Nottingham and Nottinghamshire ICS

End of Life Care

Clinical and Community Services Strategy

March 2021

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1. Executive Summary

The Integrated Care System (ICS) ambition across Nottinghamshire is to both increase the duration of people's lives and to improve the quality of those additional years, allowing people to live longer, happier, healthier and more independently into their old age and support them with personalised and responsive care at the end of life. The aim of the Clinical and Community Services Strategy (CCSS) is to support the system to achieve this by shifting the focus of our health and care delivery from reactive, hospital based treatment models to a pro-active approach of prevention and early intervention, delivered in people's homes or in community locations where this is appropriate with a long term view of beyond 5 years.

In 2018/19 8,904 adults died in Nottingham and Nottinghamshire. Between 2020 and 2030 the number of deaths is expected to grow 11% to 10,731 per annum. There has also been a shift towards increasing numbers of males, narrowing the gap between genders. In future years deaths for males are predicted to be consistently higher than for females. Deaths amongst people aged 85 years and over accounts for the greatest increase in numbers representing 56%, 6215. The end of life care needs for older people therefore having a greater impact on future demand for services.

The NHS Long Term Plan (LTP) outlines five major practical changes in the delivery of health and care, with one being a commitment to giving people more control over their own health and more personalised care when they need it. For end of life care this includes expanding the choices and control that people have over their own care, with the aim of delivering more person centred care accounting for individual values and preferences, ensuing choice and sharing control to meaningfully improve care outcomes. This it aims to achieve by creating genuine partnerships between patients, families, local authorities and voluntary sector partners, including hospices. The NHS LTP also makes a commitment to rolling out training to help staff identify and support relevant patients and introduce a proactive and personalised care plan for everyone identified as being in the last year of life. A consequence of better quality care being a reduction in avoidable emergency admissions and more people able to die in a place they have chosen.

The 2008 National Strategy for end of life care in England galvanised the health and care system with 3 insights: that people don't die in their place of choice; we need to prepare for larger number of people dying and that not everybody receives high-quality care. The Joint Strategic Needs Assessment (JSNA) for Nottinghamshire identified key gaps in the delivery of EOLC and made recommendations relating to the provision of holistic care, better information sharing and education and training. The Ambitions for Palliative and End of Life Care: A National Framework for local action 2015-2020 outlines the foundations and building blocks which local health and social care leaders can use to build the accessible, responsive, effective, and personal care needed at the end of life. In order to align to the LTP, Ambitions for Palliative and End of Life Care and consider the gaps and recommendations of the local JSNA, it is imperative to develop new models of care in the redesign of end of life care services. These need to incorporate access to the multitude of professionals and organisations in a coordinated and effective manner to ensure patients receive the right care, by the right person in the right place that reflects their wishes.

The strategy identifies major stages in the journey of those requiring end of life care and stresses a need to reorganise the way in which these services are delivered, from early recognition through to the provision of holistic care in the person's preferred place of death. A whole pathway approach in the provision of end of life care is crucial in order to maximise the clinical outcomes for patients, their quality of life and experience of end of life care services.

Completion of the Ambitions Self-Assessment Toolkit for the ICS (Appendix 1) has identified key themes along with key transformational opportunities and potential impacts have been developed which include: the development of a website for end of life care for use by citizens and healthcare professionals, adoption of consistent tools to support identification and care planning for people requiring end of life care in all settings, personalisation in the delivery of end of life care through consistent access to a single point of contact and key worker to coordinate care, access to equitable services with clear lines of access and seamless transitions across health and care through active partnerships, a universal education offer for healthcare professionals, volunteers, patients and carers and access to timely bereavement support dependent on needs.

A transformational 'Bridge to the Future' highlights current service offers across the ICS and identifies some potential long term next steps that can be taken to achieve the identified opportunities with proposed timelines and the expected outcome for our citizens of Nottinghamshire.

