Adult Social Care and Health Overview and Scrutiny Committee

Date: Wednesday 15 November 2023

Time: 11.00 am

Venue: Committee Room 2, Shire Hall

Membership

Councillor Jo Barker (Chair)

Councillor John Holland (Vice-Chair)

Councillor Colin Cape

Councillor John Cooke

Councillor Tracey Drew

Councillor Marian Humphreys

Councillor Andy Jenns

Councillor David Johnston

Councillor Chris Mills

Councillor Ish Mistry

Councillor Pamela Redford

Councillor Kate Rolfe

Councillor Ian Shenton

Councillor Sandra Smith

Councillor Mandy Tromans

Items on the agenda: -

1. General

- (1) Apologies
- (2) Disclosures of Pecuniary and Non-Pecuniary Interests
- (3) Chair's Announcements

(4) Minutes of previous meetings

5 - 14

To receive the Minutes of the committee meeting held on 27 September 2023.

2. Public Speaking

3. Questions to Portfolio Holders

Up to 30 minutes of the meeting is available for members of the Committee to put questions to the Portfolio Holder: Councillor Margaret Bell (Adult Social Care and Health) on any matters relevant to the remit of this Committee.

4. Questions to the NHS

Members of the Committee are invited to give notice of questions to NHS commissioners and service providers at least 10 working days before each meeting. A list of the questions and issues raised will be provided to members.

5. Palliative and End of Life Care Strategy 2023-2028

15 - 122

The Coventry and Warwickshire Integrated Care System is developing a joint all age strategy for Palliative and End of Life Care, on which the Committee's formal support and endorsement is sought.

6. Quarter 2 Integrated Performance Report

123 - 146

For the Committee to consider and comment on the Quarter 2 Integrated Performance Report (period covering April - September 2023).

7. Update on Covid and Flu

The Committee will receive a presentation from Public Health.

8. Work Programme

147 - 154

For the Committee to review and update its work programme.

Monica Fogarty
Chief Executive
Warwickshire County Council
Shire Hall, Warwick



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- Not participate in any discussion or vote
- Leave the meeting room until the matter has been dealt with
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Non-pecuniary interests relevant to the agenda should be declared at the commencement of the meeting.

The public reports referred to are available on the Warwickshire Web https://democracy.warwickshire.gov.uk/uuCoverPage.aspx?bcr=1

Public Speaking

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Adult Social Care and Health Overview and Scrutiny Committee Wednesday 15 November 2023





Adult Social Care and Health Overview and Scrutiny Committee

Wednesday 27 September 2023

Minutes

Attendance

Committee Members

Councillor John Holland (Vice-Chair in the Chair)

Councillor Colin Cape (Nuneaton and Bedworth Borough Council (NBBC))

Councillor John Cooke

Councillor Tracey Drew

Councillor Dave Humphreys

Councillor Marian Humphreys

Councillor David Johnson (Stratford-upon-Avon District Council)

Councillor Pam Redford (Warwick District Council)

Councillor Kate Rolfe

Councillor Ian Shenton

Councillor Sandra Smith

Councillor Mandy Tromans

Officers

Becky Hale, Janet Neale, Pete Sidgwick, Steve Smith and Paul Spencer.

Others in attendance

Councillor Margaret Bell, Portfolio Holder for Adult Social Care and Health

Chris Bain, Healthwatch Warwickshire (HWW)

Simon Doble, Kathryn Drysdale, Tim Sacks and Jamie Soden, Coventry and Warwickshire Integrated Care Board (C&WICB)

Kate Hoddell, South Warwickshire Foundation Trust (SWFT) and Katie Herbert SWFT and WCC.

1. General

(1) Apologies

Apologies for absence had been received from Councillors Jo Barker (Chair), Andy Jenns, Chris Mills (replaced by Councillor Dave Humphreys) and Sandra Smith (North Warwickshire Borough Council). Officer apologies were received from Nigel Minns (Executive Director for People) and Dr Shade Agboola (Director of Public Health).

(2) Disclosures of Pecuniary and Non-Pecuniary Interests

Councillor Humphreys declared an interest as Chair of the Children and Young People's OSC.

(3) Chair's Announcements

The Chair was mindful it was a full agenda and he urged brevity from those presenting, to allow time for questions. Everyone was welcomed to the meeting, especially Councillor David Johnston, the new representative for Stratford-upon-Avon DC. It was proposed to hold a presentation on the performance management Power BI platform. This would take place for members of the Committee at 9.30am on 15 November.

(4) Minutes of previous meetings

The minutes of the Committee meeting held on 28 June 2023 were approved as a correct record and signed by the Chair.

2. Public Speaking

None.

3. Questions to Portfolio Holders

None.

4. Questions to the NHS

Councillor Colin Cape (NBBC) had given notice of the following questions:

- How many veterans are registered with GPs in the region (what percentage of the population is this)?
- What is done to flag them as such in order to follow the directives of the AFC (Armed Forces Covenant) for health?
- What trends or variance if any appear in their health needs?

The questions had been provided to Rose Uwins of the C&W ICB who would arrange for a written response to be provided. This would be circulated to the Committee when it was received.

5. GP Services and Primary Healthcare

The Committee received a joint presentation from the Integrated Care Board (ICB) and the County Council. The presenters were Simon Doble of the C&W ICB and Janet Neale from WCC's Infrastructure Team. Tim Sacks (ICB) was also present to respond to questions. In opening the item, the Chair mentioned that the focus was on estates aspects rather than access issues. Janet Neale commenced the presentation covering the following areas:

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- The Local Plan process, with an outline of the key stages leading to formal adoption of the Local Plan. There was a clear need for both WCC and the ICB to be very involved in this process.
- Section 106 (S106). This was a legal agreement between local authorities and landowners/developers detailing obligations required as a result of a planning application. Effectively it was a charge against the land.
- Community Infrastructure Levy (CIL). A tax on net new floor space set locally and paid to the district or borough council. The requirements around levying and use of CIL were outlined. In Warwickshire to date, only the Stratford and Warwick Districts had adopted CIL, with Rugby Borough pursuing the use of CIL currently.
- Further slides showed the pros and cons of the S106 and CIL approaches.
- The proposal to introduce a new mandatory Infrastructure Levy, set locally (similar to CIL).
 This would be based on the assessed uplift value of the land, as a result of development.
 This approach had attracted strong challenge during the consultation process by a wide range of organisations.

Simon Doble then spoke to the NHS aspects:

- Primary Care Estate Context. This included the transfer from the former Clinical Commissioning Groups (CCGs), frustrations for general practice and responding to known population growth with limited funding.
- Primary Care Estate Environment. This confirmed there was no new funding, a historic lack
 of investment, before raising the challenges from existing funding streams, build costs,
 workforce aspects and ownership of premises.
- The current picture. A slide giving an understanding of the ICB's position, the baseline and portfolio of the ICB estate. It detailed the current and projected population and the known shortage of rooms for patient appointments.
- Growth areas and priorities for further work.
- Opportunities, including a collaborative working approach.

Questions and comments were invited with responses provided as indicated:

- The Stratford and Warwick District Councils were producing a joint Local Plan for the South
 of Warwickshire. Such plans included a 'target' number of new dwellings, and one
 consideration was whether to extend existing settlements, or development of new
 settlements. It was questioned from a health perspective which option would be easier to
 plan more reliable services for.
- Tim Sacks replied that there were challenges both in terms of buildings and workforce with a need to increase both, to improve access to services. The S106 funding received was not sufficient to build new premises. Options were expansion of existing premises within the funds available, or providing a new premises which was reliant on an external funding contribution to make up the shortfall, currently estimated to be around 40%. The S106 funds were used to maximise existing practices, but this meant no new premises were built due to the capital finance challenges. Simon Doble added that S106 was inflexible, which was frustrating. There was a commitment for the ICB and WCC to work effectively with districts and boroughs. For significant developments, Janet Neale touched on the potential for developers being required to build the premises, rather than negotiating a financial contribution.

- Local authorities were required to provide a prescribed number of additional houses and for the Warwick and Stratford areas this was some 39,000 homes in the next 10 years. It was questioned if the health sector made representations to the Planning Inspectorate regarding development allocations. There were real concerns about the impact of such additional development on health services due to the lack of sufficient funding to provide the services required.
- Janet Neale stated the need to work together and inform the Local Plan process at an early stage. The move from three CCGs to a single ICB and consistent approach was helpful.
 Officers were trying to address the current position and to inform future local plans at a very early stage, providing a robust evidence base of service need. This evidence would inform the Planning Inspector.
- Further points were made about the timescales for completion and adoption of a local plan, that the NHS was not speedy at dealing with such issues and developers sought to avoid or reduce commitments through S106 agreements. The member was very concerned at the impact for future health services. The Chair wondered if officers were being put in an impossible position. Officers reiterated the commitment between the ICB and WCC. There were endeavours to collaborate with all councillors and planning colleagues, to make this work.
- In North Warwickshire, the closure of a Polesworth surgery required patients to transfer to Dordon. A lack of public transport caused issues with some patients unable to access this surgery. There was a satellite surgery in Polesworth which was underused currently and could be more effective. Residents voiced their frustrations to the local councillors. The point was acknowledged. An audit was taking place of all 153 surgeries and their current utilisation. This included 33 branch surgeries, which were not used on a full-time basis. Whilst it was far more efficient to operate from a single premises, there was a known shortage of estate. Part of the review would look at the potential to make more use of underused premises. Workforce shortages were raised, along with the public transport issues and the projected population growth in both Polesworth and Dordon. A written reply would be provided on the current utilisation of the branch surgery in Polesworth.
- It was noted that some 4,500 new homes were planned for the Polesworth and Dordon areas. A view that another GP practice should be established to create competition.
- Some people needed to use medical services in neighbouring areas. This was acknowledged and for those living close to a county boundary, typically 15-20% would use services in neighbouring areas. Similarly, the S106 funding for new developments would rest with the local area where the development had taken place. There were regular discussions between adjacent ICBs. It was evident that when people moved home into Warwickshire they may stay with the previous GP and continue to use the same pharmacy.
- Discussion about primary care contracts. In some areas, alternative provider medical services (APMS) contracts were used. Additional costs were often incurred, alongside challenges for finding additional premises and issues around continuity of care where there were shorter-term contracts. Securing the funding to build a new premises was difficult so the driver was population increase, not creating competition.
- A suggestion that planning law needed to be changed so that a lack of GP services was a ground for refusing an application. However, GPs were not a consultee to the planning process. In the Stratford area, there was a high number of care and nursing homes. This placed additional demands for GPs in that area with the requirements for home visits reducing capacity. The area had lost two surgeries and the remaining surgery was struggling to cope with the service demand from 30,000 residents. The Government should be lobbied on changing planning law.

