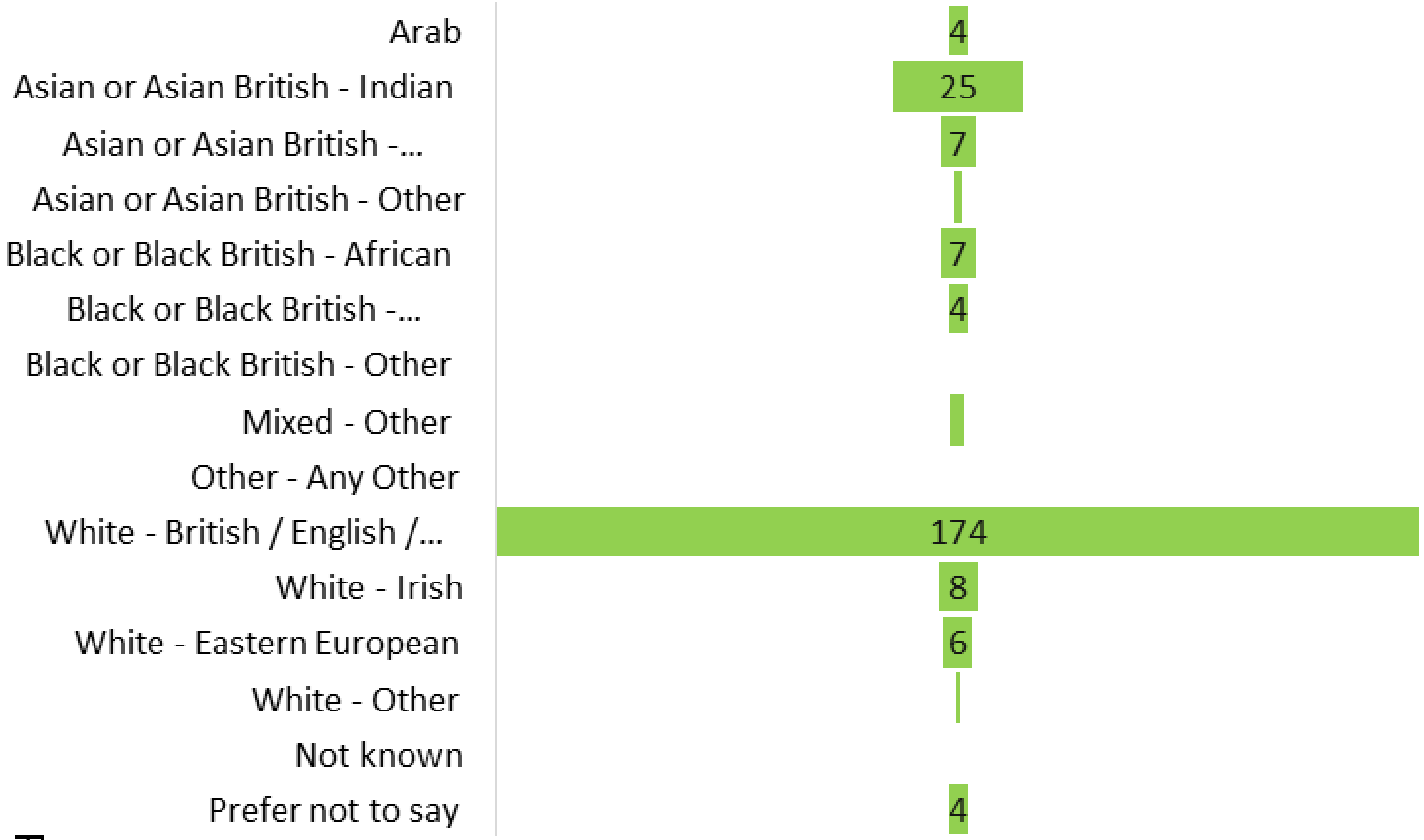
We wanted to know how confident people felt using the app and if there were any additional support they required, as the NHS App is becoming the gateway to accessing healthcare services.

96% of people said they have regular access to a smartphone, tablet, or computer that they can use the NHS App to complete registration or view medical information

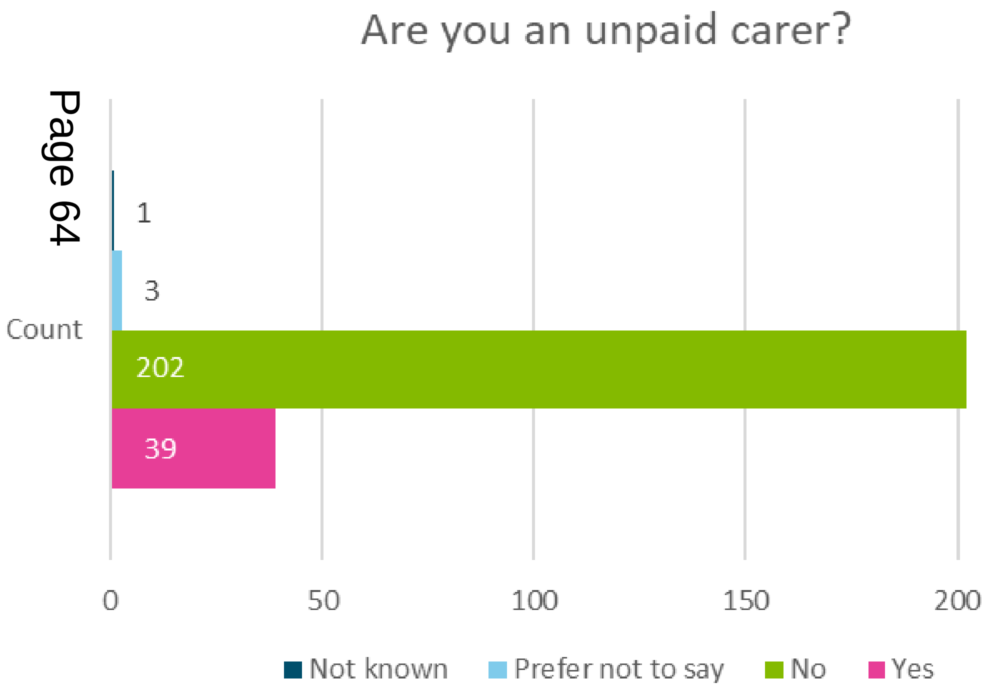
90% of people said they felt 'very confident or 'somewhat confident' using a mobile app or website to book appointments, fill in health questionnaires, or view their records

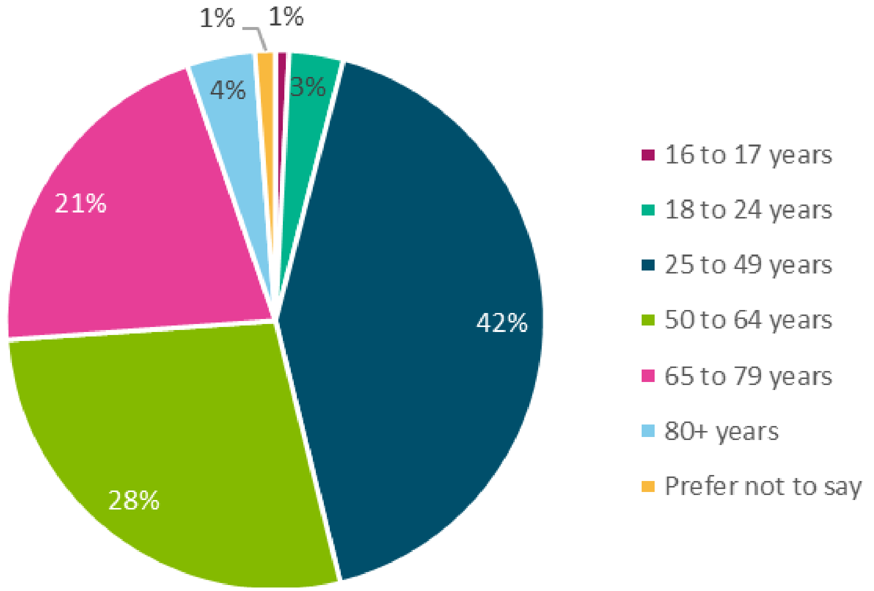
16% of people said they would need support or training to use the app or complete health forms online

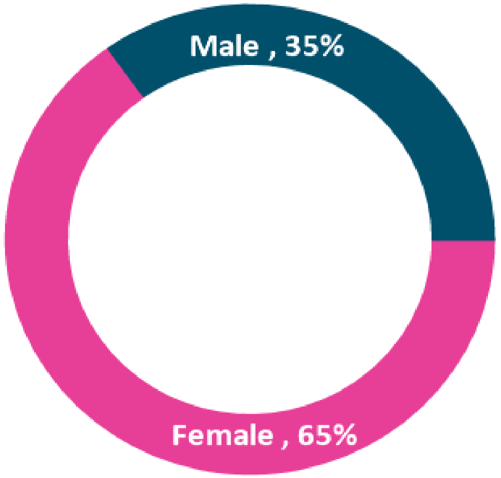
Demographic data

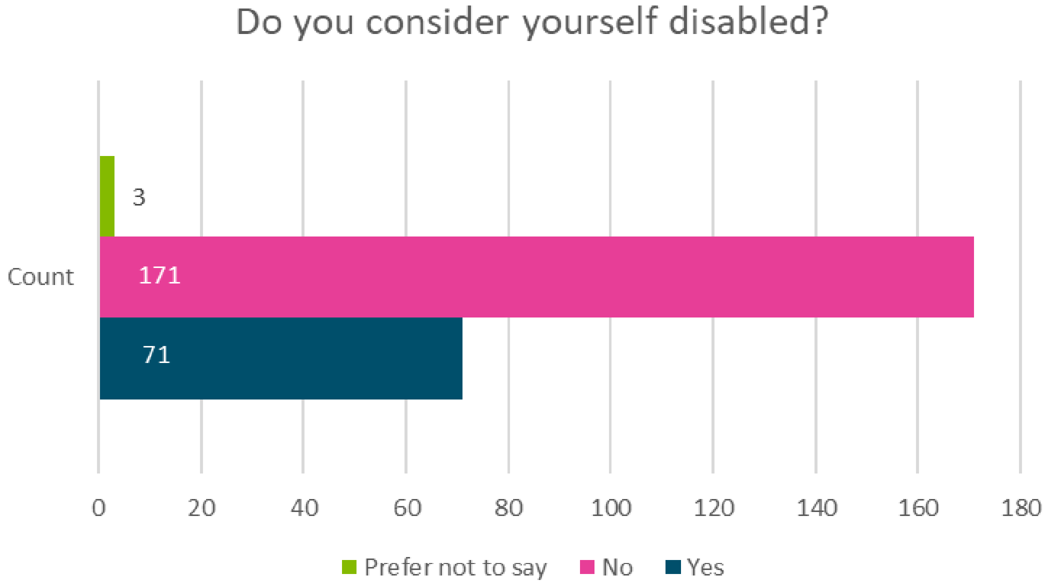


Ward	NHS App
Bablake	6
Binley and Willenhall	17
Cheylesmore	10
Earlsdon	11
Foleshill	17
Henley	28
Holbrook	17
Longford	7
Lower Stoke	11
Radford	4
Sherbourne	6
St Michaels	14
Upper Stoke	15
Wainbody	4
Westwood	22
Whoberley	22
Woodlands	11
Wyken	11
Not known	0
Out of area	12