The recommended next steps are vital in keeping the momentum of change in the future offer of improved prevention and better mental wellness for our citizens; providing the right tools for our population to support their wellbeing; providing strong communication links for our staff is vital to enable them to provide the best care for our citizens; the most appropriate models of care in hospital settings, neighbourhood and home need to be provided equitably across the ICS and be provided using best evidence, flexibly and in a patient centred holistic way for them to fulfil their maximum potential throughout their lifetime.

| **Background and Purpose** | In Nottinghamshire we have made great progress in improving people's health and wellbeing. Today, we can treat diseases and conditions we once thought untreatable. However, our health and care system faces change and this will impact on our services, for example, the growing prevalence of long-term health conditions places new strains on our system. There is inequality evident in both the location of services and in access to services. In some areas, it is easier to access a GP or than in others, or to find things to do to enable citizens to stay active and fit.

The ICS ambition across Nottinghamshire is to both increase the duration of people's lives and to improve those additional years, allowing people to live longer, happier, healthier and more independently into their old age and support them with personalised and responsive care at the end of life.

The requirement for a CCSS came from the recognition that to achieve this ambition the system has to change as a whole, rather than just in its individual acute, primary care, community and social care elements. It is recognised that only by working together to describe changes in how care is provided across the system, rather than through individual organisations, will we deliver the scale of change required. |
| --- | --- |
| **The ICS Clinical and Community Services Strategy** | The aim of the CCSS is to support the system to achieve this by shifting the focus of our health and care delivery from reactive, hospital based treatment models to a pro-active approach of prevention, early intervention and personalisation of care. This should be delivered closer to people's homes or in community locations where this enables better prevention, more supported self-care, earlier intervention and coordination of care to support citizens. The Strategy recognises that achieving this change is a long term programme that will be delivered over the next 5 years and beyond. This is also to enable a necessary long term investment in the health and care buildings and infrastructure in the system.

An overall CCSS whole life model framework has been developed to focus on the need to support people through their lives from living healthy, supporting people with illness and urgent and emergency care through to end of life care. Citizens can experience different parts of the system at different stages in their lives. With the development of the overall Strategy framework the next phase of work is to review the 20 areas of service across the ICS that collectively form approximately 80% of the volume of clinical work in the ICS. This will ensure that overall the Strategy is described as a coherent whole and generates a programme of change for the whole ICS. This review of End of Life Care Services provides the opportunity to be such a review and is part of the third phase of work. |
| **NHS Long Term Plan** | The NHS LTP is clear that to meet the challenges that face the NHS it will increasingly need to be more joined up and coordinated in its care; More proactive in the services it provides; More differentiated in its support offer to its individuals.
The ICS has focused on describing 5 areas of focus for the delivery of the NHS LTP. These requirements are reflected in each of the service reviews that collectively will describe the CCSS
1. Prevention and the wider determinants of health - More action on and improvements in the upstream prevention of avoidable illness and its exacerbations
2. Proactive care, self management and personalisation - Improve support to people at risk of and living with single and multiple long term conditions and disabilities through greater proactive care, self-management and personalisation
3. Urgent and emergency care - Redesign the urgent and emergency care system, including integrated primary care models, to ensure timely care in the most appropriate setting
4. Mental health - Re-shape and transform services and other interventions so they better respond to the MH and care needs of our population
5. Value, resilience and sustainability - Deliver increased value, resilience and sustainability across the system (including estates) |