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- A member summarised the challenges raised during the presentation, asking how they would be addressed to balance supply and demand. Simon Doble replied that this was more to do with access than estates. NHS England was undertaking a project on primary care access recovery guidance. ICBs had been asked to work with primary care in responding. Effectively this would set out the overarching approach. It would lead to a roadmap and then delivery plan to address known issues. Creating a modern general practice, implementing changes and being innovative were cited as examples. There was no capacity within budgets. Every decision to fund something had to be offset by a corresponding saving elsewhere, so using existing buildings rather than new building and making more use of technology were further examples quoted. There was not the funding to create more capacity though extra buildings in every location. There needed to be different ways of working, which were mutually agreed and making better use of existing premises.
- Further discussion about the Government's proposal for an Infrastructure Levy to be introduced as part of planning reforms. Another proposal was to reduce the time period for the local plan process from typically 8 years to 30 months. Members were encouraged to be involved actively in responding to these consultations.
- The relationship between estates and workforce was raised by Chris Bain of HWW. A need to think about timelines for recruitment and retention across both the NHS and the care sector. This may provide an assurance for the population. Points about population growth, having regard to demographic data and that from the Joint Strategic Needs Assessment (JSNA) too. On collaboration, this was seen as the way forward. A need to engage with social care, the voluntary sector and communities, as well as Healthwatch. The points raised were acknowledged, with an outline given of the joint work with primary care to match staff placements and available space. Collaboration did need to include all sectors.
- Councillor Bell, Portfolio Holder said the outcome of the NHS estate audit would be interesting to see. She spoke of the challenges faced in securing a pharmacy for a new health centre in Hartshill. It was questioned why this had proved to be so difficult. Furthermore, pharmacies were private businesses. There seemed to be a reluctance to create competition, but additional pharmacies could offer extra support for GPs. It was questioned what changes were proposed to improve internal processes for delivery of GP surgeries. Where large developments like that at Upper Lighthorne took place, people moved in, registered at existing surgeries and placed additional demands on them, long before the new surgery was available. It was important that the new facilities were built at the right time.
- Similar concerns were raised for the Kenilworth area, where 2,000 new homes would be built placing demands on the two surgeries serving that area. The local member would welcome a discussion outside the meeting. There was a recently opened school and potential for a new community facility to be provided as part of the development. It was questioned if one of these could include a room for use as a GP surgery.
- Tim Sacks agreed to pick up the points raised with the members. There was a need to be realistic as 'outreach' services were more costly in staff time when compared to having multiple clinics in the same location. If premises were of sufficient size, they effectively became a surgery and did add value.
- For the Nuneaton area, points were made about encouraging GPs to locate in areas of new development, planning tensions and the regeneration planned for this area, which may yield suitable premises for an additional surgery. It was questioned what the ICB could do to encourage GPs to locate in new or multi-use centres, or presently unused premises which could be converted to be a surgery. Tim Sacks reiterated that whichever building was used, the NHS still paid for it through a notional rent. The ICB would look at each primary care

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network (PCN) area to see what was needed and the potential to be innovative, whether it required extension to an existing practice or an additional one. The key was having a joint solution for each area, recognising the financial constraints, and the growing population to ensure access to services. He was not aware of GPs showing resistance to move into premises.

The Chair closed the item, thanking the presenters and members for their questions. Any follow up questions from this item should be submitted to Democratic Services, in order that a response could be requested.

6. Palliative and End of Life Care Strategy

The Committee received a report and presentation on the draft Coventry and Warwickshire Palliative and End of Life Care (PEoLC) Strategy, on which the Committee's feedback and support was sought. The item was introduced by Jamie Soden, Deputy Chief Nurse with a presentation from Kathryn Drysdale. They were supported by Kate Hoddell of the ICB and Katie Herbert (WCC and SWFT).

The presentation by Kathryn Drysdale covered the following areas:

- What is Palliative and End of Life Care? This was an all-age strategy for Coventry and Warwickshire.
- There had been extensive collaboration across the local NHS system and with relevant partners in all sectors, to understand current challenges and work together to make improvements.
- An outline of the approach undertaken through an overarching partnership board, with four place-based groups feeding in local information.
- The aim and vision of the strategy, to provide a delivery plan and to raise the profile of this service area.
- The Strategy would cover a five-year period commencing in January 2024. Detail was provided on the communication plan, the two-year delivery plan, equalities aspects and areas of focus based on need. This included a focus on underserved communities, building relationships with communities and co-production.
- Our Priorities: What we want to do.
 - o Providing information a focus on identification, early intervention and support.
 - o Access to timely PEoLC and support throughout for all diverse communities.
 - Support for people diagnosed with life limiting conditions and those who matter to them.
 - Improve the quality of personalised care and support planning, through education and training for all.
 - o Deliver a sustainable system of integrated care.
- The National Framework and the six ambitions for PEoLC. These were: being seen as an individual, getting fair access to care, maximising comfort and wellbeing, coordinated care, all staff being prepared to care and community support.
- How the strategy was developed. A slide showing the co-production, the engagement with stakeholders, along with meetings, surveys, and group discussions. Data was provided on the engagement undertaken, raising the profile and importance of EoLC.

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- Health Inequalities in Coventry and Warwickshire. Some communities had poorer access to information, services and planning for EoLC. Details were provided of the specific groups affected particularly young carers, veterans and South Asian women.
- Population Health Management. A need to understand the current system, the population, socio-economic and demographic factors both now and in the future. This would help to determine workforce requirements, given the known challenges currently.
- How we will deliver improvement. A need for seamless care across settings, clear referral pathways, pro-active personalised care, collaboration and clear communication.
- Programmes through which we will work. This included care collaboratives, a community integrator model, the Warwickshire Community Recovery Service and a review of the continuing health care fast track system.
- Delivery Plan for the period January 2024 December 2026. This included areas of focus for each of the five priority areas reported above.
- Remaining timeline for the strategy.

The following areas were discussed:

- A member noted the passing reference to veterans. It would have been helpful to have more specific reference to veterans in both the documents and presentation.
- The transition for those with life limiting conditions into palliative care. The twelve-month period referenced seemed too constricting. The point was acknowledged by Kathryn Drysdale, with the rationale for this timeframe within the two-year delivery plan being explained. It may be that this would be reviewed on an individual basis. It was made clear this applied to adults with a different approach being used for children and young people.
- A member asked about the PEoLC facilities available at Manor Court in Nuneaton. This would be researched, and a response circulated to the Committee.
- Regarding EoLC services in the community, some carers were not trained emotionally to support family members. Home care staff provided a key role in communities and often did not receive the recognition they deserved. The strategy did not make sufficient reference to the need to uplift training for home carers.
- Kathryn Drysdale spoke of the planned education and training framework, which would be for NHS professionals, domiciliary care workers, volunteers, community groups and the general public. It would include competencies for relevant people, but also education and communication skills for volunteers in group environments to give assurance to people being supported. It would include liaison with the private providers of domiciliary care services on training and core competencies. Where possible, existing courses would be made available free of charge to this cohort for example via video conference.
- Discussion about the coordination of appointments for PEoL patients attending clinics. A pilot scheme was underway where patients visited a day unit and saw a range of specialists depending on their needs and symptoms. They were usually via a GP referral the day before, with urgent appointments on the same day. It was questioned if this coordination reduced the numbers of appointments available. An example was given to show the benefit this could have for patients ensuring they received the required care. The approach was welcomed by the councillor. The current pilot scheme was due to be operated for another two more months and its success would then be assessed.
- The strategy was considered to be informative and ambitious. There was a lot of work to do but no additional funding, so it was questioned how realistic it was to achieve the aims

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within five years. The member asked what barriers there were to success. Kathryn replied that all options were being considered. Examples were given of a funding application to Macmillan, some monies from NHS England and thinking 'outside the box' to link funding streams. The palliative care workforce was very dedicated, with staff going above and beyond. The local system was invested with good support from partners too. There was reference to the JSNA findings and work with population health too. The scale of the task was recognised but was considered achievable through collaboration. Jamie Soden added that the five-year term was not the end of the process. There needed to be an honest assessment of the current position and work required. As delivery progressed there should be realistic 'stretch' targets focussed on the priority areas. There was confidence that significant progress would be made over the initial two and five-year periods. There would be just as many challenges for the subsequent delivery plan and strategy. It was a big challenge, but there would be realism and transparency in what could be achieved.

In closing the item, the Chair noted the importance of this and all items on the agenda each of which could take a full meeting. He thanked the presenters also noting the reference to the JSNA and the value of that work.

7. Sustainable Futures Strategy

This item was introduced by Steve Smith, Director of the Commissioning Support Unit. From October he would join the Communities Directorate and his role would include both Climate Change and Strategic Infrastructure. The draft Sustainable Futures Strategy was being submitted to all the Overview and Scrutiny Committees as part of a detailed engagement process, before its final consideration by Cabinet in November. Key information was provided in the covering report, which outlined the features of the strategy and the use of expert panels. A copy of the draft strategy, the action plan and an update on projects were provided as appendices.

Questions were submitted and discussion took place on the following areas:

- It was questioned if recent changes in national policy on timescales would impact on the council's targets and trajectory for 2030 and 2050. Steve Smith agreed this was a dynamic situation, but the targets remained unchanged. However, the route to these targets may change with the recent announcements. There would be regular updates to Cabinet and the scrutiny committees to show the progress being made. The key issue was access to funding, most of which was small external grant sources.
- Consent had just been given to open the Rosebank oil field near Shetland for another 40 years. Given the carbon emissions this would cause, it was questioned if this would outweigh local endeavours. Steve Smith replied that the Council could control its own consumption. It knew the carbon tonnages associated with building use, transport, fleet operations and street lighting. There was a lot of expectation at the contribution small and medium enterprises could provide too. Also, a need to be aware of current impacts from climate change, those for public health and flooding aspects too.