Are you an unpaid carer?
Count
1
3
202
39
0
50
100
150
200
Not known
Prefer not to say
No
Yes


1%
1%
3%
4%
21%
42%
28%
16 to 17 years
18 to 24 years
25 to 49 years
50 to 64 years
65 to 79 years
80+ years
Prefer not to say


Male , 35%
Female , 65%


Do you consider yourself disabled?
Count
3
171
71
0
20
40
60
80
100
120
140
160
180
Prefer not to say
No
Yes

What the people would like to see

It would be good that my prescription details are more accurate. They often so out of date!

would be good if the app tracked your heart health and steps

Can't add children as they are registered with a different GP practice

Appointments, follow-up and medication directly from UHCW do not appear on the NHS app. It would be very helpful if everything was all in one place.

Passwords expire and changing password makes it difficult to access

Would like a link to access a blood form on the app to save visiting the gp to get them to print off a blood form

Can't view hospital results when not in Coventry hospital

Booking online doctor appointments as I am deaf

Would like someone to show how to use it

What the people would like to see

Would like children on the app but staff at GP will not help to do this

Manage appointments for family. Get test results.

I’m carer for adult LD son 31 I want to see if I can add him on to my app

Would like to book GP appointments through the app

A more joined up approach as I can’t access all my medical records as they are with different trusts.

Can't view maternity appointments or records , have to use another app called badger notes, bit off a pain using two apps

Connect Dentist and Opticians records

The App using Ai to develop a one-page passport of all the things important to me and helpful to medical practitioners.

Would like to be able to view blood type on the app

Recommendations

We recommend these features to be considered being added to the NHS App based on how many times it was requested:

- **Display blood type -** Enable users to view their recorded blood type directly for quick reference in emergencies or personal knowledge
- **Easier family/dependent linking -** Standardise proxy access without inconsistent photo ID demands across all GP practises.
- **Standardise features utilised –** Empower patients to be able to book GP appointments via the app
- **Medical Appointment linking improvements -** To be able to see hospital appointment details on the app as well as GP records
- **Clearer pathway and instructions**-Same process for everyone to register for the NHS App regardless of which GP practice you are registered with

Our thanks

To everyone who took the time to complete our survey with us, without your support, this report would not have been possible.

Thanks to the managers at the foodbanks and community centres, who helped and supported us, to be able to speak to their service users.

A big thank you to the Healthwatch Coventry staff and volunteers who are crucial to make the work happen.

For more information

healthwatch
Coventry

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Coventry City Council

Briefing note

To: Health and Social Care Scrutiny Board

Date: 25th February 2026

Subject: Palliative and End of Life Care

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1 Purpose of the Note

2 To provide members of the Health and Social Care Scrutiny Board with the current Coventry and Warwickshire Integrated care System Palliative and End of Life Strategy and the work which enabled to co-production of this strategy.

2.1 A presentation will then be provided in the meeting on the 25th February providing an overview of:

- National context of Palliative and End of Life Care
- Coventry & Warwickshire Integrated Care System Palliative and End of Life Care Strategy: Delivery Plan – progress and next steps
- Operational delivery of palliative and end of life care in Coventry

3 Recommendations

3.1 Health and Social Care Scrutiny Board are recommended to:

a) Note the contents in the Briefing Note, Coventry & Warwickshire Palliative and End of Life Care Strategy (Appendix 1), Equality and Quality Impact Assessment Tool (Appendix 2) and the ‘You Said, We Did’ Report (Appendix 3)

b) Be assured of the sustainable delivery of palliative and end of life care within Coventry.

c) Identify any further relevant recommendations for health partners or relevant Cabinet Members.

4 Introduction

4.1 End of life care is treatment, care and support to those who are thought to be in their last 12 months of life. It can last for days to weeks to months and aims to improve the quality of life for those dying, maintaining dignity whilst managing symptoms and offering emotional social and spiritual support to the patient and their family or carers.

4.2 Palliative care is a specialised approach which focuses on improving quality of life for patient and families facing life-limiting illness such as providing pain relief. People receiving palliative care are not necessarily in end-of-life care.

4.3 Individuals should have choices on where they are provided end of life care and on the place of death. This might be at home, in a care home, a hospice or a hospital.

4.4 In medieval times, the word *hospice* was used for a way station for travellers needing assistance, this included the famous Hospice of Great Saint Bernard in the Alps. Over time the word hospice came to refer to services that care for people receiving end of life care.

4.5 The first hospice in England was opened by nuns in 1905 in East London, but it was in the 1960s and 70s that the hospice movement really started under Dame Cicely Saunders who founded St Christopher's Hospice, again in London. This led to an uneven distribution of hospices across the country, but over time the need for hospices has been better understood and there is not a requirement for the NHS to commission palliative and end of life care for their population. There are currently 135 independent adult hospice charities in England.

5 Health inequalities

5.1 End of life care should be available to all including all ages and communities, but we know that the take-up of end-of-life care and hospice care shows inequalities which might be due to acceptability or accessibility barriers. White middle-class, middle aged patients with cancer have traditionally been over-represented in hospice populations and patients with conditions other than cancer, the very old and ethnic minorities are under-represented in hospice populations.

5.2 Barriers to hospice care include uncertainty over the prognosis for some patients, institutional cultures, the particular needs of some groups and awareness of hospices in some communities (*Tobin et al. BMJ Supportive & Palliative Care 2022;**12:**142-151).*

6 National Data

6.1 The majority of people (88%) who died in England in 2024 died from one of four major conditions. These are cancer, cardiovascular disease, respiratory disease and dementia. Most of these people would have spent time in hospital before they died and nearly half of inpatient care provided by hospitals for people aged 85 years or older is for people in their last year of life. 60% of people that died in 2024 had at least one emergency admission in their last 3 months of life and nearly 7% of these had 3 or more emergency admissions in their last 3 months of life.

6.2 National data show that people who die from cancer are more likely to die at home or in a hospice whereas people who died of dementia were more likely to die in a care home. People who die from respiratory disease were more likely to die in hospital.

6.3 Most people die in hospital and relatively few people die in a hospice (5.5%). Of those that die in a hospice 79% died from cancer in 2024. Hospices in England provide care for 270,000 people each year, either in hospice units or people's homes (Hospice UK) with the proportion of people dying in hospital decreasing and the proportion dying at home increasing.

7 The funding of hospices in England

7.1 Hospice care, like NHS care, is free at the point of delivery, but unlike NHS care it is not fully funded by the State. Hospice UK estimates that it costs £1.6bn each year to run hospices in the UK. Approximately one third of the funding for hospices is received from Government with the rest of the costs covered by charitable income such as sponsored events, legacy gifts etc.

7.2 In England, each ICB has a requirement to commission palliative care services for their population, and some hospices receive money for services that have been contracted by an ICB. Some hospices also contract with local authorities for e.g. domiciliary care.

7.3 ICBs commission palliative and end of life care from a range of NHS and non-NHS providers including NHS Trusts, independent hospices, the voluntary sector, community organisations, primary care networks and local authorities.

7.4 Rising costs are an issue for hospices as they do not receive any additional monies to cover increases in salary costs for healthcare professionals when Government settles NHS pay scales every year. 16,000 healthcare professionals were employed by hospices in the UK in 2022/23 and in July 2024 this was estimated to be approx. £66m additional costs to the hospice sector.

7.5 Hospice UK estimated in September 2024 that hospices were likely to show a deficit of c.£60m in that financial year. In 2023/4 nearly two-thirds of independent adult hospices recorded a deficit, the highest proportion over the preceding ten years. Although the hospice sectors total income increased up to 2021-22, there has been a recent decline in funding in real terms, in large part due to inflation. In 2024/5 11 adult hospices in England reported service reductions or staff redundancies

7.6 In 2024, the All-Party Parliamentary Group on Hospice and End of Life care found that the reliance on charitable fundraising ‘carries huge risk’ due to the volatility in the economy and the risks associated with reliance on fundraising. This could lead to widening inequalities as hospices in deprived areas might see a greater reduction in donations (House of Lords; Hospices: State Funding; 21 October 2024).

7.7 During the Covid-19 pandemic NHS England provided the hospice sector with £384m to secure additional capacity and additional funding was given to the sector when retail activity ceased and fund-raising events had to be cancelled during lockdown.

7.8 In December 2024 the Government announced that £100m additional capital funding would be invested in adult and children’s hospices and £26m additional revenue funding invested in children and young people’s hospices.

8 Forward Look

8.1 As the population ages in the UK, more people are living with complex long-term conditions such as dementia. At the same time, more children are surviving with life-limiting conditions due to medical advances. This is contributing to more people dying in the UK (for decades there was a stable death rate) and the annual number of deaths is estimated to reach 780,000 in 2040.

8.2 The 10-year Health Plan for England includes a shift from hospital to community, and this will include the end-of-life care sector. There is an intention to include non-NHS workers in the new Neighbourhood Health Service, and this could include hospice outreach workers. This could strengthen the offer to patients in palliative care.

9 Coventry and Warwickshire Palliative and End Of Life Care Strategy

9.1 The Coventry and Warwickshire Palliative and End Of Life Care Strategy is 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.

9.2 This Strategy covers 2024-29 and focuses on the following 5 priorities

1. Provide information which focuses on identification, early intervention and support for people with palliative and end of life care needs.
2. Access to timely palliative and end of life care with support throughout, for all of our diverse communities.
3. Support people diagnosed with a life limiting condition and those who matter to them, carers and communities.
4. Improve the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.
5. Deliver a sustainable system of integrated palliative and end of life care.