Approach	This strategy has been developed through an open and inclusive process which weaves together the expertise of clinicians and care experts with commissioners and citizens in determining the future shape of services across the system. There have been a variety of stakeholder and service user events to develop a clinical and community services model. An extensive system wide piece of work is taking place across a minimum of 20 services. The CCSS Programme Board have reviewed these services against a range of quantitative and qualitative criteria and agreed the third phase of seven service reviews. These include Gastroenterology, Depression and Anxiety, Heart Health, Colorectal, Urological Health, Oncology and End of Life Care. This document discusses the approach, scope, the key issues and potential transformational opportunities within end of life care services across the ICS. Health, social care, public health and the voluntary sectors have all been considered through reviewing the current service offer across the ICS. This has been informed by completing the Ambitions Self-Assessment Tool for each ICP in the ICS. The service review was taken over approximately 14 weeks and there were two workshop held with stakeholders from across the ICS. An evidence review pack was developed which considered national and local best practice to inform the development of potential themes and new models of care where transformational change may take place across the ICS in the future.
Scope	For the purpose of the end of life care review, the following focus was agreed: **In scope:** • Adults age 18 years + - but to include transition • People who are likely to die within the next 12 months • People whose death is imminent (within a few hours or days) And those with: • Advanced progressive, incurable conditions where prognosis is difficult to predict and would benefit from advance care planning • General frailty and co-existing conditions the 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-threating acute conditions caused by sudden catastrophic events **Out of Scope:** • Children
Engagement	The end of life service review has been supported by a tailored End of Life Care Steering Group involving stakeholders and clinical experts from across the ICS. They have provided expert advice, guided, confirmed and challenged assumptions throughout the period of review and connected to other workstreams. This group has formed part of the governance process along with the CCSS Programme Board. Two virtual workshops have been held enabling a wide breadth of stakeholders (Consultants, GPs, CNS, healthcare scientists, allied health professional (AHP), Pharmacists, Heads of Service, Commissioners and others) to be proactively involved in re-evaluating current service offers across the ICS, in developing potential themes aligned with the areas of opportunity identified in the Ambitions Self-Assessment and agreeing transformational change for the future Clinical and Community Services Strategy. Patient engagement has enabled confirm and challenge of assumptions and play an active part in the co-design of any future service changes across the ICS.

Strategy Development	This Strategy Document consists of five key elements. These have been developed through a process of design and iteration at the workshop and steering group meetings and includes key stakeholders from across the system. The strategy has been developed with reference to the Evidence Review document and the patient focus group that has been held.
Priorities for Change	The work of the Steering Group and the workshop stakeholders identified and confirmed four key areas of focus that need to change in the ICS for end of life care. These were based on the Ambitions Self-Assessment results, a review of the current issues facing the ICS and the views of the Steering Group and workshop attendees. Some service user experience has also been incorporated into the development of the strategy.
Proposed Future Care System	Following the initial engagement, at subsequent steering group meetings, attendees started to develop the future care system for End of Life Care to address the Priorities for Change. The future care system is described against two dimensions and aligned to the stepped care model: • **Location** split between - Home (usual place of residence) – Hospital (including both acute and MH) with 24/7 medical presence – Neighbourhood representing all community/primary care and ambulatory care settings • **Urgency** split between - **Emergency/Crisis** requiring a service provided 24/7 to avoid crisis or risk to life – **Urgent** requiring a service 7/7 but not 24/7 to meet urgent care needs – **Planned/Scheduled** reflecting any arrangement where an appointment is agreed between a professional and a citizen The intention of the system model is to focus future care delivery closer to home and also with greater levels of scheduled care to best use the available resources and reduce demand on urgent and emergency care services. The new system to address the Priorities for Change is presented for each location and then summarised overall for the ICS.

Transformation Proposal	The Transformation proposal describes the key initiatives or programmes that are required to deliver this new model. As described earlier, for End of Life Care services, some of these programmes need to be developed in more detail. Namely,
	
	• **Priority** – What is the priority of the initiative in the view of the steering group and workshop attendees
	
	• **Alignment** – At what level of the system should we aim for a consistent approach for each initiative? This was split into two categories:
	
	  ▪ Alignment to achieve **consistency** - In most instances this is ICS or Integrated Care Provider (ICP) level where with the greater value is perceived to be in an overall consistent approach.
	