In closing the item, the Chair suggested that any further comments be submitted direct to Steve Smith.

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8. Quarter 1 Integrated Performance Report

The Committee received the Integrated Performance Report, which gave a retrospective summary of the Council's performance at the end of Quarter 1 (April - June 2023) against the strategic priorities and areas of focus set out in the Council Plan 2022-2027. Key sections of the report focussed on:

- Performance against the Performance Management Framework
- Progress on the Integrated Delivery Plan
- Management of Finance
- Management of Risk

There were no questions submitted by members.

9. Work Programme

The Committee reviewed its work programme. Prior to the next meeting on 15 November, a briefing session would take place on performance and the Power BI platform. At the recent Chair and Spokesperson meeting, discussion took place about development of the Adult Social Care Strategy and planned engagement. It was agreed to add this to the Committee's agenda in November.



Briefing note

To: Warwickshire Health and Social Care Scrutiny Board Date: 15th November 2023

Subject: Coventry and Warwickshire All Age Palliative and End of Life Care (PEoLC) Strategy 2023-2028 – Update

1 Purpose of the Note

- 1.1 The Coventry and Warwickshire Integrated Care System is developing a joint all age strategy for Palliative End of Life Care (PEoLC). This is a joint five-year strategy which is owned by the following organisations:
 - Coventry City Council (CCC)
 - NHS Coventry and Warwickshire Integrated Care Board (CWICB)
 - Warwickshire County Council (WCC)
- 1.2 The purpose of this note is to update colleagues regarding the PEoLC strategy and its delivery plan and to seek formal support for the PEOLC strategy on behalf of Warwickshire County Council for launch in January 2024.

2 Recommendations

- 2.1 Health and Social Care Scrutiny Board are requested to:
 - (i) Support the final version of the 5-year PEOLC ICS strategy.
 - (ii) Support final version of 2-year delivery plan for the strategy

3 Information/Background

- 3.1 Palliative and end of life care will impact on all of us at differing points throughout our lives.
- 3.2 More than half a million people are expected to die each year in the UK, 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. This gives us an opportunity to plan and consider people's wishes and preferences for their end-of-life care and treatment.
- 3.3 Approximately 9,000 people died in Coventry and Warwickshire in 2021. Each year, most deaths are in the adult age group though there are a small number of children and young people who pass away.
- 3.4 Within our system 45% of deaths took place in hospital, 30% at home, 20% in care homes and 4% in hospices.
- 3.5 The Strategy development is based on the National Ambitions for Palliative and End of Life Care. There are 6 National ambitions:



- 3.6 The delivery of the PEoLC Strategy will support the ICS partnership organisations to ensure PEoLC is prioritised and equitable across the system
- 3.7 Co-production has been central to the development of the draft strategy and has been achieved via:
 - Focus group with carers
 - Patient case studies
 - Out-reach to systemwide patient participation groups re: PEoLC
 - Surveys
- 3.8 Workforce co-production has been undertaken through a systemwide workshop and a PEoLC survey of health care professionals, along with input from Clinical Leads and members of the Coventry and Warwickshire PEOLC Partnership Board.
- 3.9 This work has already raised the profile of PEoLC within organisations and with some of our people. Wider systemwide engagement and linking through to our under-served communities took place in June -July 2023 and continues.
- 3.10 5 identified over-arching priorities have been identified for Palliative and End of Life Care for Coventry and Warwickshire:
 - 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
- 3.11 A delivery plan for the first 2 years of the strategy has been developed with clear areas of focus, workstreams, outcomes, measurables and responsible organisations has been developed to support the strategy. A further 3 year delivery plan will be developed from late 2024 for the final years of the strategy.
- 3.12 The development of a co-production approach to engagement was commenced through building links with our community partners. Working across Coventry and Warwickshire our aim has been and will continue to be, the building of strong links with our diverse communities in order to develop a co-production approach to the development of PEoLC services across the system. Engagement with the Cultural Inclusion Network, Coventry Community Messengers and Healthwatch have been undertaken and will continue to enable co-

- production. Links have also been made to other strategy engagements, e.g. Carer's Strategy to develop a joint approach to approaching impacted groups.
- 3.13 Work has been on-going with our system stakeholders across health, social care, independent and third sector providers to understand the challenges and ways in which the system is working well in order to ensure improvements can be developed in the most effective and efficient ways in tandem to aligning programmes of work.

4 Next Steps

Approval of the Strategy through the relevant governance processes for a launch in January 2024 with accompanying EQIA and Delivery Plan.

Kathryn Drysdale - Deputy Director of Nursing: Clinical Transformation Jamie Soden - Deputy Chief Nurse: Clinical Transformation End of Report





Coventry and Warwickshire

Palliative and End of Life

© Care Strategy

2024-2029



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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.

Joint Statement & Vision – Integrated Care Board, Coventry City Council, Warwickshire County Council



What is Palliative and End of Life Care?

- Palliative care is about improving the quality of life of anyone facing a lifelimiting 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.





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.

Page :

$\stackrel{\triangleright}{\omega}$ 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





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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:





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
- 6 Leamington Spa Hospital
- 6 Manor Court, Nuneaton
- 7 St Michael's Hospital, Warwick
- 8 Stratford Hospital
- Woodloes House, Warwick
- The Shakespeare Hospice
- 1 Myton Hospice Warwick
- Myton Hospice Coventry
- Myton Hospice Rugby
- 4 Shipston Home Nursing
- (15) Mary Ann Evans Hospice
- Toe's Place





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

of the population from minority ethnic groups

languages spoken in Coventry and Warwickshire

Most common languages spoken (after English)

Coventry

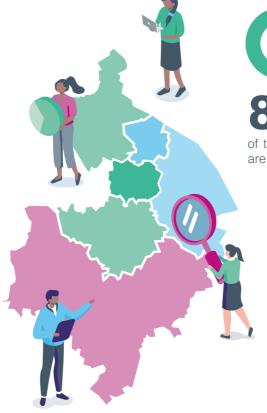
Warwickshire

- Bengali - Polish
- Polish - Punjabi
- Urdu
- Gujurati
- Tamil
- Nepalese
- Punjabi

- Urdu

English is a second language for 14% of Coventry residents





Warwickshire has an older population with

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

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



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







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



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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



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



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.







Page

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

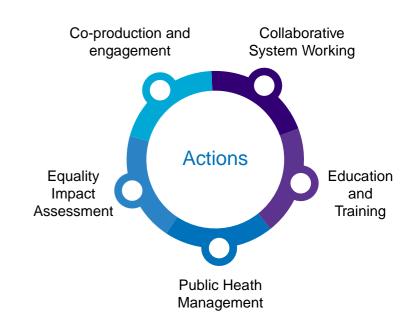
Actions we will take to promote Health Equity in Palliative and End of Life Care

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.







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.

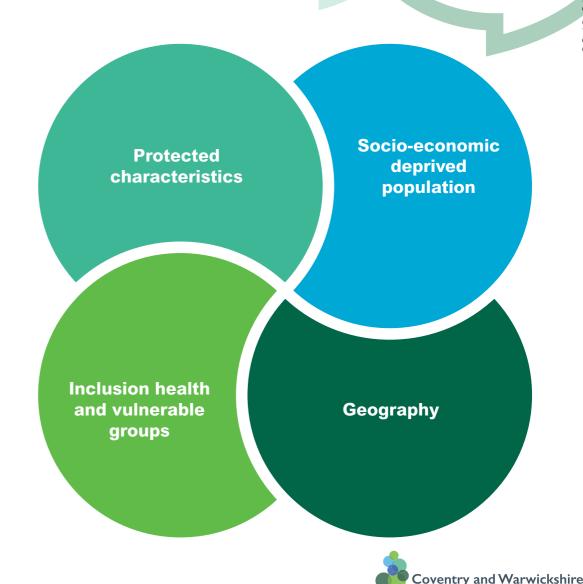
We have identified greater differences in access to palliative and care at the end of life for:

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





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:

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- 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.





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PEoLC Delivery Plan - Overview

Key priorities

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



Areas of focus

- 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



How we will deliver improvement: PEoLC Delivery Plan - Overview

Key priorities

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



Page

3. Support people diagnosed with a life limiting condition and those who matter to them. carers and communities.



Areas of focus

- 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.
- 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



How we will deliver improvement: PEoLC Delivery Plan - Overview

Key priorities

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.

Areas of focus

- Development of an Education & Training Framework for Palliative and End of Life Care
- Dying Matters: a systemwide approach to awareness raising



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5. Deliver a **sustainable** system



- A comprehensive systemwide review of workforce, pathways, roles and responsibilities.
- Integrated Commissioning Model: contracts and funding review.



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)





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Some of our Partnerships



































Appendix 1

Coventry and WarwickshirePalliative and End of Life CareStrategy Delivery Plan



Palliative and End of Life Care Strategy

2024-2029

Delivery Plan:
P January 2024 - December 2026



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
Page 2	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 PEolC 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
45	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)

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	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
Page	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"
9 46	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)

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	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
Page	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.
47	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.



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
Page	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.
ח ה	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
D	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
ייי ער	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
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_	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
Dyn	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
ው አ <i>ለ</i>	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

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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 coproduction 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.

Duicuit	Van Cald	We Did				
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 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 				
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 				

		We Did				
Priority	You Said	We Did				
Priority 3: Support	 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 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 	 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 				
Priority 4: Improve	 Palliative and end of life care in care homes 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 	the delivery plan				



5	V	The second secon			
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 	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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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	Senior Responsible Officer:	Tracy Pilcher				
	Kate Butler: Project Manager	Quality Review:	20 th July 2023				
		Equality Review:	20 th 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 coproduced 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.

	ICB: Kathryn Drysdale & Kate Butler Input from:
Name of person completing assessment:	 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	rage
Date of Assessment:	4/07/2023	
Quality Review by:	Mary Mansfield	0
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.

