Integrated Care Northamptonshire

All-Age Palliative and End of Life Care Strategy

2023-2026

Contents

1. Foreword

Northamptonshire's integrated care system (ICS), Integrated Care Northamptonshire (ICN), is committed to ensuring that individuals nearing the end of their life receive high quality and compassionate care and are supported to live well and to die with dignity in a place of their choosing.

We have a range of providers involved in providing palliative and end-of-life care across Northamptonshire. Not all these providers are commissioned by the system – however, it is integral to the success of the strategy that we work in collaboration, taking a system-wide approach to ensure the delivery of this strategy.

This strategy identifies how we, collectively, as ICN are going to locally implement the national ambitions outlined in the Palliative & End-of-Life Care (P&EoLC) Framework.

In addition, working with our Voluntary, Community and Social Enterprise (VCSE) sector partner organisations we will further explore the views and experiences of our local communities in supporting the development of services which meet the needs of our local population and are aligned with the national ambitions.

The publication of this co-produced strategy is the culmination of many months of work that has brought together the relevant stakeholders involved in P&EoLC across the county to identify how we can further enhance P&EoLC for our communities within Northamptonshire.

We have used this shared knowledge and experience to develop our local Northamptonshire ambitions to improve P&EoLC in line with national regulation, guidance, and our local ICS responsibilities.

2. Vision and purpose of the strategy

This strategy sets out the vision and priorities of the Northamptonshire P&EoLC system and describes how we will improve the quality of life of all-age individuals, their families, and carers, who are living with a life-limiting illness.

Our local vision is to ensure individuals, their families and carers receive person-centred, dignified, and compassionate P&EoLC, including bereavement support, that is coordinated, and specific choices are respected.

It is our intention that all individuals who need care in the last year of life can access P&EoLC in a time frame appropriate to the urgency of their current need and, where possible, in their preferred place of care. This strategy aligns with the Integrated Care Northamptonshire (ICN) Dementia Strategy 2023-2026.

This P&EoLC strategy will begin by addressing the gaps in service provision; proceed to introduce more efficient and coordinated ways of working; and then build the capacity of the system to ensure higher-quality and greater equality of provision of P&EoLC support across Northamptonshire.

To achieve this vision, we have identified the current gaps in service provision (see Section 9: Northamptonshire Ambitions Framework Self-Assessment Tool Findings) using the National Ambitions Self-Assessment Tool, together with local feedback through workshops on wider system issues. As part of this work, we also identified workforce development needs.

This strategy highlights what we wish to do, broadly how we intend to do it and what we believe are our priorities. A detailed Implementation Plan will follow where we will focus on what specifically needs to be done to achieve our ambitions, the resource implications, and the timescales to be adopted.

Some of the details of this work will be undertaken through task and finish groups utilising the skills and knowledge of stakeholders.

We want system partners working together to ensure that the wishes and choices of individuals, irrespective of care provider, diagnosis, circumstance, or place of residence in Northamptonshire, are met.

This strategy also reflects the new collaborative way of working following the transition from a Clinical Commissioning Group (CCG) to an ICS.

3. Benefits to individuals, their families, carers, and the system

In delivering this strategy we will see the following benefits:

3.1 Individuals, their families, and carers

The benefits align with the national ambitions for P&EoLC:

- A better experience for individuals who require P&EoLC, their families, and carers
- Timely and effective symptom control
- Easier access to information, advice, and support
- More timely interactions and service support
- P&EoLC plans are in place for every individual
- Where possible, individuals will be supported to be cared for and die in their preferred place of care
- Improved communications within the system

3.2 System benefits

Local health and care professionals, which includes all stakeholders, staff, and volunteers, would also benefit from the development of a P&EoLC integrated programme through:

- Improved coordination of service delivery
- Increased local health and care professionals' knowledge and confidence in caring for individuals at the end of life
- Improved partnership working with all organisations
- Increased local health and care professionals' skills, motivation, and achievements in being able to deliver high-quality palliative care
- Improved wellbeing for all care professionals across the system

4. Overview

The scope of this strategy includes adults, children, and young people with any advanced, progressive, or life-limiting condition, also recognising the need for a smooth transition of young people into adult services. It also includes service providers, carers, families, system influencers and commissioners.

The Ambitions Framework for P&EoLC identifies that:

'Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not.'

We recognise this to be true in Northamptonshire and note that there are areas of care that are exceptional; however, the system and communication platforms do not always allow the delivery of a seamless, well-planned, and coordinated service. Our aim is to rectify our current gaps and challenges and ensure that all individuals have the best possible experience towards and at the end of life.

In many cases clinicians identify those who are in their last year of life and actively support them to consider how they would like their care to be managed.

It is clear, however, that the needs of systems and individuals are increasing in complexity: there are more people living longer and many are living with severe frailty, and multiple co-morbidities such as dementia. One in four people will have contact with mental health services in their last two years of life.

In its annual report 2020-2021, Marie Curie indicated that by 2040 there will be a 42% increase in the need for palliative and end-of-life care. It also highlighted that as more of us are living longer, with more complex health conditions, the number of those individuals aged 85 and older is set to almost double in the UK over the next 25 years.

Palliative care services are also required for children and young people living with more complex and/or long-term conditions which are life-limiting or life-threatening.

A significant proportion of children and young people with palliative care needs (up to 15%) do not have a definitive underlying diagnosis. Children and young people with life-limiting or life-threatening conditions often have multiple complex healthcare needs, including needs related to their underlying condition, as well as palliative care needs.

Whilst the numbers are relatively small, we recognise that there are specific needs which should be catered for. Incorporating them into the strategy, and covering provision in the Implementation Plan, ensures that their needs can be best met in alignment.

Our current service provision has been analysed, highlighting gaps and potential future provision.

This strategy also recognises and encompasses the work undertaken by social care and VCSE activity in the wider support of P&EoLC across the county. The detailed development of alignment will be addressed through specific Task and Finish Groups.

Recognising that this strategy is an evolving tool, there are elements of innovation included in the ambitions and a recognition that this is a programme of constant development as new tools and services become available for use in delivery of services.

During its development, the stakeholder group for this strategy also considered the wider impacts of political, economic, sociological, technological, legal, and environmental influences on the strategy.