9.3 The full strategy, EQIA (Appendix 2) and a "You Said, We Did" document (Appendix 3) is included in the pack.

10 Taking a Neighbourhood Health approach

10.1 In Coventry Health and social care partners are working together with the voluntary sector and communities in six Integrated Neighbourhood Teams (INTs) to fundamentally change the way we support people in Coventry with their needs so that they "are able to access support close to home that enables me to live a happy healthy life that I am in control of."

10.2 An INT is a multi-professional team that brings together staff from local councils and the NHS, including community services, primary care, mental health services, and the voluntary sector, to provide coordinated health and care for a specific local area. These teams aim to simplify care pathways for residents by connecting services, strengthening collaborative working, and providing both proactive support and ongoing care for people with complex or long-term conditions.

10.3 The majority of Palliative and End of Life care happens in people’s homes and places of residence and will be an integral part of the integrated neighbourhood approach.

11 Health Inequalities Impact

11.1 Please see attached EQIA

12 Appendices attached

- Coventry and Warwickshire Palliative and End Of Life Care Strategy (Appendix 1)
- EQIA – Palliative and End of Life Care Strategy (Appendix 2)
- “You said, we did” – Palliative and End of Life Care Strategy (Appendix 3)

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Appendix 1

Coventry and Warwickshire
Integrated Care System

Coventry and Warwickshire

Palliative and End of Life Care Strategy

2024-2029

Contents

Coventry and Warwickshire
Integrated Care System

Welcome to the Coventry and Warwickshire Palliative and End of Life Care Strategy 2024-2029

This Strategy is 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.

We have asked people with palliative and end of life care needs, their carers, those who live in Coventry and Warwickshire, as well as our partners in health and social care, what we should focus on to improve the care and support we provide to people.

We have discussed all areas of palliative and end of life care, from activities aimed at improving the understanding of the importance of planning for the end of life across our communities, through provision of care and to bereavement care.

The detailed Palliative and End of Life Care Strategy: Delivery Plan, will hold us accountable for the improvements we will make over the next five years and can be found at Appendix 1

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Coventry City Council

M. Fogarty.

Monica Fogarty, Chief Executive,
Warwickshire County Council

Philip Johns, Chief Executive
Officer, Coventry and
Warwickshire ICB

Coventry and Warwickshire
Integrated Care System

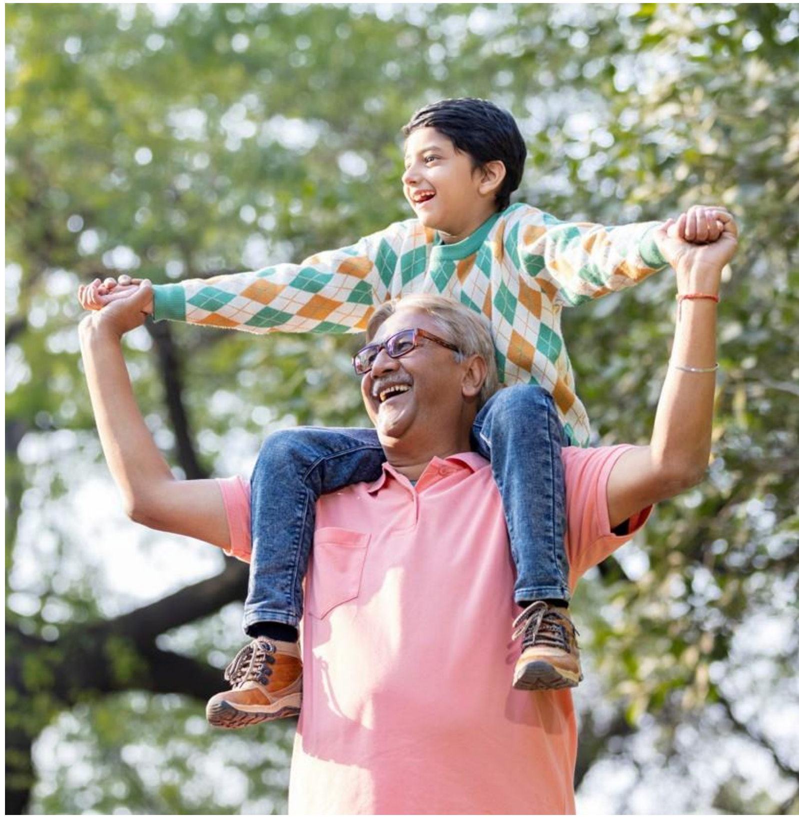
What is Palliative and End of Life Care?

- Palliative care is about improving the quality of life of anyone facing a life-limiting condition. It includes physical, emotional, social and spiritual care as well as practical support.

- Palliative and End of Life Care involves communities supported by health and social care professionals and organisations working together, to provide physical, emotional and spiritual support for the individual and those who matter to them.

- 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.

- We want our people of Coventry and Warwickshire to live as well as possible for as long as possible.



Coventry and Warwickshire
Integrated Care System

The National Framework: Ambitions for Palliative and End of Life Care

To support people to plan and consider wishes and preferences for their end-of-life care and treatment, we have a national framework to support the delivery of care: Ambitions for Palliative and End of Life Care.

The Ambitions Framework sets out 6 key areas of focus:

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

Coventry and Warwickshire
Integrated Care System

National Picture:
Palliative and End of Life Care in the UK

More than half a million people are expected to die each year, and many live with a life expectancy of less than a year at any one time.

This is set to increase with a growing older population, so more people are expected to die at an older age.

Children's palliative care is a complex and changing picture which includes rare diseases, and can see children and young people live longer with more complex needs.

Our Local Picture:
Coventry and Warwickshire

Just over 1 million people live in Coventry and Warwickshire.

The Coventry and Warwickshire Integrated Care System enables people across Coventry and Warwickshire to start well, live well and age well, promote independence and put people at the heart of everything we do.

We do this through a range of collaborative working arrangements:

- **7** Councils
- **4** Places
- Thriving Voluntary and Community Sector
- **200** Pharmacies
- **6** Collaboratives
- Education and Training providers
- **4** Partners NHS Trusts
- **6** Hospices
- **2** Healthwatch Organisations
- **1** Integrated Care Partnership
- **19** Primary Care Networks
- **1.07m** GP Registered Population
- **120** GP Practices
- **1** Ambulance Service
- **25,900** NHS Staff
- **1** Integrated Care Board

Our Local Picture:
Palliative and End of Life Care

At any one time 1% of our population: 10,000 people, will be thought to be in the last 12 months of life.

- Across Coventry and Warwickshire, we have a range of health, social and third sector providers working with communities to support people over the age of 18 years who are thought to be in the last 12 months of life.
- For babies, children and young people with life limiting conditions, support is provided through the course of their short lives, by a number of providers working together.

Our Trusts

- ● Coventry and Warwickshire Partnership NHS Trust
- ● George Eliot Hospital NHS Trust
- ● South Warwickshire NHS Foundation Trust
- ● University Hospitals Coventry and Warwickshire NHS Trust

Our main locations

- ✚ University Hospitals, Coventry
- ✚ George Eliot Hospital, Nuneaton
- ✚ Warwick Hospital
- ① Brooklands, Solihull
- ② Caludon Centre, Coventry
- ③ Ellen Badger Hospital, Shipston-on-Stour
- ④ Hospital of St Cross, Rugby
- ⑤ Leamington Spa Hospital
- ⑥ Manor Court, Nuneaton
- ⑦ St Michael's Hospital, Warwick
- ⑧ Stratford Hospital
- ⑨ Woodloes House, Warwick
- ⑩ The Shakespeare Hospice
- ⑪ Myton Hospice Warwick
- ⑫ Myton Hospice Coventry
- ⑬ Myton Hospice Rugby
- ⑭ Shipston Home Nursing
- ⑮ Mary Ann Evans Hospice
- ⑯ Zoe's Place

Coventry and Warwickshire
Integrated Care System

Our Local Picture: Our Communities

Within Coventry and Warwickshire, we have a rich diversity in our communities.

We aim to provide care at the end of life to meet the needs of our diverse communities.

Coventry

is ethnically diverse with

34%

of the population from minority ethnic groups

120

languages spoken in Coventry and Warwickshire

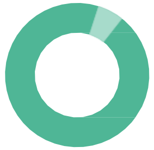
Most common languages spoken (after English)

Coventry
- Bengali
- Polish
- Urdu
- Tamil
- Punjabi

Warwickshire
- Polish
- Punjabi
- Gujurati
- Nepalese
- Urdu

English is a second language for **14%** of Coventry residents

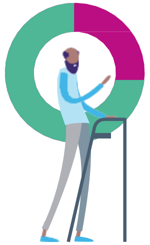
Active LGBT+ communities
Warwickshire PRIDE
Coventry PRIDE



89.6%

of the population in Warwickshire are not from minority ethnic groups

The main religions in Coventry and Warwickshire after **Christianity** are **Islam, Sikhism** and **Hinduism**



Warwickshire

has an older population with

21%

of the population over 65 – higher than both the West Midlands and National averages

Coventry

has a much younger age profile than England in general – two universities contribute to the average age being **32.1 years**,

14.6% between 18-24

Coventry and Warwickshire
Integrated Care System

How the strategy was developed: Engagement

We **co-produced** this strategy speaking to the people of Coventry & Warwickshire:

- Those diagnosed with a life limiting condition
- Their carers and loved ones
- People who had been bereaved

We held a full engagement on the draft strategy between **June-July 2023** and produced a 'You Said We Did Report' main themes identified:

- Language & Layout
- Workforce Mapping
- Access to services

We **engaged** with stakeholders from across Coventry & Warwickshire, including NHS providers, councils, community leaders & third sector providers

We held a series of **meetings, group discussions and surveys** where we discussed:

- What matters most
- Challenges and Opportunities
- Priorities

Coventry and Warwickshire
Integrated Care System

Engagement

We reached out to:

Over

1,600

people

including patients, the public, health, social and third sector professionals.

Over

300

organisations

across Coventry and Warwickshire.

We directly spoke with:

Over

30

different community

groups and health and social care organisations via face to face or small group meetings.

A series of public and stakeholder surveys have been completed with a total of

239

responses

from across the system

Coventry and Warwickshire
Integrated Care System

Our Priorities:
What we want to do

1. Provide **information** which focuses on identification, early intervention and support for people with palliative and end of life care needs.
2. **Access** to timely palliative and end of life care with support throughout, for all of our diverse communities.
3. **Support** people diagnosed with a life limiting condition and those who matter to them, carers and communities.
4. **Improve** the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.
5. Deliver a **sustainable** system of integrated palliative and end of life care.

Coventry and Warwickshire
Integrated Care System

The people we will focus on in the first 2 years of the palliative and end of life care strategy.