			OUTCOME ASSESSMENT (Please tick one)		Evidence/Comments for answers	(For	Risk rating (For negative outcomes)		Mitigating actions
AREA OF ASSESSM	IENT	Positive	Negative	Neutral		Risk impa ct (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.	Laga Ge
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.	rage 4 01 55
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		Page 6 of 55
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	V	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.	Page 7 01 33
Helping people from episodes of 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 ca people in a environment protecting them avoidable harm	and	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 coproduction 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 coproduction and community led approach to care.	Page 10 of 55
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.			Page 11 of 55
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.		age Z of Sign
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 underserved communities to be better understood and addressed and therefore increasing patient choice. Where feasible and clinically appropriate remote, digital, and selfmanagement 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	Tage 13 01 33
			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		1	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)
 - o 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.
- o 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.
 - o 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 research¹ has evidenced that certain groups of people receive inequitable access to palliative and end of life care than others with a comparable need. These identified groups include:

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

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

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

Over-arching evidence considered in this review:

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

Over-arching PEoLC evidence considered in this review:

- The Kings Fund (2023) Dying well at home: commissioning quality end-of-life care
- BMC (2023) <u>How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease?</u> A mixed methods systematic review
- BMJ (2023) <u>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.</u>
- Palliative medicine (2023) <u>Palliative and end of life care needs, experiences and preferences of LGBTQ+ individuals with serious illness; A systematic mixed-methods review.</u>
- BMJ (2022) Ethnicity and palliative care: we need better data five key considerations
- BMC Palliative Care (2022) <u>The end of life experiences of people living with socio-economic</u> deprivation in the developed world: an integrated review
- EAPC (2022) <u>Understanding parent experiences of end of life care for children: a systematic review and qualitative evidence synthesis</u>
- NHSE (2021) <u>Ambitions for Palliative and End of Life Care</u>
- 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) <u>Exploring socio-economic inequities in access to palliative and end of life</u> care in the UK: a narrative synthesis
- Cancers (2021) <u>Socio-economic deprivation and symptom burden in UK Hospice patients with</u> 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) <u>Challenges of Providing Palliative Care to a Patient with Learning Disability: A</u>
 Case Study from UK general practice
- BMJ (2021) <u>Specialist palliative care services response to ethnic minority groups with Covid-19:</u> 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) <u>A systematic review exploring palliative care for families</u> who are forced migrants
- BMJ (2020) Hospice care access inequalities: a systematic review and narrative synthesis
- European Association for Palliative Care (2020) <u>The palliative care needs of adults with</u> intellectual disabilities and their access to palliative care services: systematic review
- Manchester Metropolitan University and Community Fund (2019) <u>Good Practice Guidance</u>.
 Supporting people with substance abuse problems at end of life
- Manchester Metropolitan University (2019) <u>Palliative end of life care for people with alcohol and drug problems</u>
- NHSE (2019) Achieving more for people with severe mental illness
- NHSE (2018) <u>Care committed to me delivering high quality, personalised palliative and end of life care for Gypsies and Travellers, LGBT people and people experiencing homelessness.</u>
- 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) <u>Palliative and End of Life care for Lesiban, Gay, Bisexual and Transgender (LGBT) Cancer Patients and their caregivers</u>
- BMC Palliative Care (2018) <u>Palliative care for homeless people: a systematic review of the concerns, care needs and preferences and the barriers and facilitators for providing palliative care</u>
- 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) <u>The Challenges of providing palliative care to terminally ill prison inmates in the UK.</u>

Data sources:

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

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

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

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

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

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

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

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

³ Health Services in the last 2 years of life – Coventry and Warwickshire STP, A report by The Strategy Unit, 1 October 2020 21

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

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

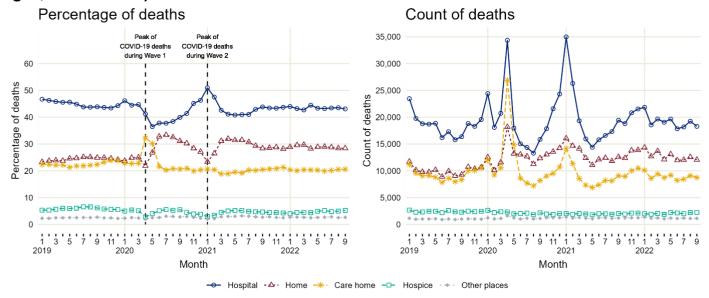
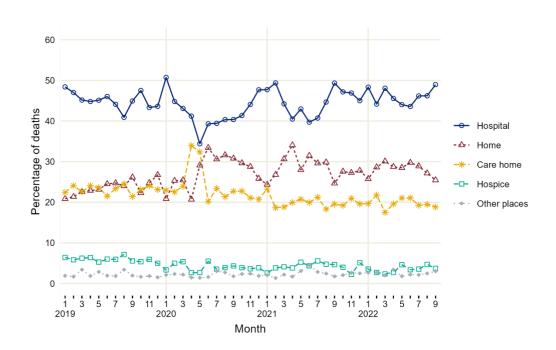


Figure 2: Monthly trend (%) in deaths (all ages) by place of death: NHS Coventry and Warwickshire CCG (2019 to 2022)



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

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

⁴ Public Health England, Palliative and End of Life Care Profiles.

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

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

2. Impact and Evidence:

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

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

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

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



- The greatest number of deaths is among those aged 85 and above. This is also the group with the largest expected increase.
- Use of emergency admissions and A&E attendances does not differ greatly by age at death. What
 drives use of these services is not age, but proximity to death.
- Whilst end of life/palliative care can cover all ages articles such as <u>Palliative care for frail older people</u> (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

⁶ Age Disparities Report (mariecurie.org.uk)

⁵ Palliative care for frail older people - PMC (nih.gov)

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 endof-life in frailty compared to other conditions.
- Poor symptom control was an issue described by some in the frail group and related to patients'
 experience of negative side effects, physicians' concerns about the potential exacerbation of other
 difficulties and normalisation of pain in older people leading to delays in recognising and addressing
 treatable problems.

Children

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

The following areas were identified:

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

The place of death was affected by various factors.

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

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

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

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

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

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

National data collected through the Family Resources Survey (<u>Family Resources Survey: financial year 2020 to 2021 - GOV.UK</u> (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 (<u>PANSI, 2021</u>) 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 a nd 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 F INAL 2.pdf highlighted lack of staff knowledge, poor understanding of the Mental Capacity Act, and communication problems as significant barriers to good care.

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

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

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

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

Life expectancy

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

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

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

Causes of death

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

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

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

Palliative care

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

This includes, for example:

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

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

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

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

Equity of access

There is growing evidence that people with intellectual disabilities face significant barriers in accessing health services, including palliative care services (Emerson & Hatton 2013). In 2016, the Care Quality Commission (CQC) carried out a review of inequalities in end of life

care https://www.cqc.org.uk/sites/default/files/20160505%20CQC EOLC OVERVIEW FINAL 3.pdf a nd 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 F INAL 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: <u>The route to success in end of life care - achieving quality for people with learning disabilities</u>

PEoLC Programme

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

Mental Health

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

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

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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 SMI¹⁰.

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

Physical Disability

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

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

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

PEoLC Programme

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

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

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

¹⁰ Powis (2019)

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

¹² Belperio et al (2022)

privacy of data and harassment.

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

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

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

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

<u>The Last Outing</u>: 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) <u>Dementia and end of life care for black, asian and minority ethnic</u> communities

In the Equality Act, this characteristic is described as:

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

Coventry: (2011 Census data)

65.5% White,

18.5% Asian, Asian British or Asian Welsh

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

3.4% Mixed or Multiple ethnic group

and

3.7% of other ethnic groups.

Warwickshire: (2011 Census data)

Stratford on Avon

95.5% White,

1.9% Asian, Asian British or Asian Welsh

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

1.7% Mixed or Multiple ethnic group

and

0.5% other ethnic group.

Warwick

84.6% White,

9.7% Asian, Asian British or Asian Welsh

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

3.0% Mixed or Multiple ethnic group

and

1.6% of other ethnic groups.

North Warwickshire

96.1% White,

1.3% Asian, Asian British or Asian Welsh

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

1.7% Mixed or Multiple ethnic group

and

0.3% of other ethnic groups.

Nuneaton & Bedworth

87.1% White,

8.0% Asian. Asian British or Asian Welsh

1.8% Black or Black British, Black Welsh, Caribbean or African

1.8% Mixed or Multiple ethnic group

and

1.2% of other ethnic groups.

Rugby

85.7% White,

7.6% Asian, Asian British or Asian Welsh

2.7% Black or Black British, Black Welsh, Caribbean or African

2.8% Mixed or Multiple ethnic group

and

1.1% other ethnic group.

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

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

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

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

Language Barriers

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

¹³ Monette et al 2021

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

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

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

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

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

Issues include understanding dietary requirements, religious prayer (and access to the appropriate chaplaincy), release of the deceased body in time for cultural or religious rituals to commence. All these factors contribute to individuals making decisions on end-of-life care. It has been suggested that cultural competency is paramount in helping individuals to make an informed decision and where there is a lack of cultural competency amongst care providers, service users will not access services 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 Muslims¹⁶.

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

Sex: A man or a woman

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

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

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

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

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

¹⁴ D. Silva et al (2016)

¹⁵ Mayeda et al (2019)

¹⁶ <u>i437-muslim-council-report_en.pdf</u> (mariecurie.org.uk)

LGBTQ+

Marie Curie (2016) <u>"Hiding who I am" The reality of end of life care for LGBT people</u>
Marie Curie <u>Palliative and end of life care for LGBTQ+ people</u>
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 scc-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 <u>UK official statistics on homelessness: Comparisons, definitions, and processes</u>

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) <u>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</u>

The University of Sheffield and Crisis (2012) Homelessness kills

Homelessness Statistics

Between April to June 2022:

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

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

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

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

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

Key barriers for Homeless people:

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

Prisoners

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

Centre for Policy on Ageing (2016) Diversity in older age – Older offenders

Hospice UK (2021) Dying behind bars. How can we better support people in prison at the end of life? Ministry of Justice Safety in Custody quarterly

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

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

Key Barriers for prisoners

- The following article explores barriers within prison systems End of Life Care in Frailty: Prisons |
 British Geriatrics Society (bgs.org.uk)
- A key issue is that a high proportion of older prisoners are convicted sex offenders, which is 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 (bigpopen.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			

		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:

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

included in the strategy.	

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.
 - o How to sensitively explore identity, relationships and identify key important people in their life (next of kin, partners, friends, and wider networks).
 - o 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.
 - o How to provide sensitive, consciously inclusive, and appropriate care services which acknowledges and involves an individual's partner or chose family.
 - o 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.
 - o 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 <u>LGBTQ+: Living with dementia |</u>
 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	2. Disability	June – July 2020	July 2020.
service.			