5. What does P&EoLC mean?

Adult palliative care is described by the World Health Organisation as a crucial part of integrated, people-centred health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care may be needed and must be available at all levels of care.

Therefore, it is an approach which aims to improve the quality of life of individuals, their families and carers facing the problems associated with life-threatening illness.

It is achieved through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to delay or slow disease progression.

Specialist palliative care is the active, total care of individuals with progressive, advanced disease and of their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training.

End-of-life care, according to the General Medical Council, is when individuals are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose deaths are imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

Children's' palliative care is provided to infants, children, and young people with life-limiting or life-threatening conditions representing an extremely wide range of diagnoses (more than 300) and there is an overlap with those with severe disabilities and complex needs.

6. The legal requirement on Integrated Care Boards

The Health and Care Act 2022 states a legal duty on Integrated Care Boards (ICBs) to commission palliative care services under s3(1) NHS Act 2006 (as amended):

1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility –

(h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service

The duty is intended to ensure that individuals of all ages with progressive illness or those nearing the end of their lives, their loved ones, and carers, receive the care and support they need to live and die well.

7. National frameworks

The NHS England Palliative and EoL National Delivery Plan (2022-2025) is a high-level NHS England approach plan indicating what should be implemented at a local level within three years. The primary focus is on improving access, quality, and sustainability.

The Health and Care Act 2022 incorporates a clear mandate for local health and care authorities to develop bespoke services to address the issue of end-of-life care and clearly establish them as a core service within the integrated care remit.

The new national Service Specification for adults', children's, and young people's P&EoLC provides service models for a comprehensive approach to delivering palliative care, from identification of need through to end of life. It sets out the intention that commissioners should aim to ensure that appropriate services are available to all ages across universal services, core services and specialist and enhanced provision.

The Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 provides a structure for each ICS to enable evaluation of local commissioning and delivery of P&EoLC services. The framework builds upon the NHS Long Term Plan 2019 commitments for palliative and end-of-life care, including increasing identification of individuals likely to be in their last 12 months of life and offering personalised care and support planning, alongside ensuring workforce training supports this.

The following national foundations underpin the vision, and their fulfilment enables us to achieve our planned ambitions.

- Personalised care planning
- Shared records
- Evidence and information
- Those important to the dying person
- Education and training
- 24/7 access
- Co-design
- Leadership

During the development of this strategy the stakeholder group considered our local fulfilment of the foundations for the national ambitions. Recognising that several of our identified actions would build our foundations, the group felt these would provide a good basis to achieve our ambitions.

The six national ambitions and their principles are:

Ambition 1: Each person is seen as an individual

Honest conversations	Integrated assessment and care planning	Electronic shared care record	Continuity of care delivery	Carer assessment and plan	Personal budgets and commissioning

Ambition 2: Each person gets fair access to care

All people predicted to be in the last year of life	A fully integrated seamless offer in place	Coordinated process for referral	Transition	Protected characteristics, homelessness, prison	EoLC dashboard

Ambition 3: Maximising comfort and wellbeing

Living well approach, enablement, and rehabilitation	People supported to die in their preferred place	Workforce confidence and skills	Specialist palliative care	Symptom management and prescribing	Safe and effective handovers, including out of hours

Ambition 4: Care is coordinated

Partnership working	Identified EoLC coordinator	24/7 access to advice and guidance	24/7 access to care	One assessment, one care plan

Ambition 5: All staff are prepared to care

One training offer	Integrated training programme	Clinical leadership	Executive leadership

Ambition 6: Each community is prepared to help

Compassionate communities across all localities	Volunteers as an arm of health and care services	Commissioning arrangements	Public prepared to talk about death and dying

These national ambitions have been used to develop our personalised, place-based, local strategy.

8. Enablers

To achieve the ambitions outlined we have identified some essential enablers:

- **Understanding the needs of our population** – whilst we do have some information on our local population, we still need to better understand Northamptonshire's population needs. We will undertake further quantitative and qualitative research on this to enable us to improve the service provision.

- **Workforce** is a major resource that we need to secure. A key to this is to ensure we provide a high level of training to our workforce to certify they have the skills, confidence, and resilience they need to deliver holistic, compassionate care for individuals, their families, and carers, regardless of where they are cared for.

- **Digital** – taking maximum advantage of a range of digital solutions and innovations is core to delivering the strategy. The use of technology within the system to collate patient outcomes measures, improve the provision of services and communications with the individual, their family and carers will be essential to delivering a more effective system. There is a need to ensure that all digital solutions link together so that all patient information can be shared to benefit their care.

- **Accessibility to services** – the work we have done to date has highlighted the public's need for greater accessibility to information, guidance, and advice, where appropriate. Whilst there are, and always will be, several information and guidance sources, it is sensible to coordinate this information through the development of a focused website.

- **Resourcing of services** – health, social care and VCSE services have always been under pressure from resource allocation. People are a key major resource that we need to develop by enabling Northamptonshire to be seen as a great place to live and work. A key to this is to ensure we provide a high level of training to professionals in various aspects of the services provided to reassure the public of their competence and to help in role satisfaction. In addition, we have a good geographical spread of facilities but some of those facilities do not yet enable equitable access to services. This needs to be addressed. It is also within our ability to enable a de-duplication of provision and support for prevention and early intervention to particularly reduce demand on hard-pressed system services that by their nature are more costly and only used because of the lack of service availability elsewhere.

- **'Education' and cultural change** – considering the inevitability of death in society, it remains very 'difficult' for those who need to deal with palliative and end-of-life care to do so. We recognise the need to enable people to address the issues that come with this with greater understanding and appropriate compassion which encompasses their cultural and spiritual beliefs. Whilst there should be some guidance and support provided, much of this should also be a community driven initiative.

9. Northamptonshire Ambitions Framework Self-Assessment Tool findings

This strategy has been co-produced with the support of all the relevant stakeholders across the county and our population. Each stakeholder assessed themselves against each of the six national ambitions for palliative and end-of-life care, indicating against each measurement the level that best describes their status across their locality.

The below table highlights the gaps that were identified in 2022.