	  ▪ Alignment for **delivery** of the proposal - There are some instances where the recommendation is for delivery to be at ICP level, alternatively, it is at Primary Care Network (PCN) level where differential delivery would benefit the needs of very local populations
	
	• **Enabling Requirements** – What is required to enable each Programme to deliver? This includes workforce, technology, estate or service configuration. There are also requirements of culture or finance and commissioning to allow the system to work together differently
	
	• **Benefits and Costs** – Where available, the key benefits of the initiative at system level are summarised

Service Vision	The 'Bridge to the Future' was generated at a further virtual steering group meeting. It summarises the current challenges for the end of life care system in the ICS now (Priorities for Change), what the ambition is and the outline steps to get there. Progress with the 'Bridge to the Future' and the partnering vision can be returned to with stakeholders as the work develops to review progress.

End of Life Key Themes

Integrated Care System Nottingham & Nottinghamshire

Person Centred Care

- Advance Care Planning
- Holistic Needs
- Bereavement Services

Equality and Access

- Services irrespective of place and diagnosis
- Social Care & reablement

Whole System Approach

- Education and Training
- Shared Records
- Coordination of Care
- Partnership Working

Compassionate Communities

- Public awareness & engagement
- Social Prescribing
- Volunteers

Ambition 1: Each person is seen as an individual

Ambition 2: Each person gets fair access to care

Ambition 3: Maximising Comfort and wellbeing
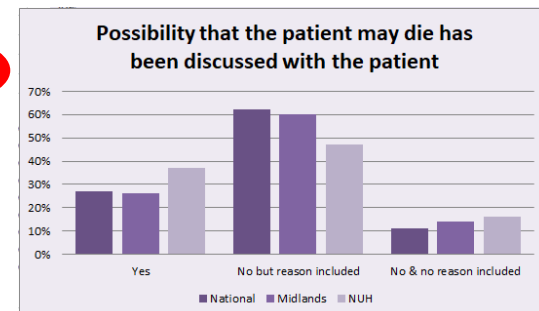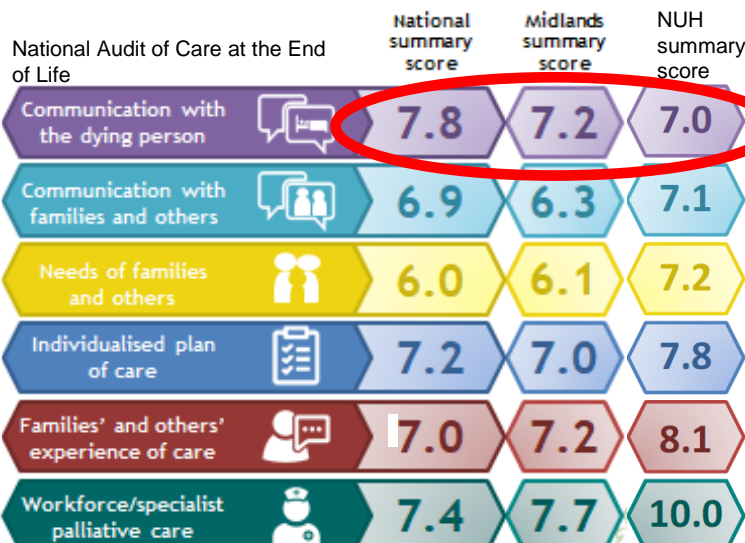
Ambition 4: Care is coordinated

Ambition 5: All staff are prepared to care

Ambition 6: Each Community is prepared to help

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If Nottingham and Nottinghamshire ICS follow the same patterns of care as observed nationally then nearly

1 in 3 palliative care patients may have died without their pain properly controlled.
Strategy Unit Report

Over half the people that die at home only have pain partially relieved or not relieved at all
Strategy Unit Report

47% of people in the last 5 years alone have been bereaved. It increases the risk of mortality and poor health, and perceived isolation.
End of Life Notts JSNA

National Audit of Care at the End of Life

	National summary score	Midlands summary score	NUH summary score
Communication with the dying person	7.8	7.2	7.0
Communication with families and others	6.9	6.3	7.1
Needs of families and others	6.0	6.1	7.2
Individualised plan of care	7.2	7.0	7.8
Families' and others' experience of care	7.0	7.2	8.1
Workforce/specialist palliative care	7.4	7.7	10.0