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	ree	13/9/2023
	TRACY PILCHER	
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.



Adult Social Care and Health Overview & Scrutiny Committee

15th November 2023

Council Plan 2022-2027 Integrated Performance Report Quarter 2 2023/24

Period under review: April 2023 to September 2023

Recommendations

That the Committee considers and comments on Quarter 2 2023/24 organisational performance, progress against the Integrated Delivery Plan, management of finances and risk.

1. Executive Summary

- 1.1 This report is a retrospective summary of the Council's performance at the end of Quarter 2 (April 2023 September 2023) against the strategic priorities and Areas of Focus set out in the Council Plan 2022-2027. All information contained within this report has been taken from the Quarter 2 Integrated Performance and Finance reports presented to Cabinet on 9th November. The paper sets out a combined picture of the Council's delivery, performance, HR, and risk:
 - performance is assessed against the Key Business Measures (KBMs) contained within the agreed Performance Management Framework (PMF) in Section 2 and <u>Appendix 1</u>;
 - progress against the Integrated Delivery Plan is summarised in Section 3 and more fully presented within Appendix 2;
 - management of Finance is summarised in Section 4 and more fully presented in Appendix 3; and
 - management of Risk is summarised in Section 5 and more detailed information is presented in <u>Appendix 4</u>.
- 1.2 This summary report and the detailed performance appendices provide the complete picture of the Council's performance enabling scrutiny and transparency for the organisation, partners and the public. It enables Overview and Scrutiny Committees to consider performance within their own remits. All Members also have continual access to the Performance Management Framework using the Performance Portal in Power BI to further monitor performance on an ongoing basis.
- 1.3 The approach to strategic performance reporting continues to evolve.

 Members will be aware that there is a wealth of information and data, and that

is used in analysis most relevant to the strategic priorities. At a service level, there is also additional performance data which allows managers to manage the performance of the service day to day. In addition, Government is developing the 'Office for Local Government' (Oflog) and Council Officers are seeking to collaborate with Oflog to ensure that a meaningful and useful data set is developed to support improvement in a proportionate manner. As such, it is our aim that we streamline our performance data over the next year or so, to ensure that Members have the right and most useful performance data possible, considering any national metrics emerging from Oflog.

- 1.4 There are some key themes that emerged last year that continue to be highlighted in the Cabinet report, and are impacted by WCC's current operating environment, including:
 - Increasing demand and costs being reported in Children & Families Services, Adult Social Care, SEND provision, Home to School Transport and in the number of applications made through the Local Welfare Scheme;
 - demand increasing much more quickly than resources is resulting in the capacity and workload issues, which has a further impact on delivery across the organisation, evidenced through staff feedback and addressing this is acknowledged as a high priority for the organisation;
 - difficulties in recruiting and retaining staff in a highly constrained national and local labour market were highlighted throughout 2022/23 and although overall there has been some improvement issues remain within specific service teams for example Children & Families, Social Care and Support, Waste & Environment, Schools, Commercial and Contracts, On-Call firefighters and Planning officers; and
 - other services have specific challenges such as staff absence levels in Business & Customer Services and Social Care and Support.

Planned improvement activity to address these issues is described in section 4 of the 9th November Cabinet report.

1.5 The 2023/24 PMF was agreed at the June Cabinet meeting and, of the 105 KBMs detailed in that PMF, 91 are available for reporting in Quarter 2. The remaining 14 that are not being reported are all new measures to the PMF and not due for reporting until Quarter 3 or Year End. There are 18 KBMs within the remit of this Committee, and 17 KBMs are available for reporting this Quarter. There is one other measure that is newly included this year and will be reported from Quarter 3. Table 1 below indicates the current assessment of performance:

Quarter	On Track	Not on Track
1	64.7%(11)	35.3%(6)
2	70.6% (12)	29.4% (5)

Table 1

Table 2 below indicates the Direction of Travel (retrospective comparison), however, please note not all measures have a status e.g. where they are new and there is no previous baseline:

Direction	On Track		Not on Track			
of Travel	Improving	Static	Declining	Improving	Static	Declining
Quarter 1	56%(5)	22%(2)	22%(2)	16.7%(1)	16.7%(1)	66.7%(4)
Quarter 2	63.6%(7)	18.2%(2)	18.2%(2)	0%(0)	20%(1)	80%(4)

Table 2

Table 3 below indicates the future projection forecast for the next reporting period:

Forecast	On Track		Not on Track			
Forecasi	Improving	Static	Declining	Improving	Static	Declining
Quarter 1	64%(7)	36%(4)	0%(0)	83%(5)	0	17%(1)
Quarter 2	66.7%(8)	33.3%(4)	0%(0)	20%(1)	60%(3)	20%(1)

Table 3

- 1.6 At Quarter 2, with a refreshed PMF and with 1 more measure being reported as On Track this Quarter, the overall position is an improvement to Quarter 1 where 64.7% of KBMs were reported as On Track and 35.3% Not on Track. This continues strong performance delivered against the PMF which is an encouraging position against the continuing volatile, uncertain, and high-risk operating environment. Appendix 1 details information for all measures within the PMF, including reasons why some measures are not being reported. Detailed measure-by-measure performance reporting is accessible through the Performance Portal.
- 1.7 The position is also positive in terms of delivery of the 23 Adult Social Care actions set out in the Integrated Delivery Plan, with 100% being On Track.
- 1.8 At the end of the first quarter the services reporting to ASC OSC are forecasting a cumulative overspend of £8.117m (after transfers from earmarked reserves are accounted for), this is equivalent to 3.3% of their revenue budget. Saving targets are forecast to be underachieved by £5.969m that represents 87% of the current year's target. The delivery of capital schemes remains on track.
- 1.9 The strategic risk register has been refreshed over Quarter 2 and there are now 7 strategic risks. Three of which may impact on Adult Social Care and Health more directly and these strategic risks are: inability to keep vulnerable children and adults safe, which is low risk; a mismatch between demand and resources, which is high risk; and insufficient skilled and experienced

- workforce, which is medium risk. At the service level there is one risk highlighted, workforce shortages, which is red (high risk) and higher than the risk target for 3 quarters or more and 3 points or more over target.
- 1.10 The wider national context remains a critical frame within which to view the Council's performance. The UK continues to experience the consequences of both significant political, global and macro-economic factors. This includes increasing demand, industrial action across many sectors, the legacy impact of the Pandemic, global conflict, high inflation and interest rates and the resulting fiscal challenges are impacting the communities of Warwickshire.
- 1.11 Such an unprecedented combination of events at a global and national level creates a period of significant uncertainty and a very challenging financial outlook in the short- to medium-term. This volatility is impacting on the Council's resources, both financial and in terms of recruitment and retention, levels of demand, and the approach to developing national policy, particularly Adult Social Care reform, levelling up, support for cost-of-living pressures and climate change.
- 1.12 Performance reporting will continue to track and highlight the impacts of this operating environment on delivery and performance. Ongoing analysis continues to inform the prioritisation of activity and resource allocation of the Integrated Delivery Plan and the Performance Management Framework.

2. Performance against the Performance Management Framework

- 2.1 The three strategic priorities set out in the <u>Council Plan 2022 2027</u> are delivered through seven Areas of Focus. In addition, there are three further themes that will help the Council to be known as 'a Great Council and Partner'. The full performance summary is contained in <u>Appendix 1</u>.
- 2.2 Comprehensive performance reporting is enabled through the Power BI

 Performance Portal as part of the Performance Management Framework.

 Where applicable, some performance figures may now have been updated on the Power BI reporting system. The number of reportable measures will change each quarter as the framework considers the availability of new data.
- 2.3 Of the 17 KBMs which are being reported at Quarter 2, 70.6% (12) are On Track and 29.4% (5) are Not on Track.
- 2.4 Notable aspects of positive performance for specific measures include:
 - The No. of people supported to live independently through provision of Social Care equipment has been continuously above target for the last year. It is predicted demand for the service will continue to grow based on the current successes of the service, forecast demand with demographic data showing an aging population for Warwickshire, and the programmes and initiatives within health and social care to promote the aim of customers staying in their own home and receiving home-based support to remain independent.

- This Quarter the % of people with long term support who have had an
 assessment or review in the last 12 months reached and exceeded the
 target. This is a new measure introduced at the start of the financial year
 and has been steadily increasing each month. This is positive as regular
 reviews benefit customers and carers by ensuring needs are continuously
 met and crises are pre-empted.
- 2.5 There are some emerging performance challenges that are becoming apparent through the PMF this Quarter:
 - Demand is rising for social care for those over 65, with the No. Of people currently in residential or nursing placement: over 65 reaching 1862 this Quarter, which is in comparison to a target of 1600 and a figure of 1625 one year ago in September 2022.
 - Alongside this the % of people open to Adult Social Care with eligible needs living in the community with support over the age of 65 has been slowly declining and has been consistently below the target for almost one year. This is in part due to increased frailty and carer strain, and further analysis is being undertaken to identify what other causes are leading people going into residential settings. It is worth noting that rising residential or nursing placements for older people can also be seen as a positive indication that care providers are maintaining the health and wellbeing of older customers.
 - Linked to this, Social Care and Support have been reporting an overspend in the older people's service across the provision of residential, nursing and domiciliary care. This pressure is due to unexpected increases in the unit cost of support, alongside an increase in the number of people requiring support. Action being taken includes restricting spend on nonstatutory services, increased reviews and improved joint working with Health colleagues. Further information can be found within the Financial Monitoring Report.
- 2.6 There are 16 measures of the 17 available for reporting where there is enough trend data available to ascertain a Direction of Travel. 68.8% (11) of measures have a Direction of Travel that is On Track, the majority of which are improving (7) or static (2), 2 have been declining. Conversely, 31.3% (5) are Not on Track, the majority (4) of which are declining.
- 2.7 All 17 reportable KBMs have a forecast projection from the responsible service for the forthcoming period. Of the 12 measures that are forecast to be On Track at Quarter 2, 8 are forecast to improve further with the other 4 to remain static in that position. Of those 5 that are forecast to be Not on Track, the majority (5) are forecast to improve by Quarter 2. As already described No. of people supported in residential or nursing care: over 65, performance is forecast to decline further at the next reporting period, full details can be found within Appendix 1 and the Performance Portal.
- 2.8 The projection provided at Quarter 1 for Quarter 2 was broadly accurate for those measures that remain in the new PMF.