In the first 2 years of the strategy, we will focus our actions on the following groups:

- People over the age of 18 years, thought to be in the last 12 months of life.
- Babies, children and young people diagnosed with a life-shortening condition or those for whom curative treatment for a life-threatening condition is not an option.

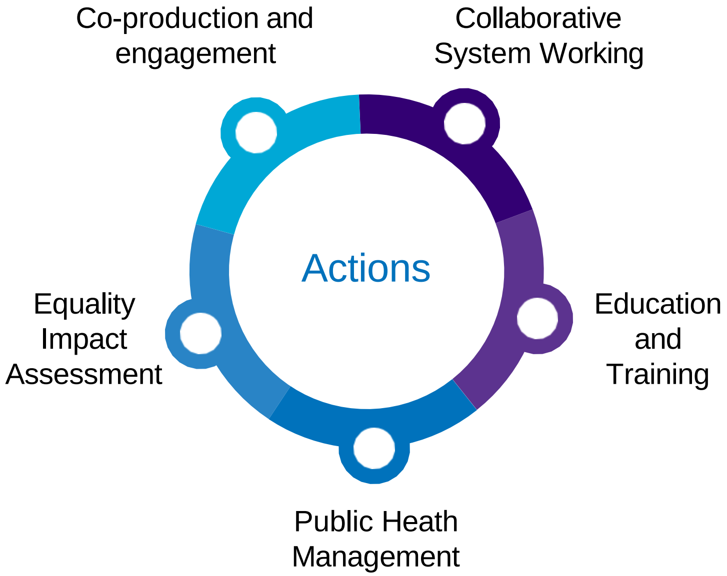
Health Inequalities in Coventry and Warwickshire

Actions we will take to promote Health Equity in Palliative and End of Life Care

We value the importance of fair access to care for our differing Communities.

We are determined to take actions to reduce health inequalities being experienced by our most vulnerable people.

We have identified the challenges we want to tackle and the actions we will take in all of our work across all ages to enable this to happen.



Coventry and Warwickshire
Integrated Care System

Health inequalities are unfair differences in health between our community groups.

In Coventry and Warwickshire these differences result in some of our communities having poorer access to information, appropriate services and planning for end-of-life care.

Our aim is to provide fair access for all our diverse communities.

We have identified greater differences in access to palliative and care at the end of life for:

- Asylum Seeker and Migrant communities
- Looked After Children
- People diagnosed with Dementia
- Ethnic Minority communities
- Gypsy, Roma and Traveller communities
- Homeless communities
- Learning Disability communities
- LGBTQIA+ communities
- People diagnosed with severe Mental Health challenges
- Prison communities

Protected characteristics

Socio-economic deprived population

Inclusion health and vulnerable groups

Geography

What does good Palliative and End of Life Care look like?

In Coventry and Warwickshire, our vision is to provide Palliative and End of Life Care for all of our diverse communities, which enables patients and their loved ones to live as well as possible, supported by their own communities.

We want to enable fair access to professional palliative and end of life care and support, when this becomes necessary, in the setting of choice for the individual and those important to them, in a planned and pro-actively supported way.

How we will provide good Palliative and End of Life Care

The Ambitions Framework enables the delivery of the NHS Long Term Plan, which contains a specific commitment to provide more personalised palliative and end of life care.

A systemwide approach with co-ordinated care across organisations and communities, is an essential element of enabling personalised, pro-actively planned care for individuals and those important to them, in the final months and weeks of life.

Personalised care in the last year(s) and months of life will result in a tailored plan around what really matters to the person, to improve experience and quality of sustainable health and care services.

Teams of professionals and community members working together to provide co-ordinated care to those thought to be in the last 12 months of life. This will be achieved through shared-decision making conversations which lead to personalised care and support planning.

How we will deliver improvement

Through the Strategy and Delivery Plan, we are aiming to provide palliative and end of life care in the following ways:

- Care seamlessly co-ordinated across settings with clear communication and referral pathways.
- Pro-active personalised care and support planning for care at the end of life.
- Collaborative approach across health and social care for those with palliative and end of life care needs.
- Clear communication with the individual and those important to them.

PEoLC Delivery Plan - Overview

Key priorities	Areas of focus

1. Provide information which focuses on identification, early intervention and support for people with palliative and end of life care needs.	• Ensure up to date information for PEoLC services, referral pathways and support options are available to patients, professionals and the public.
	• Pathway Reviews:
	  • Continuing HealthCare Fast Track
	  • Early Identification
	  • Transition from children and young people's services to adult services
	• Identify work streams across the system which dovetail into PEoLC
	• Improve availability of data regarding palliative and end of life care

See Appendix 1 for Delivery Plan in full

How we will deliver improvement: PEoLC Delivery Plan - Overview

Key priorities	Areas of focus

2. Access to timely palliative and end of life care with support throughout, for all of our diverse communities.	• Identification of underserved communities
	• Pathway Reviews:
	  • 24/7 access to care
	  • Psychological Therapy
	  • Bereavement
	  • Personal Health Budgets
	• Access to medication workstream
	• Review of support for emotional and spiritual as well as practical living needs.

3. Support people diagnosed with a life limiting condition and those who matter to them, carers and communities.	• Personalised Care & Support Planning to include
	  • Advance Care Planning Review:
	  • Documentation
	  • Systemwide communication
	• Pathway Reviews:
	  • Unpaid Carer Support
	  • Children & Young People: Sibling and Friend Support
	• Poverty Proofing Workstream

See Appendix 1 for Delivery Plan in full

How we will deliver improvement: PEoLC Delivery Plan - Overview

Key priorities	Areas of focus
4. Improve the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.	• Development of an Education & Training Framework for Palliative and End of Life Care • Dying Matters: a systemwide approach to awareness raising
5. Deliver a sustainable system	• A comprehensive systemwide review of workforce, pathways, roles and responsibilities. • Integrated Commissioning Model: contracts and funding review.

See Appendix 1 for Delivery Plan in full

Glossary

- Advance Care Plan (ACP) - A record of your preferences about your future care and support, including decisions about medical treatment and end of life care. It is sometimes known as an Advance Statement.
- Babies, Children and Young Peoples (BCYP) services
- Inclusion health and vulnerable groups - For example Gypsy, Roma, Travellers and Boater communities, people experiencing homelessness, offenders/ former offenders and sex workers.
- Integrated Commissioning Model - Integrated commissioning is when two or more agencies come together to commission services which are delivered across the system for service users with Health, Social Care and/or Educational needs.
- Geography - For example, population composition, built and natural environment, levels of social connectedness, and features of specific geographies such as urban, rural and coastal.
- Palliative and End of Life Care (PEoLC)
- Protected characteristics - Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation.
- Rapid Response (RR)
- Socio-economic deprived population - Includes impact of wider determinants, for example: education, low-income, occupation, unemployment and housing.
- Urgent Care Response (UCR)

Some of our Partnerships

Warwickshire County Council

Coventry City Council

North Warwickshire Borough Council

Nuneaton & Bedworth
United to Achieve

Borough Rugby Council

Stratford-on-Avon District Council

Warwick District Council

NHS
Coventry and Warwickshire

NHS
Coventry and Warwickshire Partnership
NHS Trust

NHS
George Eliot Hospital
NHS Trust

NHS
University Hospitals Coventry and Warwickshire
NHS Trust

NHS
South Warwickshire University
NHS Foundation Trust

NHS
West Midlands Ambulance Service
University NHS Foundation Trust

Shipston Home Nursing
Hospice Care at Home

The Shakespeare Hospice

Carers Trust
Heart of England

Zoë's Place
Baby Hospice

acorns
Your local children's hospice

Marie Curie
Care and support through terminal illness

Mary Ann
Your Local Hospice

myton hospice

Coventry and Warwickshire
Integrated Care System

Appendix 1

– Coventry and Warwickshire Palliative and End of Life Care Strategy Delivery Plan

Coventry and Warwickshire
Integrated Care System

Palliative and End of Life Care Strategy

2024-2029

Delivery Plan:
January 2024 - December 2026

Coventry and Warwickshire
Integrated Care System

Overview

Coventry and Warwickshire Palliative and End of Life Care (PEoLC) Strategy Delivery Plan

This Delivery plan is intended to support the delivery of the Palliative and End of life Care Strategy for Coventry and Warwickshire.

Identified Priorities for PEoLC

5 priorities have been identified for our Palliative and End of life care strategy:

- Information
- Access
- Support
- Improving
- Sustainability

Coventry and Warwickshire Partnership Board

In January 2023 the PEoLC Partnership Board was launched, bringing together health, social care, local authority, third sector and lived experience representatives to drive forward PEoLC across Coventry and Warwickshire. This Board enables PEoLC oversight across the Integrated Care System, including this delivery plan, which will be monitored through reporting of the identified workstreams to the Board support the delivery of the Palliative End of Life Care Strategy 2024-9.

Information

Information which focuses on identification, early intervention and support for people with palliative and end of life care needs.

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Improve identification of people in the last 12 months of life.	Improve access to and quality of data around palliative and end of life care.	Apr-24	Increase in the number of adults identified as likely to be in the last 12 months of life: focus on under-served communities including frail elderly. Review of CYP identification with palliative and end of life care needs.	Robust systemwide processes in place to proactively identify adults who is thought to be in the last year of life. Assurance that CYP palliative and end of life care identification processes are robust.	Agreement of system wide approach to identification of adults thought to be in the last year of life. Robust process in place for Information gathering across the system.	NHSE Core Metric 1: Pallaitive and End of life identification & PCSP for adults Agree Core Data measures for PEoIC for the system, to be utilised to assure the Pallaitive & End of Life Partnership Board of improvements and developments.	Lead: ICB Support from: System wide providers
Health and social care staff will have access to information in order to understand the all-age palliative and end of life care pathways and services which are available to support people across Coventry & Warwickshire.	Ensure up to date information re: PEoLC services, referral pathways and support options are available to professionals.	Nov-24	Increase awareness of available systemwide support, improve collaborative working and the quality of care through a seamless, systemwide delivery of palliative and end of life care.	Robust up to date PEoLC information , accessible to health and social care professionals	Information mapping across the system Identify portal to host information Identify key administrator of the site	Metrics data: e.g. Clicks on the portal Feedback from professionals Formal survey	Lead: ICB Support from: System wide providers