Percentage of deaths that occur in care homes (All ages)

Trends for **NHS Nottingham and Nottinghamshire CCG**

Compared with England ● Lower ● Similar ● Higher

Fingertips
PHE Fingertips

Three quarters of the bereaved say they didn't get the support they required.
End of Life Notts JSNA

In 2019 51% of all Nottingham City resident deaths in hospital (45% nationally)

Possibility that the patient may die has been discussed with the patient
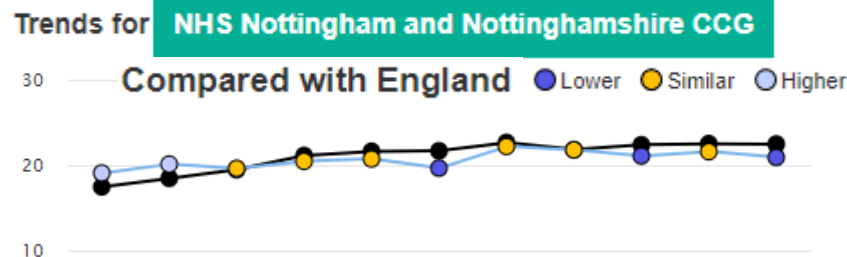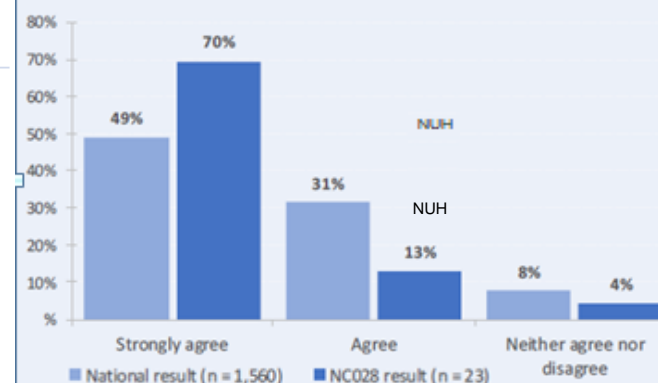
■ National ■ Midlands ■ NUH

National Audit of Care at the End of Life

At NUH 43% of patients for no recorded reason do not have the risks/benefits of hydration discussed with them (more than double the 20% national average) & likewise 34% for nutrition (22% nationally).
National Audit of Care at the End of Life

The hospital was the right place for the person to die

NUH

	Strongly agree	Agree	Neither agree nor disagree
National result (n = 1,560)	49%	31%	8%
NC028 result (n = 23)	70%	13%	4%

National Audit of Care at the End of Life

Priorities for Change – Info-graphics

Figure 1 : Deaths in England, long term trends and forecasts

Legend: Deaths — Forecast

Strategy Unit Report

Figure 3 : Forecast deaths by age group - Nottingham and Nottinghamshire ICS

6,215 (56%)
3,989

3,496 (28%)
2,738

1,569
1,336
1,401 (-11%)
1,000 (-21%)

60
43 (-29%)

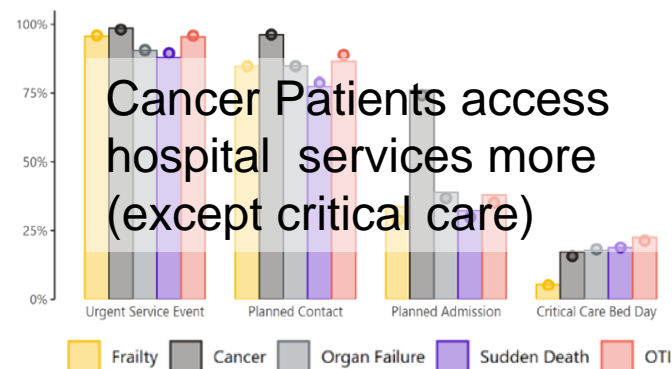**Sharp rise in deaths expected – services will experience higher demand. Forecast additional 200 beds required in the ICS by 2040.** Strategy Unit Report

0.75%-1% of the population dying nationally each year.