Ambition	Identified Gap (in no particular order)
Ambition 1: Each person is seen as an individual	• Lack of informative data • Lack of investment in IT which impacts on many elements, including data sharing • Education for professionals, volunteers, and the public • Addressing inequalities • Bereavement services
Ambition 2: Each person gets access to fair care	• Lack of informative data • Lack of investment in IT which impacts on many elements, including data sharing • Service user feedback
Ambition 3: Maximising comfort and wellbeing	• Education and training for professionals, volunteers, and the public • Accessibility to services for all • Addressing inequalities • 24/7 access to P&EoLC • Workforce depletion
Ambition 4: Care is coordinated	• Lack of investment in IT which impacts on many elements, including data sharing • Addressing inequalities • 24/7 access to P&EoLC
Ambition 5: All health and care professionals are prepared to care	• Lack of investment in IT which impacts on many elements, including data sharing • Education and training for professionals, volunteers, and the public
Ambition 6: Each community is prepared to care	• Education and training for professionals, volunteers, and the public • Accessibility to services for all • Workforce depletion

In addition to the individual stakeholder assessment, we undertook a series of workshops to help identify potential service and system gaps.

The development of an accessible wellbeing service across the whole county was identified as a service gap and the coordination of service delivery, information, advice and guidance and leadership were identified as system gaps.

10. Northamptonshire's P&EoLC ambitions

Having undertaken this activity and using the NHS England Ambitions Framework Self-Assessment Tool, we benchmarked the Northamptonshire P&EoLC provision. This enabled us to formulate our priorities with 'what we want' to achieve for Northamptonshire and 'how we will do this'. We have captured the results in the tables below.

Ambition 1	**Each person accessing P&EoLC in Northamptonshire is seen as an individual**
We want to:	**We will do this by:**
Empower individuals, their families, and carers in Northamptonshire to know what, where, and how to access end of life services.	Developing and coordinating 24/7 access to P&EoLC advice and guidance. Establishing a countywide P&EoLC information platform. Providing information in a variety of formats to meet people's needs.
Provide a systematic approach in identifying individuals in the last year of life and offer a holistic assessment and a plan of advanced care needs which is tailored to the individual.	Developing a system wide P&EoLC Care register to improve individuals' outcomes. Ensuring all healthcare professionals follow an identified system of assessment and referral that ensures appropriate identification of an individual at the end of life. Ensuring all individuals who are in their last year of life are recorded on an Electronic Palliative and Care Coordination System (EPaCCS). Involving individuals in their personal care planning and ensuring reviews of the plan occur to meet their changing needs or requirements and are recorded on EPaCCS. Ensuring individuals are supported with rapid access to needs-based social care. Promoting honest conversations between individuals and professionals about treatment escalation and resuscitation decisions, that are timely, clearly documented and communicated. Replacing the county Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form with Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) to aid communication and appropriate planning.
Use person-centred validated tools to measure individual outcomes against their personal goals, and for these to be utilised across the system with equal access to all providers.	Identifying and implementing mechanisms for collecting and collating patient outcome measures from individuals who are receiving P&EoLC Services.

Ambition 2	Each person gets fair access to care across Northamptonshire
We want to:	**We will do this by:**
Address inequalities using a local population-based health needs assessment, that will ensure all individuals have appropriate access to fair care and support across the county.	Developing a local population-based analysis of current needs. Developing a local population-based analysis of future needs as identified by long-term population projections. Undertaking a local population-based needs assessment project to identify individuals at risk of inequitable access to P&EoLC services. Developing a gap analysis for the county and specifically addressing the needs of those at risk of receiving inadequate access to P&EoLC in future planning, education, commissioning, and delivery of services.
Ensure representatives of the population are involved in the current and future formation of delivery of P&EoLC services	Developing community partnerships between faith groups, cultural communities, and organisations. Ensuring that 'user by experience' groups are represented at the All-Age Last Years of Life Delivery Group (AALYoLDG) and subgroups. Ensuring there is full wider stakeholder engagement across the system.
Ensure that individuals, their families, and carers can access information in a language and format that they can read and/or understand.	Publishing key material in all languages. Ensuring that P&EoLC Services can access responsive translation services when required to do so. Ensuring that information can be accessed in written and digital formats. Providing information in a variety of formats, including supporting those individuals who have a sensory impairment, have a learning disability and/or autism, including easy to read versions of key material, using audio and social story videos.
Ensure that individuals who are identified as being within the Core20PLUS5 population receive support to reduce their health inequalities.	Identifying end-of-life individuals who are within the Core20PLUS5 population and providing appropriate information and guidance. Providing information regarding available support via a single P&EoLC information platform. Signposting individuals, their families, and carers to relevant support organisations.
Ensure that every individual has equitable access to being identified and assessed for end-of-life care; this must also include signposting to support services.	Ensuring all healthcare professionals follow an identified system of assessment and referral that ensures appropriate identification of an individual at the end of life. Ensuring accurate signposting information is shared with the individual at the time of referral to ensure that they know who, how, when and where they can access support.

Ambition 3	Maximising comfort and wellbeing to individuals, their families, and carers across Northamptonshire
We want to:	**We will do this by:**
Support early access to palliative care whenever it is needed, not just in the final few hours of life.	Increasing staff awareness of when to make early palliative care referrals.
Enhance timely access to hospice inpatient care.	Developing a proposal to improve accessibility of 'in-house' hospice service provision to 24/7 access helping avoid A&E admissions, reduce direct ambulance admissions to A&E and consider nurse-led service provision
Provide holistic, individualised end-of-life care that addresses the spiritual, psychological, social, and physical needs of the individual.	Supporting the identification of individuals' goals and priorities with their families, carers, and other professionals and ensure it is recorded on the local EPaCCS. Treating individuals with consideration to their needs and wishes and priorities as well as their physical symptoms.
Provide 24/7 access to P&EoLC services offering information, advice, guidance, and signposting.	Developing and coordinating 24/7 access to P&EoLC information, advice, and guidance.
Ensure effective support and symptom control management is available to all when it is needed. Provide equal access to out-of-hour medications to ensure they are obtainable for all. Ensure that individuals have their equipment needs assessed and that equipment is subsequently delivered and collected in a timely manner.	Ensuring Advance Care Plans (ACP) are personalised to include discussion around predictable complications with patients, their families and carers, and a plan for its management and for choice of drugs for anticipated symptom control. Exploring the opportunity of adopting a local lay carer policy to administer needle-less as-needed subcutaneous medication for common breakthrough symptoms. Increasing the availability of community pharmacies. Ensuring access to specialist advice. Pre-empting the need for anticipatory prescribing and equipment and ensuring robust arrangements for provider services are in place and, if not, commission these to ensure accessibility to these without delay. Supporting inequitable availability and delivery across the county. Developing links with the West Northamptonshire Commissioning and Quality Outcomes Team to enhance service delivery.
Recognise when individuals, their families and carers are experiencing emotional and physical distress and respond appropriately.	Ensuring all health and care professionals are appropriately trained to support distressed individuals. Ensuring individuals are regularly reviewed for their mental and physical wellbeing along with any other symptoms and that they are supported, signposted, or referred to relevant appropriate services in a timely way. Ensuring equitable wellbeing services exist for all individuals across Northamptonshire.