Information (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
The people of Coventry and Warwickshire will be able to access all-age information regarding palliative, end of life care and support services across Coventry and Warwickshire.	Ensure up to date information re: PEoLC services, referral pathways and support options is made accessible to the general public.	Nov-24	Increase awareness of available PEoLC systemwide care and support options.	Robust up to date information , accessible to anyone.	Information mapping across the system Review host site Identify key administrator of the site	Metrics data: e.g. Clicks on the portal Feedback from EBEs and the public Formal survey	"Lead: ICB Support from: System wide providers"
Transition from children and young people's services to adult services for PEoLC	Collation and process map Transition Pathways for PEoLC Using the Mapping, gap analysis and pathway consolidation to inform needs and requirements moving forward	Sept 2024 April 2025	Improved and supported PEoLC transition from CYP to Adult services.	Support and planning which is clear and transparent, with clear expectations for both the patient and their families	Working across the system with key stakeholders to map current processes and identify where there may be gaps in support. Develop Action Plan for improvement in 2024-5.	Patients of transition age will make a smooth transition to adults services -the success of this will be measured by patient/ carer experience surveys and professional feedback	ICB, NHS, LA & Third Sector Providers

Information (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Identification of CHC FastTrack	Review CHC Fast track pathway for PEoLC care in the community	Mapping & data baseline: June 2024 Pathway review April 2025	Improved systemwide patient flow, more effective utilisation of available community support services, early discharge from hospital setting and improved experience for patients and those important to them.	Timely access to the most appropriate PEoLC support for individual need with PCSP.	Mapping CHC Fast track current pathway. Identify current system challenges and opportunities to improve the PEoLC CHC FT pathway. Patient & Carer surveys. Develop Action Plan to support opportunities for quality improvement and mitigate challenges.	Improved identification of appropriate CHC Fast Track patients. Improved patient and carer experience.	ICB, CHC, NHS, LA & Third Sector providers.
Urgent and Emergency Care (UEC) /Urgent Community Response (UCR) for palliative and end of life care.	Baseline of available UEC / UCR data for people thought to be in the last 12 months of life. Pathway mapping for PEoLC in the UEC / UCR setting with identification of points of challenge. Develop systemwide approach taking into account the individuality of place to support access to UEC/UCR in the individual's preferred place of care.	April 2024 Sept 2024 April 2025	Learning from this deep dive will support the further development of PEoLC community UEC/ UCR pathways, improve access for underserved communities and patient/carer experience.	24/7 systemwide response to urgent and emergency palliative care cases, increase in the number of patients where clinically appropriate, who can be cared for in their preferred place.	Systemwide approach with partners including WMAS to further develop robust, easily navigable pathways of communication, care and support.	Measurement of data metrics, e.g. Number of episodes of urgent and emergency care utilised by people in the last 12 months of life. Number of episodes of urgent and emergency care utilised by people in the last 12 months of life were people could stay in their preferred place of care. Patient and carer feedback.	ICB & NHS & Third sector Providers

Information (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Un-optimised co-ordination between programmes of work.	Identify the main workstreams across the system which dovetail into PEoLC. Map current position of PEoLC within each identified workstream. Deep dive into challenges within each work stream for the timely delivery of care at the end of life.	April 2024 Sept 2024 Dec 2025	Develop clear and co-ordinated work across programmes and PEoLC programme with a collaborative system approach, e.g. Dementia; Frailty; Learning Disabilities; Long Term Conditions; Ageing Well, Virtual Wards etc	Systemwide collaborative approach to programme working. Shared understanding of services and quality improvement work. Improved quality of PEoLC across the workstreams.	Joint Forward Plan Networking Attending programme meetings Information sharing Joint areas of workstream development	Increase number of people identified as thought to be in the last 12 months of life. Improvements in access to information /signposting	System & workstream leads.

Access

Access to timely palliative and end of life care with support throughout, for all of our diverse communities.

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Identification of underserved communities.	Engagement Equality and Quality impact Assessment (EQIA) Mapping of currently available services Gap analysis	Oct-24	Improved equity of access to PEoLC for the whole of Coventry and Warwickshire	Under-served communities identified. EQIA completed and agreed across the system and reviewed every 12 months. Engagement and on-going co-production to develop greater understanding of challenges within current service provision.	Utilise national and local data, identify quality issue with current data sets. Research & clinical evidence reviewed and EQIA completed. Areas of focus identified to support equitable provision.	Service user demographic data. Feedback through engagement with communities identified as underserved.	ICB
24/7 availability of care	Mapping of services Gap Analysis Pathway development to scope co-ordinated and collaborative out of hours PEoLC provision	Sept 2024 April 2025	Increased quality of life and ease of access to responsive care for people with PEoLC needs and those important to them.	24/7 care which is resilient and able to meet the needs of the population and is clearly communicated across the system / place.	Identification of current challenges and review of available resources to develop clear pathways of support 24/7.	Reduction in utilisation of urgent and emergency care services. Reduction of incidents and complaints regarding out of hours services.	ICB, NHS Providers & third Sector Providers.

Coventry and Warwickshire
Integrated Care System

Access (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Psychological Therapy	Mapping Gap analysis Current Pathway review to understand needs and requirements Development of an equitable proposal for access to psychological therapies for those with PEoLC needs across the system	"Sept 2024 April 2025"	All patients and those who matter to them with PEoLC needs across Coventry and Warwickshire have equity of access to psychological support services when clinically required. Staff should have access to health and wellbeing support as required.	Access to psychological support in each place area	Work with NHS and other provider organisations to establish what is currently in existence and where gaps in provision are impacting on patients' access to psychological support.	Activity of access to psychological services across the system. Allocation of psychological support services in each place. Feedback from patients and staff.	ICB, NHS Providers & third Sector Providers.
Bereavement	Map the current bereavement offer across the system Establish where there is inequity or gaps in service. Review provision for the system and equity of access.	"Nov 2023 April 2024 Dec 2025"	Clear, available information to support signposting our population to available bereavement services. Clear understanding of the gaps of provision in each place. Review of strategies to support equity of access for all communitites.	There is a range of pre- and post-bereavement support services available which can be accessed by bereaved people in a timely and efficient way.	Working with system partners to build on the work already done to review bereavement services and fully understand the current statutory and voluntary / community service provision.	Mapping and needs analysis review undertaken Information available for the public and professionals.	System

Access (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
24/7 access to anticipatory medication is available	Develop the work commenced in the Access to medication workstream to scope a robust proposal for 24/7 access to anticipatory medication and that anticipatory prescribing is utilised and in place when needed	Dec-25	Mapping to clarify processes and identify gaps. Identification of areas of challenge. Review current service provision. Develop options apprisal for a robust systemwide process to 24/7 access to anticipatory medication.	Agree system approach for access to anticipatory medication. 24/7 access to anticipatory medication which enables those important to people with end of life care needs to spend the optimum amount of time with them.	Systemwide Task and Finish Group which includes experts by experience.	Agreed systemwide approach to the provision of anticipatory medication. Agreed systemwide pathway for access to anticipatory medication 24/7. Reduction in complaints and reduction of incidents where poor patient/family experience is reported.	System
Personal Health Budgets for EoL patients	Review the systemwide approach to the utilisation of personal health budgets for care at the end of life. Determine if increased utilisation of PEoLC PHBs could increase personalised care provision for care at the end of life.	Dec-25	Improved experience of care at the end of life which is tailored to the patient's needs and enables care in their preferred place.	People who become eligible for NHS Continuing Healthcare funding under the fast track pathway have a legal right to have a personal health budget	Systemwide review of the utilisation of PHBs and how this works for patient's in the last months of life	Increase in patients in the last 12 weeks of life accessing a personal health budget.	System

Access (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Support for emotional and spiritual needs as well as practical living support where needed.	Continue to engage with and support compassionate communities development work	Dec-25	Enhance the "safety net" of support around a person with PEoLC needs and those important to them is strengthen through community support - Everyone is prepared to care	How we come together to care and support people through life experiences is instrumental to our health, quality of life and happiness. Increased quality of care and community support for people at the end of life.	Work with colleagues and groups across the system to develop this approach and raise the profile of compassionate communities.	Collation of information to develop resources of support networks for the people and health and social care professionals. Develop a collaborative approach with colleagues in the arts and communities to raise the profile of what matters most at the end of life.	System wide. Lead: UHCW leading Compassionate Communities Workstream

Support

Support people diagnosed with a life limiting condition and those who matter to them, their carers and their communities to prevent crisis.

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Support for Carers	Mapping of services and available support for carers Gap analysis Pathway consolidation	Dec-24 Apr-25 Dec-25	Map of current pathways and available support. Gap analysis: Under-served communities Service provision Increased identification of PEoLC unpaid carers and referral for support. Increase in the completion of carer's assessments.	Unpaid carers are identified. Unpaid carers are referred / signposted for needs assessment and support. Pro-actively support people with palliative and end of life needs and their unpaid carers across health and social care to prevent crisis.	Unpaid carers are identified and offered a needs assessment. Unpaid Carer Experience Surveys.	Increase inf the number of identified unpaid carers for those with palliative and end of life needs in C & W. Increased numbers of individuals accessing carer support services. Gap Analysis: understanding of where issues sit within our system. Delivery of webpages for people of C & W on current PEoLC services and support services https://csnat.org/	System wide
Socio-economic demographics (Poverty proofing)	Mapping Gap analysis Pathway consolidation to inform needs and requirements Expand the learning from the PEoLC Poverty Proofing work conducted in the North of Warwickshire across the system to determine opportunities to improve care.	Dec 2024 June 2025	Address barriers faced by those in poverty throughout care but particularly those identified as having palliative and end of life care needs.	'No activity or planned activity will identify, exclude, treat differently or make assumptions about those who have less financial resource.'	Learning from the Poverty Proofing report, work with colleagues across health and social care to understand the barriers presented by poverty and identify actions to support equity of care.	Review and monitor 'Considerations' identified within the Poverty Proofing report. Identification of opportunities / pilots, proof of concept projects to eliviate the barriers identified through the Poverty Proofing report.	Systemwide

Support (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Siblings/ Friendships	CYP support for Siblings / Friends - review of available support. Children and young people experience grief just as much as adults but show it in different ways. They may need help to understand what has happened and to express their feelings.	"Nov 2023 - identification of current available support Dec 2025 - systemwide review to include gap analysis	Clear avenues of support and signposting are available for siblings , family and friends of those children and young people who are thought to be at the end of their lives.	Identification of services and community groups and referral pathways accessible to the public and professionals.	Map current offer Identify gaps Connect with providers who offer support	Collated support services information publically available.	Systemwide
Advance Care Planning (include. DNACPR/ ReSPECT)	Work across the system to agree consistent documentation and access to this information Pro-active PCSP to include ACP Collect data on ethnicity of those accessing PEoLC services across the system	Dec-25	Increased pro-active care planning for people identified as being in the last 12 months of life.	Planning care in advance makes it more likely that wishes will be understood and pro-actively planned for, resulting in more people being cared for and dying in their preferred place.	Workstream to review current PEoLC documentation, communication avenues and how this is improved through Shared Care Record opportunities. Education and Training Framework for PEoLC to develop our communities and workforce to support those with end of life care needs.	No. of people identified with PEoLC who have PCSP to include ACP. Development of consistent competency framework for PEoLC Education and Training for Coventry & Warwickshire.	Systemwide