GP's workload – average 20 deaths/GP/yr approximate proportions

- Sudden Unexpected Death 1-2
- Cancer 5
- Organ Failure 5-6
- Frailty / Co-morbidity / Dementia 8

Notts ICS population accessing healthcare activity 2 years prior to death: (circle midlands)

Cancer Patients access hospital services more (except critical care)

Legend: Frailty, Cancer, Organ Failure, Sudden Death, OTI

Axis: Urgent Service Event, Planned Contact, Planned Admission, Critical Care Bed Day

- WW1
- peak in births after WW1
- WW2
- peak in births after WW2
- peak of 1960's
- Abortion Act 1967 came into force
- peak in deaths at end of WW1
- peak in deaths during WW2
- births less than deaths, 1976 and 1977

Rise in deaths in those age 85+ is due to the peak in births post world war 2.

Only 6% of patients with end of life heart failure are referred to palliative care National Heart Failure Audit
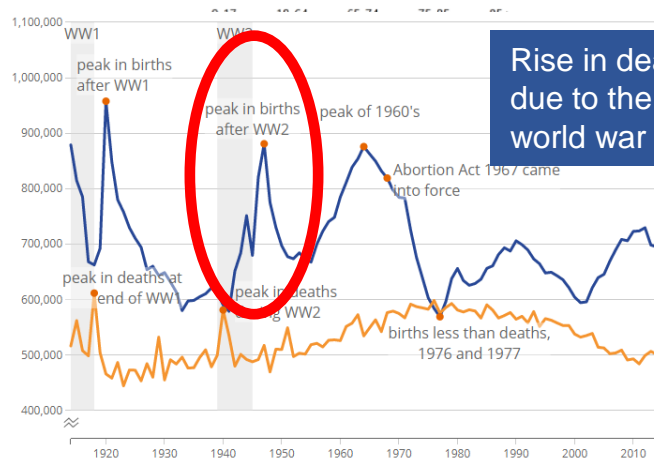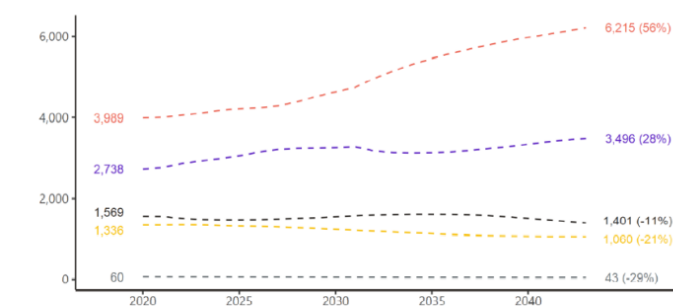
Nottingham City has a very young population with 50% below the age of 30. 1 in 8 are students. Therefore a lower % will be in the last year of their life.

Integrated Care System
Nottingham & Nottinghamshire

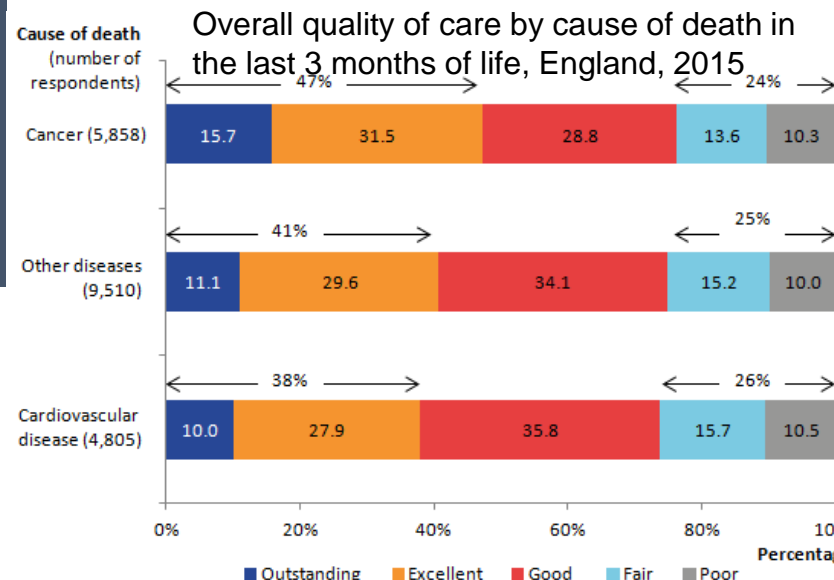## Nottingham and Nottinghamshire ICS / Midlands