Ambition 3	Maximising comfort and wellbeing to individuals, their families, and carers across Northamptonshire
We want to:	**We will do this by:**
Ensure equitable bereavement services exist for all.	Reviewing bereavement services to understand the demand, current provision and any gaps that need to be addressed. Coordinating and developing a countywide equitable bereavement service.
Verify death in a compassionate and timely manner.	Training and supporting appropriate individuals to verify death.

Ambition 4	Care is coordinated across Northamptonshire
We want to:	**We will do this by:**
Create a single P&EoLC record that all system partners can access. Ensure care plans have input from a range of professionals.	Commissioning and implementing an EPaCCS that meets national requirements and can hold an electronic version of decisions relating to treatment escalation and cardiopulmonary resuscitation. Providing access that allows system partners to update records contemporaneously and can be seen by relevant health and care professionals.
Provide 24/7 access to P&EoLC services offering information, advice, guidance, and signposting.	Developing and coordinating 24/7 access to P&EoLC advice and guidance.
Ensure that P&EoLC services have clearly defined routes of access, with interlinking services being equally direct and visible.	Mapping service offer and provision. Agreeing access criteria as a system, supported by contractual mechanisms. Including P&EoLC Services in the system Directory of Services (DoS).
Provide clear, concise, timely and informative communication across services and to user by experience groups.	Providing conditions in which integration and partnership working between relevant health, social and voluntary care services can thrive. Ensuring a clear specification of services exists, with defined functions, areas of responsibility, quality standards and key performance indicators. Replacing the county DNACPR form with ReSPECT. Actively seeking feedback from user by experience individuals. their families, and carers and use it to monitor that services continue to meet their needs. Using the feedback to modify or change services as necessary whilst driving ongoing improvements.
Ensure that individuals, their families, and carers, are involved in the planning and	Facilitating completion of an ACP by providing health and care professionals with a clear set of actions when they identify someone as being in their last year of life.

Ambition 4	Care is coordinated across Northamptonshire
We want to:	**We will do this by:**
coordination of their care and the services they use.	Allocating key professionals to the individual, their family, and carers to provide continuity of care for all conditions.
Support staff in recognising the requirement for early access to P&EoLC services.	Educating all members of the workforce to recognise when to make a timely palliative care referral. Using technology and data to support with identifying individuals who are potentially in the last year of life.

Ambition 5	All health and care professionals in Northamptonshire are prepared to care
We want to:	**We will do this by:**
Ensure a workforce that has the knowledge, skills, and confidence to deliver evidence-based compassionate P&EoLC services.	Undertaking a Training Needs Analysis to address gaps and formulating an education plan and prospectus of P&EoLC courses. Ensuring that the formulated education plan provides consistent, equitable P&EoLC education which is appropriate to the skill and knowledge level of the professional; this will consider language barriers, ethnic and cultural diversity. Ensuring sustainable funding is provided to ensure a workforce that has the knowledge, skills, and confidence to deliver evidence-based, compassionate P&EoLC services
Have a resilient and supported workforce, with an open culture where staff seek help as they need.	Ensuring organisations recognise, prioritise and value education for the workforce. Ensuring staff are offered regular supervision, mentorship, and support. Ensuring access to occupational health services and counselling services are valued and openly available to the workforce.
Manage the health and social care workforce to ensure there are enough staff with enough time to provide quality care.	Reviewing the current workforce. Managing future workforce challenges in line with other system workforce analysis and anticipated changes to population and demographics. Considering future workforce requirements in the context of improving technology Including P&EoLC workforce requirements in the 2023 ICB Workforce Strategy.

Ambition 6	Each community in Northamptonshire is prepared to help
We want to:	**We will do this by:**
Provide support and information. Provide appropriate training for community organisations. Provide training in end of life to local families and carers.	Developing and coordinating 24/7 access to P&EoLC advice and guidance for local communities, families, and carers to access. Understanding what communities exist to further comprehend what end of life looks like for them. Ensuring high-quality and equitable services exist for all. Engaging with social prescribers to facilitate support to relevant services. Ensuring access to training in P&EoLC is available.
Build capacity in the local community that encourages participation in local and national initiatives regarding death, dying and bereavement.	Increasing the profile of P&EoLC services across Northamptonshire. Addressing funding issues related to extending education across the county.
Provide equal access to literature, education and services for communities providing support to an individual with a palliative diagnosis or in the last year of life.	Engaging with all communities as well as populations in areas of deprivation within the county to ensure they are supported to help.
Ensure ReSPECT and ACP are acknowledged as an integral part of life and made available to the whole population, not just within the context of ill health.	Reviewing promotional tools to allow ACP to be shared to the public and not just those with a life-limiting condition. Developing a plan to share ACP widely across the system not limited to an end-of-life diagnosis. Promoting ACP to the public of Northamptonshire. Implementing ReSPECT.
Review what community provision exists within the county to establish what they are providing and what support they require.	Seeking support from social prescribers, Healthwatch, Northamptonshire Carers and other VCSE sector stakeholders.

11. Developing the ambitions for children and young people

The National Children's and Young People's Palliative and End of Life Care service specification provides a whole-system approach to delivering palliative care, from identification of need through to end of life, setting out requirements for the provision of universal services, core services and specialist services. The ambitions for children and young people mirror the ambitions developed for adult services.