Improve

Improve the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Education and Training Framework across the system	Develop a competency framework for the system including a training directory for public through to specialist palliative care clinicians.	Dec-25	Increase access to PEoLC education programmes for communities, health and social care professionals and carers. Increase the confidence of those caring for people at the end of their life. Increase the quality of palliative and end of life care available within the system.	Work collaboratively regarding Education and Training across health and social care to support providing palliative and end of life care. Increased confidence and competence of all staff delivering PEoLC. Increase confidence of communitites in supporting their members with palliative and end of life care needs.	Training Needs Analysis. Mapping of current training provision Training gap analysis. Development of PEoLC Systemwide Education and Training Framework.	Raise awareness to health and social care professionals of education packages. Report from training providers detailing the number of staff / public accessing training sessions Undertake survey of training with participants following sessions.	Systemwide
Dying Matters awareness week - system co-ordination	Establish a Task and Finish group to plan an annual system wide approach to Dying Matters week	May 2024 and then annually	Collaborative communication plan to raise the profile of PEoLC across Coventry & Warwickshire	Engage with communities, system partners in health and social care, arts providers, radio and local TV and compassionate communities to raise the profile of PEoLC.	Systemwide Task and Finish Group to Commence planning Jan 2024	Delivery of systemwide co-ordinated Dying Matters Week Events. Further evaluation methods to be identified through the Task and Finish group	Systemwide

Sustainability

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Finance Mapping	Map current financial provision for PEoLC service delivery across the system Benchmark PEoLC provision in Coventry & Warwickshire in line with NHSE guidance.	Apr-24	Understand the current financial commitment to PEoLC services in Coventry & Warwickshire. Development of gap analysis in service provision.	Sustainable financial position for PEoLC for the system	Integrated system working with needs analysis, gap analysis and comparison to current position.	Review and identification of potential funding gap, other avenues of support or funding. Understanding of current service impact on urgent and emergency care utilisation.	ICS
Contract mapping	Map current contractual arrangements for PEoLC service delivery across the system to include service specifications.	Apr-24	Scope a cohesive contracting approach to PEoLC services across the system, taking into account wider pieces of system review, e.g. Out of Hospital Contract Review	Collaborative commissioning model with clear, aligned service specifications which work in an integrated way to support the development of PEoLC across the system.	Task & Finish group to review current position and develop options for a future commissioning model for the system, in line with wider workstreams.	Options appraisal of proposed commissioning models	ICS
Workforce	In line with wider system workforce review, map current PEoLC staffing for health and social care across Coventry & Warwickshire. Undertake gap analysis.	April 2024	Understand the current PEoLC workforce position and challenges in relation to recruitment and retention.	Clear picture of current PEoLC workforce position and future trajectory. Identification of issues and risks over next 5 years.	Integrated system working with needs analysis, gap analysis and comparison to current workforce position.	Options appraisal of proposed workforce models	ICS

Sustainability (continued)

Issue to be addressed	Action	By When	Outcome	What good looks like	How will we get there	How will we measure success	Organisations responsible /lead
Integrated Commissioning Model	Development of a systemwide approach to PEoLC through a collaborative, integrated commissioning model which supports the Strategy and Delivery Plan.	April 2024	Commissioning model development	Systemwide agreement of a commissioning model for PEoLC.	Collaborative approach in line with Out of Hospital Services programme and Improving Lives programme	Options appraisal of proposed commissioning models	ICS

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:	20th July 2023
		Equality Review:	20th July 2023
Intended impact of scheme:	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. 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. 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.		

	PEoLC services can be delivered in any setting, and they include the following services: • 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
How will it be achieved:	PEoLC strategy development, implementation and the engagement that supports this is likely to comprise of the following activities: • 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.

Name of person completing assessment:	ICB: Kathryn Drysdale & Kate Butler Input from: • 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

Position:	Deputy Director of Nursing & PEoLC 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 PEoLC 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-serviced 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	✓			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. "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,				

					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				

					of life care. All PEoLC services will adhere to up-to-date IPC guidance and policies. 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.				
Patient services Could the proposal impact positively or negatively on any of the following:	A modern model of integrated care, with key focus on multiple long-term conditions and clinical risk factors	✓			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. 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.				
	Access to the highest quality urgent and emergency care	✓			Timely access to urgent and emergency care services which can direct palliative patients and their carers to the most appropriate service,				

					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 pro-active 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				

					delivery plan over the next 5 years. Patients will be fully involved in their care planning. Friends and Family feedback will inform service development. Compassionate Communities development work will support with an integrated approach to co-production and community led approach to care.				
	Patient Choice	✓			The 5 priority areas identified within the strategy include: 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. 3.Support – mapping and reviewing options for those who are unpaid carers, increasing knowledge of health and social care professionals as to				

					currently available support offers in increase choice. Where feasible and clinically appropriate remote, digital, and self-management options will be offered 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.				
	Patients are fully empowered in their own care	✓			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))				

	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				

					need for personalised care and support planning for all our diverse communities. In patient bed access Access to digital technology will be considered				
	Integration	✓			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.				
Compliance with NHS Constitution	Quality of care and environment	✓			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.				

	Nationally approved treatment/drugs			✓	NICE guidance and local guidance will be followed. Current working group set up to review access to PEoLC 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	✓			Patients will be fully involved in their care planning through shared decision-making, personalised care, and support planning. Those who matter to the patients will also be involved in shared care decision making and advance care planning where appropriate.				
	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, personlised 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
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.
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. 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. 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. 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.

Review of this research[1] 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 review[2] 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, LGBT+ 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.

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[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 Lesiban, 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 STP[3]

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

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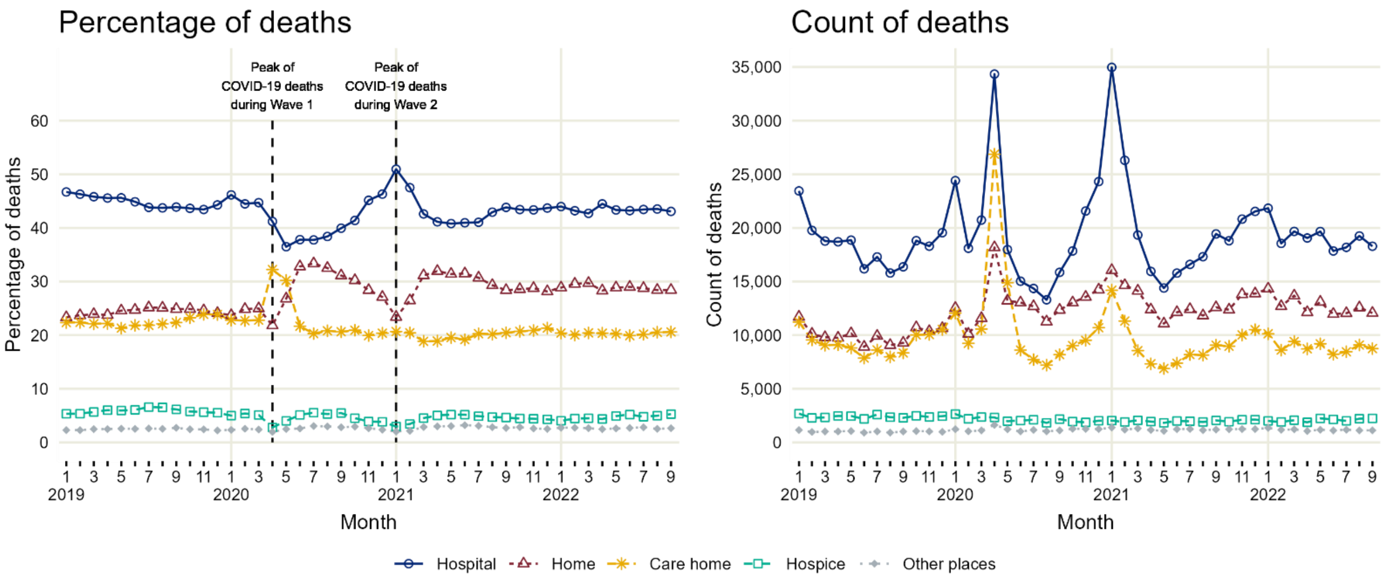
[3] Health Services in the last 2 years of life – Coventry and Warwickshire STP, A report by The Strategy Unit, 1 October 2020

- 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

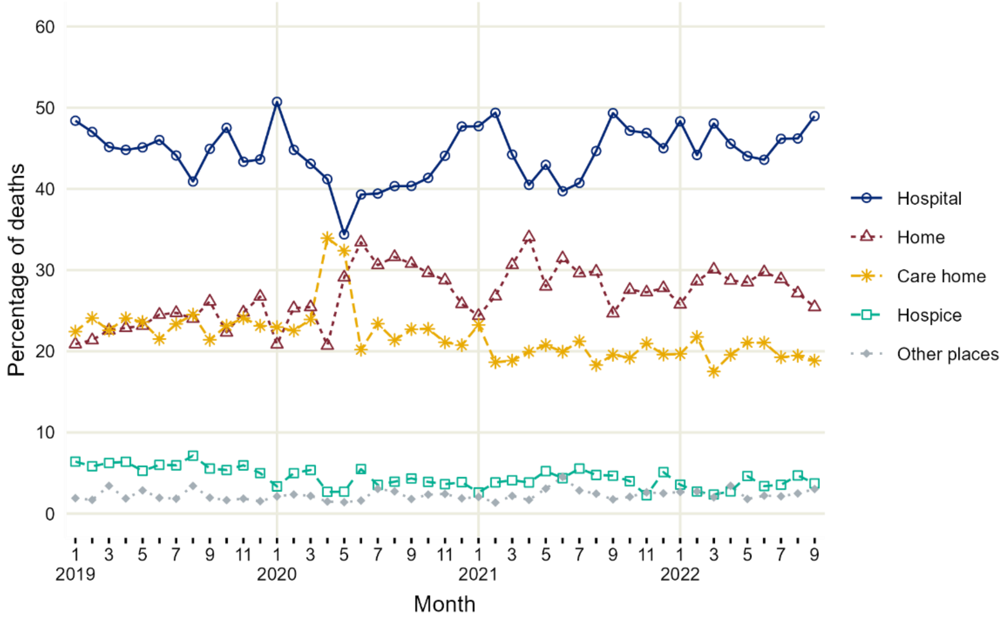
Figure 1: Monthly trends in % of deaths and count of deaths by place of death: England (all ages, 2019 to 2022)



Percentage of deaths

Count of deaths

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 2021[4]:

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

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[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.