People with cancer are more likely to die in their own homes or in a hospice than those dying of other causes. A lower proportion of people with cancer die in a hospice in our ICS than in the Midlands.

The Strategy Unit

Overall quality of care by cause of death in the last 3 months of life, England, 2015

Cause of death (number of respondents)	Outstanding	Excellent	Good	Fair	Poor
Cancer (5,858)	15.7	31.5	28.8	13.6	10.3
Other diseases (9,510)	11.1	29.6	34.1	15.2	10.0
Cardiovascular disease (4,805)	10.0	27.9	35.8	15.7	10.5

Cancer: 47% / 24%
Other diseases: 41% / 25%
Cardiovascular disease: 38% / 26%

Nottinghamshire Hospice support patients and all those involved in their care on 15,872 occasions in 2019 working with more than 3,000 people.

794

2,598

2,376

2,380

5,078

2,644
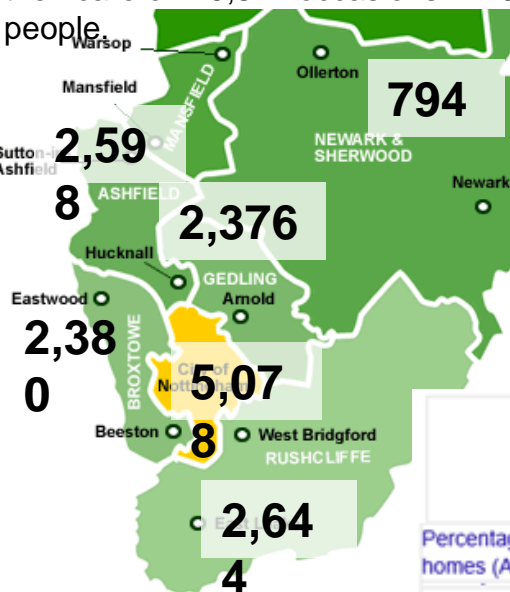
Nottinghamshire has a very low number of beds for End of Life Care per head of population. 32 beds for a population of 1.1M

People with cancer are most likely to rate their care in the last 3 months of their life as outstanding or excellent.

Indicator	Period	Recent Trend	Nottingham Count	Value	Region Value	England Value	Lowest	Range	Highest
Percentage of deaths that occur in care homes (All ages)	2019	→	370	15.6%	23.1%	22.5%	6.8%		32.2%
Percentage of deaths that occur in hospice (All ages)	2019	–	96	4.0%	4.9%	5.8%	0.2%		16.1%

In Mid Notts, people registered on Electronic Palliative Care Co-ordination

System (EPaCCS) are 70%+

likely to achieve their priorities

for care as opposed to <40%

for those who haven't.

Notts JSNA

ICP	Population	EoL Register (ePACCs)	% on EoL Register
Mid Notts	335,305	2,665	0.79%
South Notts	379,550	2,680	0.71%
City	391,445	1,955	0.50%
ICS	1,106,300	7,300	0.66%

Admissions and death on an acute hospital ward are significantly less likely for those who have been identified on EPaCCS.

Notts JSNA

Notts JSNA assumes ¾ of the 1% expected to die each year will require EoL care, so identification is high against this objective, but areas that can be improved upon (heart failure for instance).