Whilst there are fewer children and young people than there are adults needing palliative and end-of-life care across Northamptonshire, it is nevertheless vitally important that this cohort is properly supported and there is a clear pathway which includes those transitioning into adulthood.

Our vision is to promote the best possible quality of life and care for every child with a life-limiting or life-threatening condition and their family. Giving families real choice is key to this approach as well as putting the child at the centre of decision-making to produce a plan for care that is right for them.

Children's palliative care should be an active and dynamic approach to care, from diagnosis through to death and in bereavement. Families will move between levels of service provision throughout their child's illness and will need support to enable smooth transitions and handover between services.

Significant work to review gaps in the provision of core and specialist services at a local and regional level has resulted in the development of various proposals to improve our current offer. This includes actions within Northamptonshire as well as actions to be taken in collaboration across East Midlands:

1. Local children and young people commissioners and providers will undertake further research to identify the number of children and young people who should be within the scope of support across Northamptonshire.
2. Children and young people commissioners will continue to develop options for the improvement and transformation of 'core services' and 'specialist services' within Northamptonshire, building on the findings and recommendations identified within Project Cygnet[1].
3. Children and young people commissioners will continue to influence the development of 'specialist services' for children and young people provided across the East Midlands, to provide the most effective service.
4. Children and young people commissioners will work with the relevant theme groups to develop the provision of appropriate transition arrangements for those moving into adulthood and, by implication, being subsequently supported locally across Northamptonshire.
5. Introduce EPaCCS to ensure Advance Care Plans are completed with the child and their family to define their health needs, identify the team around the family and facilitate their chosen place of death when the child moves into the End-of-Life Pathway.

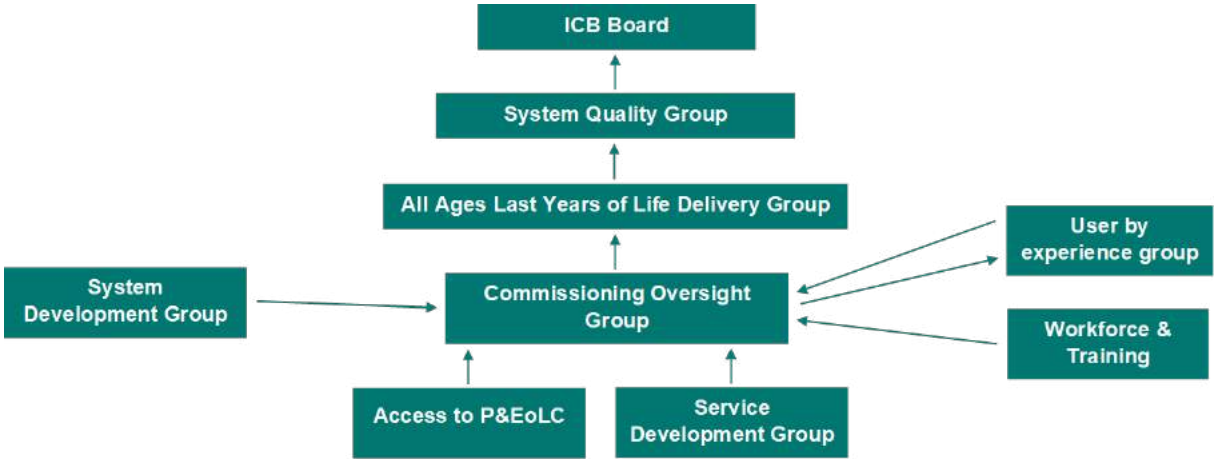
[1] NHS Northamptonshire CCG commissioned an independent review of paediatric Palliative and End of Life services across the county in 2021, known as "Project Cygnet", to understand the strengths and weaknesses of current service models and delivery for children with life limiting and life-threatening conditions, and create service solution options.

12. Delivery, accountability, and governance

Delivering the Northamptonshire P&EoLC Ambitions set out in this strategy will be the responsibility of all the stakeholders. This will be achieved by four themed groups and further using dedicated task and finish groups, which are time-limited groups responsible to deliver specified objectives. An annual detailed Implementation Plan will be developed which will identify actions for completion to achieve our local ambitions.

Development and progress of the strategy will be overseen by the Commissioning Oversight Group (COG) which will report into the All-Age Last Years of Life Delivery Group (AALYoLDG). This group reports into the System Quality Group (SQG) which further reports into the ICB and ICP.

The ICB's Senior Responsible Officer (SRO) for P&EoLC is accountable for the delivery of the programme.



13. Where people are dying in Northamptonshire

The latest available national data on where people in Northamptonshire die is from 2021 and provided by OHID's (Office for Health Improvement and Disparities) Palliative and End of Life Care Profiles.

While the impacts of COVID-19 mean this may not be a typical year, these impacts were felt across the country.

From the data we can see that:

- Northamptonshire has a significantly higher proportion of deaths which occur in hospital. If we were at the England average, we would see 299 fewer deaths in hospital and a full 788 fewer if we matched the ICB with the lowest rate.
- Conversely, deaths at home are significantly lower in Northamptonshire than the England average, mostly in people over 75. In our county, 163 more people would die at home if we matched the national average and 530 if we matched the rate of the highest performing ICB.
- Deaths in hospices are also lower than average in Northamptonshire, although numbers for this cohort are smaller. So, in our county, 54 more hospice deaths would be recorded if we matched the England average and 221 if we matched the rate of the highest performing ICB.

As noted above, 2021 data must be treated with some caution generally and this data specifically does not consider differences in service model and other factors. However, in simple terms, we have 9% more deaths in hospital and 22% fewer deaths in hospice than the England average.

The increased demand for services in the last months of a person's life is well documented. Last year 2,872 of our patients died in hospital, which we know from national data is statistically higher than national rates, and significantly fewer of our patients die at home. We know that on average last year:

- 8% of our hospital beds (102) were occupied by people who died in hospital.

The length of time these patients spent in hospital before they died varied greatly.

- 7% on the day of admission
- 10% one day after admission
- 7% two days after admission
- 55% (1,589) more than a week
- 13% more than a month.

This does not consider any previous admissions many of these patients may have had in the year before their death.