A set of high-level, cross-cutting, long-term Warwickshire Outcome Measures, which the Council can influence but are not solely responsible for, are also contained in the Performance Management Framework. These are reported within a <u>dashboard</u> informing the ongoing State of Warwickshire reporting and includes Levelling Up and the Cost of Living metrics. A summary position will be included in the Year End Integrated Performance Report.

3 Progress against the Integrated Delivery Plan

- 3.1 The Integrated Delivery Plan aligns priority activity from across all service areas against all Areas of Focus within the Council Plan 2022-27. The plan shows how activity across services collectively contributes to delivering these priorities.
- 3.2 Detailed information on the performance summary of the Integrated Delivery Plan is included at <u>Appendix 2</u>. A new <u>Power BI reporting dashboard</u> is now available and will enable Members to track progress by Service, status, Council Plan Area of Focus, Overview and Scrutiny Committee and Portfolio Holder.
- 3.3 Of the 197 actions within the Integrated Delivery Plan, 23 are attributable to the Adult Social Care OSC. 100% of deliverables are On Track. Detail can be found in Appendix 2.

4 Management of Finance

- 4.1 The key metrics of financial management are summarised below with further information available in Appendix 3 and in the Quarter 2 Finance monitoring Report presented to Cabinet on 9th November 2023.
- 4.2 In response to the forecast overspend that emerged at Q1 Corporate Board developed an action plan aiming to contain and minimise the 2023/24 overspend, ensure the nature and impact of pressures is understood and key staff members as well as elected members are engaged in identifying solutions and developing long term transformation plans.
- 4.3 As part of the Financial Recovery Strategy all Directors with a forecast overspend have been asked to develop a Financial Recovery Plan with primary focus on the areas of Social Care and Support, Children and Families, SEND (linked to the Delivering Best Value plan), Home to School Transport and Enabling Services (utilities).
- 4.4 As part of the strategy a review of short-term budget balancing options is taking place as well as a review of all transformation activity.
- 4.5 The impact of the Financial Recovery Strategy on both one-off and permanent cost will be reflected in the MTFS when it is presented to Cabinet in December 2023.

Metric	Target	Performance at Q2 2023/24
Performance against the latest approved revenue budget as measured by forecast under/overspend	On budget or no more than 2% underspent	5.2% overspend
Performance against the approved savings target as measured by forecast under/overachievement	100%	87% not achieved
Performance against the approved capital programme as measured by forecast delays in delivery	No more than 5% delay	1.1%

5 Management of Risk

- 5.1 Risks are monitored in risk registers at a strategic level and at service level. At a strategic level the following strategic risk are more related to Adult Social Care, whilst also being relevant for Children and Young People Overview & Scrutiny Committee:
 - being unable to keep the vulnerable children and adults safe, medium
- 5.2 Mitigating controls are in place including the Council Plan and Integrated Delivery Plan, which have driven priority initiatives. An Adult Social Care Strategy is being developed to further set out the aspirations of the area, Adult Social Care Plans are in place and associated action plans are being monitored and updated as necessary.
- 5.3 Additional strategic risks, which are rated red, high level, may also impact on the activities associated with the Committee and these are a mismatch between demand and resources and insufficient skilled & experienced workforce. Mitigating controls are in place and actions in development to help further manage these risks.
- 5.4 At a Service level there are 16 risks recorded against services relating to this Committee. There is one red, high level, risk highlighted where the risk level has been higher than the risk target for 3 quarters or more and 3 points or more over target, a table illustrating this information is provided at Appendix 4. This risk is:
 - workforce shortages.

- 5.5 There are two risks which are red. These risks have not exceeded their respective targets for three quarters in a row, as follows:
 - market failure and lack of sustainability of the care market; and
 - · demand for services and current market forces.
- 5.6 Mitigating controls are in place in relation to these key risks, including an overarching People Strategy, applicable to all service areas and specific activity in adult social care to support the commissioned suppliers in recruitment, training and retention. The use of a market viability framework, use of market intelligence, market shaping, developing dashboards to highlight providers at risk and greater use of the data to enhance effectiveness of projections.
- 5.7 Additionally, collaborative working across the Council and with partner organisations, reviews of public health priorities against available resources, enabling community and Voluntary and Community Sector (VCS) driven solutions, and involvement in the engagement with the Integrated Care Systems are all being progressed. However, wider environmental pressures continue to be a challenge and influence the market for both services and the availability of resources.
- 5.8 Over the summer, strategic risks have been reviewed and updated to ensure that the most significant risks are captured. Over the course of the autumn and winter periods, aspects of the Strategic Risk Management Framework will be refreshed along with any implications for the practical application of the Framework to ensure all aspects are fit for purpose.

6 **Environmental Implications**

6.1 There are none specific to this report.

Appendices

Appendix 1 – Quarterly Performance Report

Appendix 2 – Progress on the Integrated Delivery Plan

Appendix 3 – Management of Financial Risk

Appendix 4 – Management of Risk

Background Papers

Cabinet Report 9th November 2023

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Holder	Holder for Adult Social Care &	
	Health	



1. Adult Social Care OSC Quarterly Performance Report Quarter 2

- 1.1 Detailed measure-by-measure performance reporting is accessible through the **Performance Portal**.
- 1.2 The three strategic priorities set out in the Council Plan 2022 2027 are delivered through seven Areas of Focus. In addition to these, there are three further areas to support the Council to be known as 'a Great Council and Partner'. These are detailed in the table below alongside the number of KBMs that will be used to assess delivery, and the number being reported at Year End.

Area of Focus	No. of KBMs	No. of KBMs available for reporting this Quarter
Create vibrant places with safe and inclusive communities	8	8
Deliver major infrastructure, digital connectivity and major transport options	17	14
Promote inclusive, sustainable economic growth, successful business, good quality jobs and future skills	9	8
Tackle climate change, promote biodiversity and deliver on our commitment to Net Zero	7	4
Deliver our Child Friendly Warwickshire strategy - Happy, healthy, safe children	7	6
Through education, improve life opportunities for children, young people and those with special educational needs and disabilities	21	17
Support people to live healthy, happy, and independent lives and work with partners to reduce health inequalities	21	19
A Great Council and Partner	No. of KBMs	No. of KBMs available for reporting this Quarter
Harnessing community power	3	3
Our people and the way we work	8	8
Using our data and digital solutions to improve service delivery	4	4

1.3 Key Insights for Quarter 2 2023/4

There are 18 KBMs in total that are in the remit of this Committee. Chart 1 details the reported status of the 17 KBMs which are being reported at this Quarter. One other measure is new to the Performance Management Framework and a mechanism for accurate data collection is currently being investigated; this measure will be reported on later in the performance year.

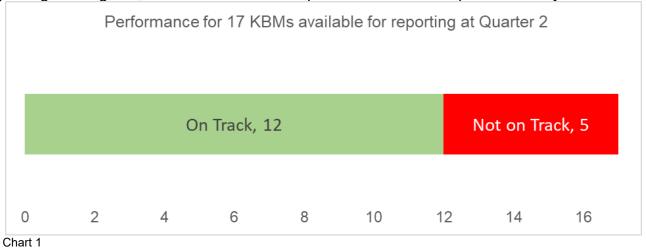


Chart 2 details the overall Direction of Travel, where trend data is available, assessing whether the performance has been improving or declining.

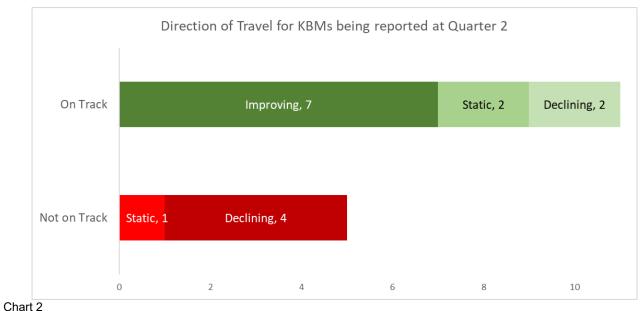
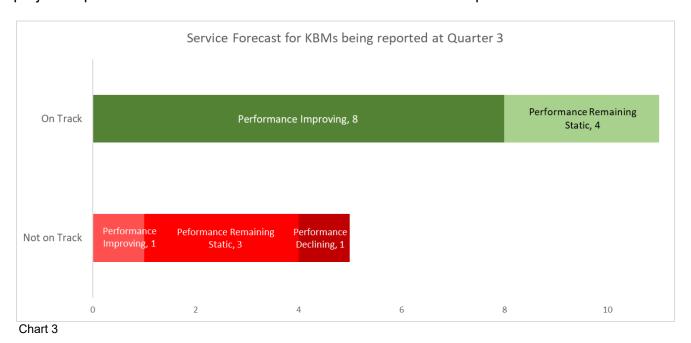


Chart 3 details the projected performance based on the Service forecast of the 17 reportable KBMs at the next Quarter.



Explanatory Notes on Summary Tables

The following sections provide an overview of current performance by Area of Focus. The measure summary tables are a representation of the tables in the full Committee report on Power BI and are interactive. Please note:

- data is being added into the system as it becomes available so new information may be in the reports since the writing of this Quarterly position report;
- measure names in the summary tables and where highlighted are all links to take the reader directly to the measure report page in Power BI which provides full detail on the measure including charted data, performance narrative, improvement activity, trends and targets if applicable;
- a measure status is included based on performance either against the target and polarity of measure or where there is no target on improving/ declining performance;
- Services provide a forecast of where performance is heading over the next reporting period, this is informed by local knowledge, improvement activity and trend information;
- where the measure status or projection is Not Applicable, this is due to exceptional circumstances regarding the measure such as it is setting a baseline this year, the Power BI report will provide the reason by measure;
- the Latest Figure column represents the most current data available including last quarter, previous year or longer if data is lagged, full details are on Power Bi report;

- not all measures have targets and the approach now is to have improving performance and targets where appropriate;
- Direction of Travel is an indication of whether performance is improving based on trend data where available; and,
- as the framework is more responsive there are annual or termly measures included on the tables with no reported data, this will be added as the relevant data becomes available e.g. attainment data from November.