Living longer with **greater need**

	Healthy Life Expectancy (years)	Years spent in **poor health**	Total life expectancy
Coventry			
	61.1 (males)	16.9 years	78 years
	64 (females)	18 years	82 years
Warwickshire			
	62.1 (males)	17.6 years	79.7 years
	64.1 (females)	19.3 years	83.4 years

- 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

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[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 Research[7], 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

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[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 states[8] 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

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[8] WCCC-1350011118-3095 (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=Iym7SMB78cw%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.
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.

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 population[9]. 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

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[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 SMI[10].

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 diagnosis[11].

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 2022[12], 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

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[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 individual[13].

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.

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[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 care[14].

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 available[15].

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 Muslims[16].

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).

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[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 be 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) 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 is 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 PEoLC 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).

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[17] https://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 bourne 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).

For all the groups above consider challenge of access to GP, PEoLC 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 PEoLC 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

		care. **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**
Equality – right not to be discriminated against based on your protected characteristics	How will this process ensure that people are not discriminated against and have their needs met and identified?	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. **This links to Ambition 1: each person is seen as an individual and Ambition 2: each person gets fair access to care.**
Dignity – the right not to be treated in a degrading way	How will you ensure that individuals are not being treated in an inhuman or degrading way?	Usual ICB, Local Authority and or Provider Policies relating to respect and consent will be applied. 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. **This links to Ambition 2: each person gets fair access to care;** **Ambition 3: maximising comfort and wellbeing**

Autonomy – right to respect for private & family life; being able to make informed decisions and choices	How will individuals have the opportunity to be involved in discussions and decisions about their own healthcare?	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. **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.**
Right to **Life**	Will or could it affect someone's right to life? How?	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.
Right to **Liberty**	Will or could someone be deprived of their liberty? How?	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.

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 8th 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 27th 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 25th 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 20th 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 22nd November 2022

included in the strategy.		

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, PEoLC 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 PEoLC 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 LBGT 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)	

Once complete, please send to the ICB’s Governance Team.

You Said - We Did Report

August 2023

Coventry and Warwickshire Palliative and End of Life Care Strategy and Delivery Plan 2024-29 Engagement.

Background

This document is an overview of the feedback we have received though the co-production and engagement undertaken to support the development of the Palliative and End of Life Care (PEoLC) strategy, which was undertaken in various stages from June 2022 – July 2023.

The PEoLC Strategy details 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.

This strategy is for everyone in Coventry and Warwickshire both for the people who live here and the people who work in health, social and third sector organisations across the system.

We have asked people with palliative and end of life care needs, their carers, those who live in Coventry and Warwickshire, as well as our partners in health and social care, what we should focus on to improve the care and support we provide to people who are nearing the end of their lives. We have listened to many people about what matters most to them when experiencing care themselves or caring for someone important to them.

How the strategy was developed: Engagement Summary

We **co-produced** this strategy speaking to the people of Coventry & Warwickshire:
- Those diagnosed with a life limiting condition
- Their carers and loved ones
- People who had been bereaved

We held a full engagement on the draft strategy between **June-July 2023** and produced a 'You Said We Did Report' main themes identified:
- Language & Layout
- Workforce Mapping
- Access to services

We **engaged** with stakeholders from across Coventry & Warwickshire, including NHS providers, councils, community leaders & third sector providers

We held a series of **meetings, group discussions and surveys** where we discussed:
- What matters most
- Challenges and Opportunities
- Priorities

Palliative and End of Life Strategy

Through engagement we reached out to:

- Over **1,600** people including patients, the public, health, social and third sector professionals.
- Over **300** organisations across Coventry and Warwickshire

Through co-production and engagement:

- We have directly spoken with representatives from over **30** different community groups and health and social care organisations via face to face or small group meetings.
- We have undertaken a series of public and stakeholder surveys and received a total of **239** responses from across the system.

We would like to take this opportunity to thank everyone who took the time to actively participate in the engagement.

Your feedback has enabled the development of the Coventry and Warwickshire Palliative and End of Life Care Strategy and has helped to ensure the 2-year Delivery Plan focuses on the right priorities which will have the greatest impact on improving care for people in Coventry & Warwickshire who are approaching the end of their lives.

We will continue our engagement and co-production ethos throughout the life of the strategy to ensure we are working with people, communities and professionals to develop effective and efficient end of life care for all our diverse communities.

We have developed 5 priorities based on feedback we have received through the development process of this Strategy.

Our Priorities: What we want to do.
1. Provide **information** which focuses on identification, early intervention, and support for people with palliative and end of life care needs.
2. **Access** to timely palliative and end of life care with support throughout, for all of our diverse communities.
3. **Support** people diagnosed with a life limiting condition and those who matter to them, carers and communities.
4. **Improve** the quality of personalised care and support planning for people with palliative care needs, including planning for the end of life, through education and training for all.
5. Deliver a **sustainable** system of integrated palliative and end of life care

General Feedback Received

The engagement has provided us with a wealth of information to help shape the final strategy.

In general, the responses have been positive, including the following statements:

"It was an easy read and pleased to see consideration to those with protected characteristics and groups with largest gap of inequalities"

"I am happy that the delivery plan provides a robust high-level approach"

"It looks a good piece of work"

"I thought infographics are good"

"I feel all the points and priorities are covered"

"Overall, I think this is a great piece of work with an easily accessible format"

"I think this is a very well written and considered document, summarising all the stakeholders work and input"

"The strategy document itself is straightforward and well written. I would agree with all priorities"

"I thought there were a number of positives about the strategy – including that there was a detailed delivery plan linked to it, it had a clear focus on health inequalities, and it used easily memorable priorities"

We have collated the received feedback in the table below, which we have grouped thematically and utilised in several ways to further develop and finalise the Palliative and End of Life Care Strategy.

We have detailed how we have utilised this specific feedback to develop a robust delivery plan with clear actions and outcomes to improve palliative and end of life care.

Priority	You Said	We Did

Priority 1: Information	• Tools for identification need to be agreed for the system as a priority
	• Patient information leaflet should be developed and promoted
	• Need for consistent documentation for Advance Care Planning, as well as a consistent approach on recording and sharing
	• Need for public education around death and dying
	• Explore an approach to a joined-up system Single Point of Access
	• Better understanding needed of terminology used e.g., distinction between Specialist Palliative Care and End of Life Management with associated palliative support
		• Systemwide agreement for development of a PEoLC identification pathway is in the delivery plan
		• Systemwide agreement for development of PEoLC service directory and service information for the public, health and social care professionals
		• Systemwide agreement for review of current advanced care planning documentation and electronic methods of information sharing.
		• Plan a systemwide approach for Dying Matters week 2024
		• Continue to work in collaboration with the Out of Hospital review
		• Continue to work in collaboration with the CASTLE Expert Advisory Group
		• Agreed Task & Finish groups to be established:
		  • Identification Pathways
		  • Advance Care Planning
		  • Review of iPlan
		  • Website Design

Priority 2: Access	• Awareness of workforce gaps e.g., Clinical Psychology provision
	• Overuse of UCR (Urgent Community Response) & rapid response
	• 24/7 access to medications:
	  • Difficult to access in communities
	  • Needs patient voice
	• Challenges in accessing:
	  • 24-hour hospice care
	  • Equipment for patients to die in their home
		• Systemwide mapping of workforce underway
		• Systemwide mapping of current services underway
		• Review of utilisation of urgent and emergency care services by patients in the last 3 months of life commenced.
		• Access to medications workstream set up with systemwide representation
		• Data workstream to look at cross boarder sharing
		• Proactive and unplanned care to be incorporated into the delivery plan
		• Continue to work in collaboration with the Out of Hospital

Priority	You Said	We Did
	- Data across counties e.g., a child under Birmingham Childrens hospital & Warwickshire - Hospices for children over 5 - After-death clinical provision for deaths in A&E	review

Priority 3: Support	- Lack of availability of information around the existing support options for end-of-life care
	- Lack of collaborative working between different specialities
	- Patients not prepared or supported for shared decision-making conversations
	- Support needs identified:
	  - Siblings and identification of siblings in need of support
	  - Face to face support for patients to enable encourage to access services
	  - Bereavement needs for those who have lost a child or young person
	  - Needs patient voice
	  - Formal acknowledgment for the role of the carer
	- Training needs identified
	  - Palliative and end of life care in care homes
		- Systemwide agreement for development of PEoLC service directory and service information for the public, health and social care professionals
		- Mapping of different programmes aligned to PEoLC, e.g., dementia, long term conditions, frailty, learning disabilities, virtual wards etc included in the delivery plan.
		- Education and training Framework for the system to be developed as part of the delivery plan to support staff, patients and those important to them, including scoping of currently available training.
		- Explore support available specifically for siblings and ways to measure sibling experience
		- Loss of a child or young person will be included in our bereavement scoping work
		- Promotion of social prescribing

Priority 4: Improve	- Competency framework for the system including training directory for all levels, training/education passport - Teaching healthcare professionals and the public on the recognition of dying - Sharing good practice about what makes a good PCSP	- Development of a PEoLC Competency Framework part of the delivery plan - Work with CASTLE Education group and other PEoLC Education leads across the system to develop plans - Systemwide approach for dying matters week - Education and training scoping underway and to include