14. Implementation Plan

With agreement on the vision in the strategy, we will be able to develop fully the Implementation Plan required to achieve our vision. Using the Implementation Plan, the ICB's All-Age Last Years of Life Delivery Group (AALYoLDG) will be able to monitor performance through highlight reports which will be provided by the relevant task and finish groups.

15. How we will monitor and measure success

To ensure that the actions we are taking are helping to improve services, enhance the experiences of individuals, their families, and carers, and deliver the six ambitions, we will track our progress against local quantitative, qualitative, and national metrics as well as user by experience feedback.

Many of the below outcome ambitions either do not have specific measures or, where measures are available, they are subject to a significant time delay in reporting. The introduction of an EPACCS system in the county will allow more detailed and varied outcomes to be collected and be standardised and consistent.

In advance of the introduction of an EPACCS system, measures are being identified to provide initial insight into delivery and assurance on the development of P&EoLC, and the outcomes achieved for our patients.

Summary outcomes, measures, and evaluations

Desired Outcome	Individual / Family / Carer Outcome	System Outcome	Metrics and Evaluation	Frequency of Measurement
People are treated as individuals and die with dignity and their wishes are respected.	Individuals can choose where they are cared for and die with dignity. Their wishes, and those of their loved ones, are met, wherever possible. Symptom control is effectively managed for the dying patient in all settings.	Increase in achievement of preferred place of care and death.	Upward trend in positive response to the question: 'Overall do you feel the person close to you died in the right place?' Percentage of people achieving their preferred place of death. Feedback from individuals, families, and carers (including surveys, complaints, and compliments).	Annual TBC (Requires EPACCs for regular monitoring) Annual
P&EoLC is available when individuals, families and carers need it.	Individuals, their families, and carers have access to rapid advice and support, including out of hours or in a crisis, in the community. Trips to, and stays in, hospital are minimised for people at end of life, only happening when clinically necessary.	The general workforce has access to specialist telephone advice and support when needed. More people are being supported in the community.	Downward trend in unplanned admissions to hospital in the last three months of life. Reduction in the number of people dying in hospital. Feedback from individuals, families, and carers (including surveys, complaints, and compliments).	Monthly/ Secondary Uses Service (SUS) Monthly/SUS Annual

Desired Outcome	Individual / Family / Carer Outcome	System Outcome	Metrics and Evaluation	Frequency of Measurement
P&EoLC needs across all health conditions are identified early and support is provided.	P&EoLC needs are identified early on, and a care offer is made from the start. Individuals are given the opportunity to plan and be involved in decisions about their care.	Timely identification of palliative care needs for all disease types, with appropriate support.	Evidence from general practice palliative care registers that all disease types are represented. Increase in the number of people of GP palliative care registers. Feedback from individuals, families, and carers.	To explore once metric is established Monthly, from GP System, confirm description
P&EoLC is coordinated.	Individuals, their families, and carers experience coordinated care, with clear and consistent information and different organisations coming together to seamlessly wrap care around the individual.	Partners are working together effectively to provide coordinated care. Continued expansion of advance care planning (ReSPECT etc) with effective solutions to share clinical records and care plans to enable the system to work efficiently.	Increase in the number of personalised care plans created. Increase in the number of personalised care plans being reviewed and updated. Reduction in number of people receiving multiple admissions in the last three months of life. Feedback from individuals, families, and carers (including system-wide survey, complaints, and compliments).	Monthly GP data TBC (Requires EPACCs for regular monitoring) Monthly (Currently only deaths in hospital) Annual
The public receive compassionate care from well-trained health and care professionals across the system.	Individuals feel cared ‘about’ and not just cared ‘for’.	Staff feel valued in their roles and feel positively challenged to maintain compassionate and quality care support.	Positive staff feedback and Continuing Professional Development (CPD) achievements being attained. Feedback from individuals, families, and carers.	Annual Annual

Desired Outcome	Individual / Family / Carer Outcome	System Outcome	Metrics and Evaluation	Frequency of Measurement
The community is engaged with supporting the end-of-life care for individuals, families and carers through diagnosis, death, and bereavement.	The next of kin is offered bereavement support.	Development of bereavement support provides coordinated care.	% Of next of kin offered bereavement support. % Of next of kin accessing bereavement support. Feedback from individuals, families, and carers.	Quarterly Quarterly Annual

16. Next Steps

Following publication of this strategy, all the P&EoLC work programmes that exist will be reviewed to ensure they are aligned with Northamptonshire's local ambitions. The implementation plan and the relevant task and finish groups will be reviewed and refreshed, as they will further develop as the local and national context shifts.

17. Acknowledgements

We would like to thank all contributors to this work including, but not limited to, colleagues from:

- Age UK Northamptonshire
- Cransley Hospice Trust
- Cynthia Spencer Hospice
- East Midlands Ambulance Service NHS Trust
- Healthwatch North Northamptonshire and West Northamptonshire
- Kettering General Hospital NHS Foundation Trust
- Lakelands Hospice
- Macmillan Cancer Support
- Marie Curie
- NHS Northamptonshire Integrated Care Board
- Northampton General Hospital NHS Trust
- Northamptonshire Care Home Managers
- Northamptonshire Carers
- Northamptonshire Healthcare NHS Foundation Trust
- North Northamptonshire Council
- University of Northampton
- West Northamptonshire Council

18. Appendices

Appendix 1: How we shaped the strategy

Appendix 2: References

Appendix 3: Current service provision

Appendix 4: Core20PLUS5 information

Appendix 5: Glossary of terms

Appendix 1: How we shaped the strategy

This strategy has been developed as a co-production piece with the support of all the relevant stakeholders across the county.

We used some classical methods to achieve our aims with some detailed results highlighted.

Desk research

Much of the generic background information was obtained via desk research.

In 2017 the population of Northamptonshire was estimated to be 741,200. In 2021 the local authority arrangements for the county changed with the setup of two unitary authorities – West North Northamptonshire Councils.

Changes in population are expected to be slightly higher in North Northamptonshire compared to West Northamptonshire, mainly due to increases predicted in Corby (15.7% from 2016-2026) which is much higher than all other districts (ranging from 6% to 9%). Generally, people are living longer and the percentage change in older people in Northamptonshire is expected to increase over time.