1.4 All measures in the remit of this Committee support the Area of Focus: **Support people to live healthy, happy, and independent lives and work with partners to reduce health inequalities**

	Measure Name	Latest Actual	Target	Measure Status	Direction of Travel	Service Forecast for next period
	% of people open to Adult Social Care with eligible needs living in the community with support under the age of 65	82	82	On Track	Static	On Track Performance Remaining Static
	% of people open to Adult Social Care with eligible needs living in the community with support over the age of 65	57	60	Not on Track	Declining	Not on Track Performance Remaining Static
D	No. of people supported to live independently through the provision of social care equipment	1,074*	1,500	On Track	Improving	On Track Performance Improving
700	No. of unique carers to receive support in month	252	255	On Track	Improving	On Track Performance Improving
	No. of carer assessments and reviews completed	133	133	On Track	Improving	On Track Performance Improving
	% of people with long term support who have had an assessment or review in the last 12 months	82	80	On Track	Improving	On Track Performance Improving
	% of Adult Social Care users receiving a Direct Payment at the end of the month	22	25	Not on Track	Static	Not on Track Performance Remaining Static
	No. of people awaiting a domiciliary care package to be commissioned at the end of the month	6	25	On Track	Improving	On Track Performance Improving
(No. of providers that exit the care home, domiciliary care or supported living markets, in Warwickshire, through business failure	0	0	On Track	Static	On Track Performance Remaining Static
	No. of people supported in residential or nursing care: under 65	393	380	Not on Track	Declining	Not on Track Performance Improving

Measure Name	Latest Actual	Target	Measure Status	Direction of Travel	Service Forecast for next period
No. of people supported in residential or nursing care: over 65	1,862	1,600	Not on Track	Declining	Not on Track Performance Declining
No. of people with a learning disability or autism in an inpatient unit commissioned by the ICB	9	9	On Track	Improving	On Track Performance Improving
No. of people awaiting allocation for an assessment	New annual measure due for reporting at Quarter 3				
% Smoking prevalence in adults	13.9	13	On Track	N/A insufficient trend data	On Track Performance Improving
% of successful completions as a proportion of all in treatment (Opiates)	5.89	4.8	On Track	Improving	On Track Performance Remaining Static
% of successful completions as a proportion of all in treatment (Non Opiates)	28.51	37.2	Not on Track	Declining	Not on Track Performance Remaining Static
% of successful completions as a proportion of all in treatment (Alcohol)	29.23	27.6	On Track	Declining	On Track Performance Improving
% of successful completions as a proportion of all in treatment (Non Opiates and Alcohol)	22.22	21.7	On Track	Declining	On Track Performance Remaining Static

^{*} Please note that his figure accounts for only two out of the three months in the Quarter. A full and final figure will be updated in Power BI once available.

At Quarter 2 performance within this Area of Focus is within expected levels and most measures (12 out of 17 being reported) are On Track and forecast to remain On Track with either static or improved performance at the next reporting period. This is an almost identical position to Quarter 1, with all measures that were On Track at Quarter 1 remaining On Track at Quarter 2. One additional measure has moved to On Track this Quarter; % of people with long term support who have had an assessment or review in the last 12 months. Despite increased demand, this measure has been steadily improving since the start of the performance year. For the 5 measures that are Not On Track at Quarter 2, 3 are forecasting static performance and 1 is forecast to improve over the next Quarter. The No. of people supported in residential or nursing care: over 65 has been declining to date, and is set to continue to decline further due to an overall increased demand for residential and nursing placements for older people.

Area of good progress as despite increases in demand in this area, performance consistently remains high:

- No. of carer assessments and reviews completed
- No. of people awaiting a domiciliary care package to be commissioned at the end of the month
- No. of people supported to live independently through the provision of social care equipment

• % of people with long term support who have had an assessment or review in the last 12 months

Improvement activity as experiencing increased demand for older people, with a reducing trend in performance:

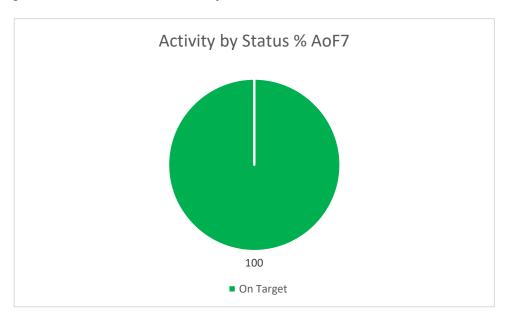
- % of people open to Adult Social Care with eligible needs living in the community with support over the age of 65
- No. of people supported in residential or nursing care: over 65

²age 139

1. Adult Social Care OSC Progress on the Integrated Delivery Plan Quarter 2

1.1 Key Insights for Quarter 2 2023/24

Of the 206 actions within the Integrated Delivery Plan, 23 are attributable to the Adult Social Care OSC. There is positive progress within this Quarter with all activities being on track to achieve their objectives within the set timeframes.



There are no exceptions to report upon this Quarter.

2 The following activities are On Track

Activity

Implement the Market Sustainability Plan across all adult social care markets, constructed as part of the Fair Cost of Care exercise.

Develop a strategic plan for accommodation-based care services for adults, informed by a needs assessment, the Adult Social Care strategy, the national Cost of Care requirements and funding programmes.

Support the development of Integrated Pathways including services and interventions for vulnerable people to include Falls, Stroke, Frailty, dementia and Hospital to Home: Propose and implement changes to the current Warwickshire health and social care discharge arrangements to reflect national hospital discharge policy and meet operational requirements.

Support the development of Integrated Pathways including services and interventions for vulnerable people to include Falls, Stroke, Frailty, dementia and Hospital to Home: Commencement of the "Living Well with Dementia" strategy Delivery Plan and work with key partners and stakeholders to deliver the Year 1 priorities, overseen by the Delivery Board.

Improve the offer of Assistive Technology (AT) solutions to support people in Warwickshire to stay safe, healthy and independent to include: Umplementing and reviewing 2 pilots that can demonstrate the range of opportunities to support customers to regain and maintain their independence.

Expanding the Assistive Technology (AT) solutions to support people in Warwickshire to stay safe, healthy and independent to include: Expanding the Assistive Technology offer in Warwickshire through procurement of a service to deliver a wide range of AT solutions, including life-line provision and self-assessment for customers wishing to purchase their own equipment.

Support partners with the implementation of the Warwickshire Homelessness Strategy, including the continued commissioning of the Homeless Physical Health Nursing service and completing the Pathway Needs Assessments for all the local NHS trusts.

Promote the benefits of healthier lifestyle choices and provide effective services and support to enable people to make sustained improvements: Support the continued implementation of the national diabetes prevention programme working with partners and key stakeholders.

Promote the benefits of healthier lifestyle choices and provide effective services and support to enable people to make sustained improvements: Mobilise the new Healthier Lifestyle services to improve access and deliver a one stop shop approach. This new service will incorporate smoking cessation services.

Improve the mental health and well-being of adults living in Warwickshire: Support the refresh and delivery of the multi-agency suicide prevention strategy for Coventry and Warwickshire.

Establish the strategic role of Extra Care Housing and Specialised Supported Housing in the Council's wider strategies for housing with support and its Adult Social Care Act duties to include: **Developing a 5-10 year plan for Council commissioning of Extra Care Housing and Residential/Nursing Homes that address issues of balance of services**; **projections of future demand**; **adequate capacity in key localities**; **affordability**; **innovative design e.g. to include ' Care Villages' & use of Council Capital/Land**.

Establish the strategic role of Extra Care Housing and Specialised Supported Housing in the Council's wider strategies for housing with support and its Adult Social Care Act duties to include: Reviewing the impact of the Extra Care Housing (ECH) and Specialised Supported Housing (SSH/SHAD) programme to date and plan/commence Phase 2.

Deliver the significant service provision changes that will be needed to meet the new Mental Capacity (Amendment) Act 2019, and its new Liberty Protection Safeguards (LPS) scheme that will supersede current consent arrangements for vulnerable people.

Review the Hospital to Home Service with partners in health to understand impact and make recommendations for future delivery and commissioning.

Develop a Community Recovery Service jointly with health partners as part of the national discharge Front Runner to ensure that all people with all people in hospital, who need further support at home to recover, will have access to effective therapeutic intermediate care services. Unithin 24 hours of no longer meeting the criteria to reside in hospital.

Implement required processes, capability, staff resources and skillsets to successfully manage increased service demand and administer Care Cap.

Prepare and be suitably resourced for CQC inspection of the Adult Service.

Support the delivery of the National Drug Strategy by reviewing the drug and alcohol services to ensure they meet statutory requirements and recommendations from the Needs Assessment; also deliver the Drug and Alcohol Strategic Partnership requirements.

Embed a continuous improvement approach across the Benefits Assessment and Income Charging teams, which will support the on-going redesign of core processes: Embed Better Care Finance self-service portal for financial assessments.

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Management of Financial Risk

1. The table below details performance against the latest approved revenue budget as measured by the forecast outturn position at Quarter 2.

	Approved	Forecast		% Change	Represented by:			
Service Area	Approved Budget			nd from Budget	Investment	Impact on Earmarked	Remaining Service	
					Funds	Reserves	Variance (RSV)	
	£m	£m	£m	%	£m	£m	£m	
Social Care & Support	208.932	220.842	11.910	5.7%	0.000	3.398	8.512	
Strategic Commissioner for People	36.424	37.384	0.960	2.6%	0.000	1.355	(0.395)	
Subtotal	245.356	258.226	12.870	5.2%	0.000	4.753	8.117	

2. Performance against the approved savings target as measured against outturn delivery under/overachievement.

At Quarter 2, Social Care and Support is forecasting 5% (£0.300m) delivery against the 8 saving targets (£6.269m) for the 2023/24 financial year and Strategic Commissioning for People reporting 100% delivery against 3 saving targets (£0.551m).

3. The table below details performance against the approved capital programme as measured by forecast delays in delivery.