Priority	You Said	We Did
	(Personalised Care and Support Planning) and how to achieve this • Requirements for specialist and generalist end of life care • Ensuring access to training for anyone who needs it e.g., standalone care providers • Awareness of the diversity of the community we serve	standalone care providers • EQIA (Equality and Quality Impact Assessment) undertaken • Continued engagement with our population of Coventry & Warwickshire, including hard to reach communities
Priority 5: Sustainability	• Need a better understanding of current roles and gaps in services • Workforce Planning should align with the national workforce plan for the next 15 years	• Systemwide workforce mapping underway • Recognition of national workforce plans to be incorporated as part of the delivery plan.
Language & Layout	• Abbreviations need clarification & clearer infographics needed • Terminology used	• All abbreviations reviewed and a glossary added • Improved infographics to be sourced during design phase of strategy • Terminology used has been sourced to ensure consistency with language use nationally in the public forum.
Promote Collaborative working across the System	• Need to develop relationships and increase the ways of working together • Delivery of the strategy relies on integration and communication between all services	• Collaborative working has been at the heart of our strategy draft and engagement and will continue to be promoted in the action and delivery plan, as well as any workstreams created
Other	• Has an Equality Quality Impact Assessment been completed • How might you measure 'what does good look like' in terms of patient experience. • Mental health issues including dementia should be added to the list of health inequalities • Looked after Children and Adopted should be added	• EQIA has been completed • To explore patient experience feedback across the system • Both added to health inequalities list

Priority	You Said	We Did
	to the list of health inequalities - How are we tackling access and financing information & resources for non-English speaking and reading population? - Understanding the holistic needs of the population	- This has been explored in our EQIA and we will continue to engage with these communities to identify the support they require - Personalised care is the golden thread throughout the strategy

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Health and Social Care Scrutiny Board Work Programme 2025/26

Last updated: 13 February 2026

17 September 25
Adult Social Care Performance - Self-Assessment and Annual Report (Local Account) 2024/25 Cabinet Member Portfolio Priorities Training of Care Staff supporting patients with Dementia
22 October 25 (moved from 8th)
Improving Lives – Impact on Adult Social Care Director of Public Health's Annual report
19 November 25 (moved from 12th)
Young person's risky behaviours service Prioritisation of NHS Services i) Prioritisation Process ii) Gluten-free prescribing
17 December 25
UHCW Performance – to take place at the hospital
21 January 26
Access to Dentistry and All age Oral Health Carers Strategy & Action Plan Update
25 February 26
End of Life Strategy and Hospices Healthwatch Update: a. NHS Survey report b. Housing with Care – Enter and Views report
11 March 26
Mental Health of the elderly Emergency Services Partnerships relating to Health - Ambulance Service / Fire Service Primary Care
1 April 26
Health of Students
TBC
Digital Access to Health Integrated Health and Care Delivery Plan Mental Health Older People and A&E Health and care of students in Coventry Neighbourhood Health Early Adopter Programme Impact of Climate Change on Health Safeguarding Adults Annual Report Disabled Facilities Grant Trans/Non-binary/Intersex Health Virtual Beds Update end of 25/26
2026/27
Public Health and Adult Social Care working together on Prevention Improving Lives – Impact on Adult Social Care UHCW Performance Community Pharmacists Healthwatch Annual Report (June / July 2026) Update on The Physical Activity and Sport Strategy

Date	**Title**	**Detail**	**Cabinet Member/ Lead Officer/ Organisation**
17 September 25	Adult Social Care Performance - Self-Assessment and Annual Report (Local Account) 2024/25	To consider the Cabinet Report of 30th September 2025 and identify any further recommendations.	Andrew Errington / Cllr Bigham / Pete Fahy
	Cabinet Member Portfolio Priorities	To invite Cllrs Caan and Bigham to identify their priorities for the coming year to identify future items and hold Cabinet Members to account	Cllr Caan / Cllr Bigham
	Training of Care Staff supporting patients with Dementia	Sufficiency of training of care staff who support patients with dementia	Cllr Bigham Pete Fahy Jon Reading
22 October 25 (moved from 8th)	Improving Lives – Impact on Adult Social Care	A follow up item from the meeting on 10th April 2024, to review following 12 months of implementation of a whole city approach To include clarification around how ASC is allocated based from need. (Referred from SCRUCO Transformation Programme Item)	Pete Fahy UHCW Cllr Bigham Cllr Caan
	Director of Public Health's Annual report	This report focuses on the city's rich cultural diversity and health inequalities that are facing migrant populations.	Cllr Caan, Allison Duggal
19 November 25 (moved from 12th)	Young person's risky behaviours service	Update on service development before recommissioning	Cllr Caan/ Rachel Chapman

Date	**Title**	**Detail**	**Cabinet Member/ Lead Officer/ Organisation**
	Prioritisation of NHS Services i) Prioritisation Process ii) Gluten-free prescribing	Led by ICB	Rose Uwins
17 December 25	UHCW Performance – to take place at the hospital	To consider steps being taken in the light of the league table position. To include: Updates on waiting times – complaints on hospital appointments availability. Review following 12 months of SB5 last visit - to identify any changes and improvements	UHCW Andy Hardy ICB - Ali Cartwright Cllr Caan
21 January 26	Access to Dentistry and All age Oral Health	Update from recommendations raised during January 2025 - Public Health to work collaboratively with the ICB on the following: o dental promotion o promotion of dental hygiene in school settings o appointment availability across the city o dental availability and awareness in areas of inequality and deprivation across the city.	R Uwins Cllr Caan
	Carers Strategy & Action Plan Update		P Fahy / Cllr Bigham
25 February 26	End of Life Strategy and Hospices		R Uwins / A Duggal

Date	**Title**	**Detail**	**Cabinet Member/ Lead Officer/ Organisation**
	Healthwatch Update: a. NHS Survey report b. Housing with Care – Enter and Views report		Leigh-anne Howatt Cllr Caan, Cllr Bigham
11 March 26	Mental Health of the elderly	Mental health support for older adults Any current challenges, including access, waiting times, or system pressures. Preventative or community-based work already underway. Opportunities for closer partnership working or service improvement	CWPT
	Emergency Services Partnerships relating to Health - Ambulance Service / Fire Service	Partnership working - Improved partnership working between the ambulance and fire services. To include WMFS to provide further information on safe and well, or strong checks that's provided within the City	Vivek Khashu, Rachel Danter ICB Area Manager – Matthew Stanton
	Primary Care	Update in 12 months' time - To cover access to GP's and other primary care, particularly in relation to reducing pressure on A&E. For Coventry City Council to use its resources to work as a conduit with	R Uwins / Alison Cartwright – Coventry Care Collaborative

Date	Title	Detail	Cabinet Member/ Lead Officer/ Organisation
		community organisations to improve knowledge of and access to the NHS for all residents of Coventry	/ Cllr Caan/ Pete Fahy
1 April 26	Health of Students	Health and wellbeing support available to your student community, including physical activity provision and initiatives that promote healthy lifestyles. How students access NHS and other health services, and any challenges or pressures this may be creating for your institutions or for local health partners. Areas where additional support, partnership working, or shared learning with the Council, public health colleagues, or other agencies may be beneficial. Any upcoming projects, innovations, or good practice examples	Warwick University / Coventry University
TBC	Digital Access to Health	Partners supporting switch to digital To include: The number of patients using the NHS App month by month including a demographic breakdown if available. How to raise awareness	Rose Uwins / A Duggal / Caan

Date	Title	Detail	Cabinet Member/ Lead Officer/ Organisation
		of the NHS App including linking with the Council's Digital Inclusion Team and Cov Connects on Digital Inclusion.	
	Integrated Health and Care Delivery Plan	To identify which of the 3 areas of focus the board would like to look at. Including work with newly arrived communities. Understand how the transition to this cluster will be managed - What will be the positive/negative impacts for Coventry residents from the clustering	ICB Rose Uwins
	Mental Health	Mental health services, particularly the demand and availability of local services, and the impact of long wait times. To include input from the Crisis teams.	CWPT
	Older People and A&E	Update around work undertaken by Age UK of experience of elderly in A&E - 'Corridor Care'	
	Health and care of students in Coventry	Visit to Warwick University for members, health, and care of students in the City	
	Neighbourhood Health Early Adopter Programme	SB5 involvement potentially if the bid is successful	Pete Fahy Cllr Bigham

Date	**Title**	**Detail**	**Cabinet Member/ Lead Officer/ Organisation**
	Impact of Climate Change on Health	How health services are geared up to respond to the impact of climate change on health	Cllr Caan Cllr O’Boyle Allison Duggal/ Rhian Palmer
	Safeguarding Adults Annual Report	Update	R Eaves Cllr Bigham
	Disabled Facilities Grant	Delivery and waiting times	Cllr Bigham P Fahy Aideen Staunton
	Trans/Non-binary/Intersex Health		A Duggal Cllr Caan
	Virtual Beds Update end of 25/26	Update on the development of Virtual Wards	UHCW/P Fahy / Cllr Bigham
2026/27	Public Health and Adult Social Care working together on Prevention	Picked up during Cabinet Member Priorities - How Public Health and Social Care are working together to prevent ill health.	A Duggal / P Fahy – Cllr Caan / Cllr Bigham
	Improving Lives – Impact on Adult Social Care	That feedback from service users be included in the next update report.	Cllr Bigham / P Fahy
	UHCW Performance	Update on performance (March 2027)	A Hardy
	Community Pharmacists	To include Pharmacy First	

Date	**Title**	**Detail**	**Cabinet Member/ Lead Officer/ Organisation**
	Healthwatch Annual Report (June / July 2026)	To consider the work of Healthwatch and how scrutiny can use their findings	
	Update on The Physical Activity and Sport Strategy	Progress of the draft Physical Activity and Sport Strategy to be brought back to the Board in the 2025/26 Municipal Year. To include the 6 play zones being delivered across the city and work to encourage older people to be active, as well as link with Public Health and other partner organisations such as Age UK Added to SCRUCO work programme to align with Cabinet in March.	P Fahy / J Hunt / D Nuttall / Cllr Caan

Frequently Used Health and Social Care Acronyms

- ASC – Adult Social Care
- CQC – Care Quality Commission
- CWPT – Coventry and Warwickshire Partnership Trust
- CWS – Coventry Warwickshire Solihull
- DFG – Disabled Facilities Grant
- DPH – Director of Public Health
- ENAS – Extended non-attendance at school
- EOL – End of Life
- GEH – George Elliott Hospital

- JHOSC – Joint Health Overview and Scrutiny Committee
- H&WB – Health and Wellbeing
- H&WBB – Health and Wellbeing Board
- HOSC – Health Overview and Scrutiny
- ICB – Integrated Care Board
- ICP – Integrated Care Partnership
- ICS - Integrated Care System
- LMC – Local Medical Council
- MAT – Multi Academy Trust
- MSP – Making Safeguarding Personal
- PCN – Primary Care Network
- SAB – Safeguarding Adults Board
- SAR – Safeguarding Adults Reviews
- SWFT – South Warwickshire Foundation Trust
- UHCW – University Hospitals Coventry and Warwickshire
- WMAS – West Midlands Ambulance Service
- WMFS – West Midlands Fire Service

Work Programme Decision Flow Chart