We identified several national and local drivers for change.

We reviewed several other P&EoLC strategies including Leeds, Hampshire, Shropshire, Derbyshire, and Herefordshire & Worcestershire.

Current stakeholder analysis

The initial phase of designing this strategy used an already established system group the All-Age Last Years of Life Delivery Group (AALYoLDG), which focuses on the operational and strategic delivery of care in the last years of life, to establish our current situation.

The membership of this group includes representatives from providers of P&EoLC for the county and wider system partners, such as those from the VCSE sector and the ambulance service. The group is well established and has a wealth of knowledge and experience across its membership.

Basecamp reviews

We have held a series of system-wide workshops, to explore and establish what operationally currently works well and what gaps we need to address over the next three years. The conclusions of each basecamp have informed the strategic and operational recommendations included in the strategy. These events were well attended.

Public engagement

We have incorporated feedback from a range of public engagement events and a public engagement survey that was available between December 2022 and January 2023.

We know that death and dying can be difficult to talk about and we wanted to hear from individuals with living experience, their families, and carers, to ensure that future services are in line with what is needed, and what is important to them.

We will continue to involve individuals, families, carers, and local communities to plan and co-design the solutions to implementing our strategy.

Interviews

We undertook several informal interviews with staff across the P&EoLC system both to gather individual viewpoints, triangulate opinions against facts and to ensure that we engaged positively across the system.

Appendix 2: References

In preparing this strategy we have referred to several documents, articles and reports which relate to generic health and social care strategic developments and specific documents in support of the strategy recommendations.

- General Medical Council guidance – Treatment and care towards the end of life: good practice in decision making
- World Health Organisation Health Topics – Palliative Care
- National P&EoLC Partnership – Ambitions for Palliative and End of Life Care: A national framework for local action: 2021-2026, NHS England
- National P&EoLC Partnership – Ambitions for P&EoLC: A national framework for local action: 2015-2020
- The Health and Care Act 2022
- Leadership Alliance for the Care of Dying People – One chance to get it right: Improving people's experience of care in the last few days and hours of life London: Department of Health; 2014
- National Institute for Health and Care Excellence – Clinical guidelines for care of dying adults in the last days of life (NG31) London: NICE; 2015
- National Institute for Health and Care Excellence – Quality standards for care of dying adults in the last days of life (QS144) London: NICE; 2017
- National Benchmarking Network – National Audit of Care at the End of Life (NACEL) 2019 Office for Health and Improvement and Disparities. *Please note that the outcomes from the NACEL 2022 was not available when this strategy was developed.*
- Office for Health Improvement and Disparities: Fingertips Public Health Data P&EoLC profiles
- Northamptonshire primary care data

Appendix 3: Current service provision

There are many P&EoLC services across the county that provide different levels of support to individuals.

Kettering and Northampton General Hospitals each deliver a specialist palliative care service seven days a week, available to all adult individuals with a life-limiting illness or who are dying. The teams work in collaboration with their system colleagues to achieve the preferred place of care or death for individuals as well as offering specialist palliative clinical support to colleagues, and symptom management, complex physical, psychological, and social support to individuals.

Two hospices, Cransley Hospice in North Northamptonshire and Cynthia Spencer Hospice in West Northamptonshire are jointly commissioned by the charities and the ICB and are delivered by Northamptonshire Healthcare NHS Foundation Trust (NHFT). They collectively offer 25 beds to individuals requiring specialist P&EoLC. Lymphoedema and wellbeing services are accessible to all individuals in the county and are based at the Cynthia Spencer Hospice site, with family support, chaplaincy and psychology support being offered across both hospice sites.

Associated with both hospices is the Hospice at Home service, which consists of registered nurses and care assistants who are experienced in end-of-life care. The team provide nursing care, symptom control and emotional support to facilitate care at home in conjunction with existing community services.

Lakelands Day Hospice is an independent charity based in Corby. It provides support to adults living with life-limiting illness within a 20-mile radius of Corby. It conducts various support activities during the day, as well as offering a Hospice at Home service at night for patients at the end of their life. Lakelands also runs a bereavement support group once a week in addition to a one-to-one bereavement counselling service.

Direct bereavement services for the county are limited, with Cruse Bereavement Care being the main referral point. This service is reportedly limited in its ability to meet the needs of the county as it has a long waiting list due to the large number of referrals and limited resource. The specialist services listed within this appendix offer what bereavement support they can within the sphere of their knowledge and capability, however this strategy acknowledges a distinct lack of professionally governed bereavement support across Northamptonshire.

The Community P&EoLC Team is a multi-professional team working across Northamptonshire, providing specialist palliative support to individuals in the management of complex symptoms as well as emotional, psychological, and practical support, while ensuring that individuals can maintain their quality of life and live as independently as possible in their preferred place of care. The community teams will refer on to the Hospice at Home Team if the patient is deemed to be in their last weeks of life and wishes to remain at home or the Marie Curie Rapid Response Team if the patient is in their last eight weeks of life.

The Marie Curie Rapid Response team clinically supports the patient in their own home, offering care and nursing support. Its 24/7 telephone line is run by a national team with one nurse available overnight to cover Northamptonshire and attend for symptom management support or nursing interventions.

The Extra Help Team, provided by Age UK Northamptonshire, works alongside Marie Curie to provide end of life care in the community to individuals deemed to be in the last eight weeks of life. The service is fully funded by health, via a subcontract from Marie Curie, to provide 550 hours of care per week. The service is available to adults aged 18 and over who are registered with a Northamptonshire GP, providing all aspects of personal care with

specialist knowledge in respect of end-of-life care supporting individuals, families, and carers.

The Northamptonshire Carers Organisation (NCO) also plays an active role within the county. It has a team of community-based carer support workers at Kettering and Northampton General Hospitals who offer advice, information, and a statutory carers assessment with links to the wider services that NCO provides, including a telephone support line, a young carers service, hospital discharge services (including regulated care) and a menu of support groups, activities, and specific community assets groups. These are not all solely focused on P&EoLC but do provide a key element of support to this group of individuals.