Service Area	Approved 2022-23 capital programme	New projects in year	Net over / underspend	Total capital programme	Budget Reprofile	Delays	Forecast In year capital spend	% Delays
	£m	£m	£m	£m	£m	£m	£m	
Social Care and Support	0	0	0	0	0	0	0	0.0%
Strategic Commissioning for people & Public Health	5.870	0.447	0	6.317	0	(0.071)	6.246	-1.1%
Total	5.870	0.447	0	6.317	0	0	6.246	-1.1%

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Strategic Commissioning for People and Public Health - £0.071m:

• Adult Social Care modernisation (£0.071m) Delay in the installation of Changing Places facilities, it is now anticipated that expenditure will take place in 2024/25.

Appendix 4 Adult Social Care OSC Management of Risk

Key Service Risks Summary

Adult Social Care and Health

At a Service level there are 16 risks recorded against services associated with this Committee. Key risks are highlighted where they are red risks (high risk) and where a risk level has been higher than the risk target for 3 quarters or more and is currently 3 points or more over target.

Key Service Risks	Net risk is currently green or amber	Net risk is currently red
Risk level has not exceeded the target for 3 quarters in a row	13 other risks	 (Adult Social Care) Demand for services and current market forces (Adult Social Care) Market failure and lack of sustainability in the market
Risk level has exceeded target for 3 quarters in a row and is currently more than 3 points above target	There are no risks in this category.	(People Strategy & Commissioning) Workforce shortages



Adult Social Care and Health Overview and Scrutiny Committee 15 November 2023

Work Programme

1. Recommendation

1.1 That the Committee considers and approves its work programme.

2. Work Programme

2.1 The committee's work programme is attached at Appendix A to this report. A copy of the work programme will be submitted to each meeting for members to review and update, suggesting new topics and reprioritising the programme.

3. Forward Plan of the Cabinet

3.1 The Cabinet and Portfolio Holder decisions relevant to the remit of this Committee are provided for the committee to consider as potential areas for pre-decision scrutiny. Members are encouraged to seek updates on decisions too. The Portfolio Holder, Councillor Bell has been invited to the meeting to answer questions from the Committee.

Date	Report
14 December 2023	Cabinet: Transfer of Commissioning Responsibility for Falls Prevention and Community Dietetics from Warwickshire County Council (WCC) to Coventry and Warwickshire Integrated Care Board.
14 December 2023	Cabinet: WCC Strategy for Adult Social Care. To seek Cabinet's views on the need to develop a strategy.

4. Forward Plan of Warwickshire District and Borough Councils

4.1 This section of the report details the areas being considered by district and borough councils at their scrutiny / committee meetings that are relevant to health and wellbeing. The information available is listed below. Further updates will be sought, and co-opted members are invited to expand on these or other areas of planned activity.

North Warwickshire Borough Council (NWBC) In North Warwickshire, the meeting structure is operated through a series of boards with reports to the Community and Environment Board. There is a Health and Wellbeing Working Party and a Warwickshire North Health and Wellbeing Partnership (covering both North Warwickshire and Nuneaton and Bedworth). From the NWBC website, the Community and Environment Board met on 16 October. The agenda included an item on Air Quality. The Board will next meet on 22 January 2024. Nuneaton and Bedworth Borough Council (NBBC) The NBBC Housing, Environment and Health OS Panel met on 5 October 2023. There were no items linked to health at this meeting. The next meeting is scheduled for 23 November and includes an update on mental health (CAMHS). For the 1 February meeting the work programme lists the following items: Healthwatch - concerns and priorities George Eliot Hospital - current services and funding situation, including the provision of additional hospice beds Air quality update • Primary Care/General Practice. A report to inform the Panel of the future plans for Primary Care Rugby Borough Council – Overview and Scrutiny Committee (OSC) The Borough Council (BC) has a single OSC with the use of task groups. The OSC met on 11 September. Its agenda included an update on the task and finish group on Access to Emergency Health Care Provision. The next meeting is scheduled for 20 November. Stratford-upon-Avon District Council – Overview and Scrutiny Committee (OSC) The District Council's OSC met on 3 November. The agenda included an update from the Coventry and Warwickshire Integrated Care Board on the provision of healthcare in the District. Warwick District Council – Overview and Scrutiny Committee (OSC) The OSC met on 31 October. There were no items linked to health discussed at the meeting. The OSC will meet again on 5 December 2023 and the agenda includes an update on the HEART (Home Environment Assessment and Response Team) shared service.

5 Task and Finish Groups (TFGs)

The Menopause Services TFG has now held four meetings. Since the last committee the TFG has met with the specialist group Action Menopause Warwickshire and heard from Healthwatch Warwickshire on its menopause survey. On 7 November, the TFG met with staff from Human Resources and Organisational Development, to hear about the range of menopause information and advice available to staff.

6 Briefing Notes

6.1 The work programme at Appendix A lists the briefing notes requested and circulated to the Committee. Members may wish to raise questions and to suggest areas for future scrutiny activity, having considered those briefing notes.

7 Financial Implications

None arising directly from this report.

8 Environmental Implications

None arising directly from this report.

Appendices: Appendix A Work Programme

Background Papers: None

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Director	Sarah Duxbury	Director of Governance and Policy
Executive Director	Rob Powell	Executive Director for Resources
Portfolio Holder	n/a	

The report was circulated to the following members prior to publication:

Local Member(s): None

Other members: Councillor Jo Barker



Adult Social Care and Health Overview and Scrutiny Committee Work Programme 2023/24

Date of meeting	Item	Report detail
15 November 2023	Palliative and End of Life Care Strategy	The Committee will revisit this item to consider formal approval and endorsement of the strategy.
15 November 2023	Quarter 2 Integrated Performance Report	For the Committee to consider and comment on the Quarter 2 Integrated Performance Report (period covering April - September 2023).
15 November 2023	Update on Covid and Flu	The Committee will receive a presentation from Public Health.
14 February 2024	Quarter 3 Integrated Performance Report	For the Committee to consider and comment on Quarter 3 Integrated Performance Report (period covering April - December 2023).
19 June 2024	Year End Integrated Performance Report 2023/24	For the Committee to consider and comment on the Year End Integrated Performance Report 2023/24 (period covering April 2023 to March 2024).
Date TBC	Prescription Ordering Direct	For the Committee to consider a briefing from the Coventry and Warwickshire Integrated Care Board on a case for change for NHS Prescription Ordering Direct.
Date TBC	Annual Health Checks	Added to the work programme at the Chair and spokesperson meeting in March. This item concerns GPs undertaking an annual health check for patients with a long-term mental illness.
Date TBC	Direct Payments	Added to the work programme at the Chair and spokesperson meeting in October. A low proportion of older service users are opting to receive a direct payment. There are a number of contributors, and many are opting for domiciliary care instead. The item could include promotion of the service and career potential, national and focussed recruitment efforts. Also, the challenges in securing care at a reasonable price, and making it easier for people to use the direct payment option.

Date TBC	People aged over 65 supported in a residential or nursing care placement	Added to the work programme at the Chair and spokesperson meeting in October. A challenged area with an increasing trajectory of service need based on population health with an associated budgetary impact.
Date TBC	Stroke Services	Added to the work programme at the Chair and spokesperson meeting in October. Generally, the revised pathway seems to be going well. Areas of focus to include ambulance response times, whether all suspected stroke patients are taken direct to the hyperacute stroke unit at University Hospitals Coventry and Warwickshire, whether other acute trusts had patients arrive at their A&E departments, and onward care in community settings after hospital discharge.
Date TBC	Patients Presenting at Emergency Departments needing Mental Health support.	Added to the work programme at the Chair and spokesperson meeting in October. This concerns patients (both adults and children) presenting at A&E or the emergency department with mental health problems (and no physical health conditions), the length of wait before transfer to a more appropriate service and the support available.

BRIEFING NOTES

Date Requested	Date Received	Title of Briefing	Organisation/Officer responsible	
	4 July 2023	A briefing from the Integrated Care Board on the Community Diagnostic Centres in Warwickshire.	Rose Uwins C&W Integrated Care Board	
28 June 2023	29 June 2023	A councillor asked for more information about greenhouse gas emissions and the Council's performance.	Matt Whitehead Climate Change Programme	
19 April 2023	7 June 2023	The Committee asked for further information on drug and alcohol treatment outcomes, specifically in relation to opiates.	Rachel Jackson Lead Commissioner (Vulnerable People)	
	1 March 2023	Coventry and Warwickshire ICB provided a briefing note to engage about the permanent relocation of Neurorehabilitation Level 2b Beds from Coventry to a specialist rehabilitation centre within Warwickshire.	Rose Uwins C&W Integrated Care Board	

16 November 2022	5 December 2022	Follow up information on the Customer Feedback Report 2021/22, to provide more detail on complaints received by district/borough and local	
21 September 2022	15 November 2022	Addiction outcomes. A briefing to give more background on the 16.2% of successful completions of all treatments, including a breakdown of the data across each district and borough area and by addiction type.	Multi-agency, with the Director of Public Health being the lead for WCC
31 August 2022	12 October 2022	Developing an Integrated Care Strategy and Integrated Care 5 Year Plan for Coventry and Warwickshire (C&W)	Rose Uwins C&W Integrated Care Board
14 July 2022	4 August 2022	Community Hospital Review. Periodic updates will be provided by briefing note and this item will be reconsidered by the Committee in February 2023.	Katie Herbert, Integrated Lead Commissioner, People Directorate

BRIEFING SESSIONS PRIOR TO THE COMMITTEE

ge ,	Date	Title	Description
53	15 November 2023	Performance and Power BI	To demonstrate the capabilities of the Power BI platform in providing up-to-date performance information for committee members.
	TBC	Duties Under the Care Act	Suggested in June 2021, to provide a briefing for the committee on the Council's duties under the Care Act.

TASK AND FINISH GROUPS

ITEM AND LEAD OFFICER	OBJECTIVE OF SCRUTINY	TIMESCALE	FURTHER INFORMATION
GP Services	A follow up review with the key focus being the adequacy of future primary care facilities.	Completed	Review report approved by the OSC, Cabinet and the Health and Wellbeing Board.
Menopause Services	To understand the commissioned NHS services in Warwickshire and the support the Council provides to its staff.	TBC	The TFG has held four meetings to date, most recently on 7 November to hear about the range of menopause information and advice available to staff.

MEMBER DEVELOPMENT SESSIONS

DEVELOPMENT SESSION	DATE	FURTHER INFORMATION
Woodland Strategy	17 November 10.00am	Scott Tompkins and Dave Lowe