In Northamptonshire, some individuals who live near the southern county border access the most central hospice and hospital services of Northampton General Hospital and Cynthia Spencer Hospice. Seven GPs serving the south of Northamptonshire are specifically linked to Katharine House Hospice, which are commissioned to support palliative individuals who live on the Oxfordshire and Northamptonshire border. The hospice is directly linked to Oxford University Hospitals NHS Foundation Trust and works to a similar remit to Northamptonshire hospices.

Commissioning of P&EoLC services is complex with several funding bodies contributing to this area of work. Coordinating this element of work will lead to enhanced and effective services being delivered.

Appendix 4: Core20PLUS5 (adults) – an approach to reducing healthcare inequalities

Core20PLUS5 is a national NHS England approach to support the reduction of health inequalities at both national and system level. The approach defines a target population cohort and identifies '5' focus clinical areas requiring accelerated improvement.

The approach focuses on healthcare inequalities experienced by adults and children and young people.

Core20

The most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD). The IMD has seven domains with indicators accounting for a wide range of social determinants of health.

PLUS

PLUS, population groups include ethnic minority communities; inclusion health groups; people with a learning disability and autistic people; coastal communities with pockets of deprivation hidden amongst relative affluence; people with multi-morbidities; and protected characteristic groups; amongst others. Specific consideration should be taken for the inclusion of young carers, looked after children/care leavers and those in contact with the justice system.

Inclusion health groups include people experiencing homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system, victims of modern slavery and other socially excluded groups.

5

The final part sets out five clinical areas of focus which forms part of the wider actions for Integrated Care Boards and Integrated Care Partnerships (ICP) to achieve system change and improve care for children and young people. Governance for these five focus areas sits with national programmes; national and regional teams coordinate local systems to achieve aims.

Appendix 5: Glossary of Terms

Advance Care Plan (ACP) is the process of making decisions about what kind of care an individual would like to have in the future. It ensures that anybody who is caring for an individual knows what matters to them.

All Aged Last Year of Life Delivery Group (AALYoLDG) – this group consists of individuals and organisations who work within the PE&OLC environment. Members influence decisions that ensure people, and their families and carers receive care and support that is coordinated, and which meets their individual needs – irrespective of care provider, diagnosis, circumstance, or place of residence in Northamptonshire – from diagnosis through to bereavement.

Commissioning is the process of assessing needs, planning, prioritising, purchasing, and monitoring health services, to get the best health outcomes.

Do not attempt cardiopulmonary resuscitation (DNACPR) is a decision made by an individual and/or their doctor or healthcare team that if their heart or breathing stops the healthcare team will not try to restart it. A DNACPR decision is usually recorded on a special form which is easily recognised by doctors, nurses, and healthcare workers, so they know what to do in an emergency. This form is kept in an individual's medical records. It may also be printed and kept at home or in a care home.

Electronic Palliative and Care Coordination System (EPaCCS) is a nationally recognised system for enabling improved communication and better coordination of care. It facilitates the recording and sharing of accurate, consistent, and timely information about patients in their last year of life, so that the right information is available in the right place, for the right person, to make the right decisions, at the right time. The overall aim of EPaCCS is to improve patient experience and care at the end of life, by putting patients' wishes and preferences at the centre and helping to create an environment where healthcare professionals (regardless of employer) can work easily together.

Healthwatch is a health and social care champion and encourages feedback from service users of GPs, hospitals, dentists, pharmacies, care homes or other support services. Healthwatch is an independent statutory body, which has the power to make sure NHS leaders and other decision-makers listen to service user feedback and improve standards of care.

Hospice care aims to improve the quality of life and wellbeing of adults, children and young people who have a terminal illness or a long-term condition that cannot be cured, also known as life-limiting. It is free for patients, their carers and family members. Hospice care can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, and social, practical, emotional, and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be. This type of care is also known as palliative care, and can also be provided in other places, such as in a hospital, at home, or in a community setting.

Integrated Care Board (ICB) is a statutory body responsible for local NHS services, functions, performance, and budgets. It is directly accountable to the NHS and is made up of local NHS trusts, primary care providers, and local authorities. Northamptonshire's ICB is called NHS Northamptonshire Integrated Care Board.

Integrated Care Systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. Northamptonshire's integrated care system is called Integrated Care Northamptonshire (ICN).

Integrated Care Partnership (ICP) is a statutory committee jointly formed between the NHS ICB and all upper-tier local authorities that fall within the ICS area. The ICP brings together a broad alliance of partners concerned with improving the care, health, and wellbeing of the population, with membership determined locally. The ICP is responsible for producing an integrated care strategy on how to meet the health and wellbeing needs of the population in the ICS area. Northamptonshire's ICP is called Northamptonshire Integrated Care Partnership.

Lay carer refers to family members or friends or other lay carers looking after their loved one at home, and who are not paid to do this work. It includes healthcare professionals acting in the lay carer role for a loved one. A policy would support willing and able lay carers to administer needle-less as-needed subcutaneous medication for common breakthrough symptoms which includes pain, nausea / vomiting, restlessness / agitation, noisy breathing / rattling, and breathlessness in the last days of life of individuals who wish to be at home when they die.

Northamptonshire Healthcare NHS Foundation Trust (NHFT) provides P&EoLC services as well as mental health, community nursing, sexual health, physiotherapy, and a range of others including specialty services across Northamptonshire.

Occupational health promotes and maintains the health and wellbeing of employees.

Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences. This happens within a system that supports people to stay well for longer and makes the most of the expertise, capacity and potential of people, families, and communities in delivering better health and wellbeing outcomes and experiences.

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a process which creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. Individual preferences and clinical recommendations are discussed and recorded on a non-legally binding form which can be reviewed and adapted if circumstances change.

Social prescribers are link workers who, through shared decision-making or personalised care, support individuals to access a range of non-clinical services and groups.

Social prescribing is a key component of personalised care, enabling GPs, nurses, and other primary care professionals to refer individuals to a range of local, non-clinical services to support their health and wellbeing.

Task and finish groups are time-limited groups responsible to deliver specified objectives.

The Voluntary, Community and Social Enterprise (VCSE) sector comprises charities (registered and unregistered), community groups, community interest companies, friendly societies, social clubs, many sports clubs, churches and other faith groups, and voluntary organisations.