GSF training improves EOL
9 care homes in Nottinghamshire achieved this standard
50-60 Care homes achieved a shortened GSF training accreditation

Notts JSNA 2015

Respondents that had received training in End of Life Care said it helped them engage more sensitively, respectfully and creatively with dying individuals.

A qualitative study from Nursing Times found that although many staff in care homes were not trained in EOLC, they would be open to training to develop their confidence and practice.

Notts JSNA

Integrated Care System
Nottingham & Nottinghamshire

ICP	EoL Register (ePACCs)	Social prescribing referral	% EoL with social prescribing
Mid Notts	2,665	525	19.70%
South Notts	2,680	135	5.04%
City	1,955	40	2.05%
ICS	7,300	700	9.59%

eHealthScope

There is great variation in the use of social prescribing for End of Life care from 2% in Nottingham City to 20% in Mid-Notts.

Staff and patients alike will benefit from a **doubling** of the **number of volunteers** also helping across the NHS. **NHS Long Term Plan**

Around 3 million people volunteer for the health, disability and welfare organisations in England comparable to the combined NHS and social Care workforce. Helpforce

An average return on investment in volunteering of at least 11 times the actual cost. Helpforce

Volunteers form an integral part of hospice teams, receiving training, support and development. There are at least 125,000 volunteers in the UK supporting care in wards, day services and the community. Helpforce

Volunteers have been supporting the NHS hospitals since 1948. Ways that high impact volunteers are making a difference for hospitals today includes ensuring **no one dies alone** through trained volunteers providing emotional support to patients, families and carers. Helpforce

The review identified 4 key areas of focus highlighting potential areas of change which include:

- Person Centred Care (with consideration of advance care planning to support earlier identification to plan care and anticipate needs, recognising all forms of distress with access to support, access to timely pre-bereavement and bereavement support);
- Equality and Access (access to services irrespective of place and diagnosis and inclusive of approaches to all groups, assessment of social care and reablement needs to support people in achieving individual goals);
- Whole System Approach (developing a consistent approach to education and training for the workforce and inclusive of paid and non-paid carers, systems to support visibility and access to records across all settings to enable person centred coordinated care, palliative care MDT informed through data sharing and widespread adoption of advance care plans aligned with patient wishes and preferences and with active partnerships to coordinate care);
- Compassionate Communities (by enhancing public awareness of death and dying through engagement and by mapping existing community networks to a central and locally inclusive information pointy, consolidating and growing community networks with social prescribing support, reviewing and promoting opportunities for volunteers).

| Person Centred Care | Person centred care at end of life is highlighted both in the NHS LTP and The Ambitions for Palliative and End of Life Care (EoLC). Ambition 1 in the framework being that 'each person sees me as an individual', supporting everybody approaching the end of life (EoL) to have the opportunity to create a personalised care plan, with honest conversations between the person nearing EoL, those important to them and their professional carers. This includes capturing an individual's preferred place of care and death. In Nottinghamshire 66% of people express a wish to die at home, but only 26% do so. Capturing and recording preferences for care and personal goals which are reviewed regularly supports delivery of care in a coordinated way, with clear expectations to help people reaching EoL to take control. The Electronic Palliative Care Coordination System (EPaCCS) supports earlier identification to plan care, anticipate needs and capturing preferences and wishes to enhance access to support, leading to care coordination. In Mid Notts, people registered on EPaCCS are 70% more likely to achieve their priorities for care as opposed to <40% for those not registered. Locally, EPaCCS is not accessible across all settings including: 111 , OOH, EMAS, care homes, domiciliary care and secondary care. The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process creates personalised recommendations for a person's clinical care in a future emergency, providing further opportunity to personalise care. Locally, uptake of this process is inconsistent, with widespread adoption providing further opportunity to personalise care.

Many people approaching death are fearful of being in pain or distress, alongside powerful sources of emotional turmoil, social isolation and spiritual distress. If Nottingham and Nottinghamshire ICS follow the same pattern of care as observed nationally, then nearly 1 in 3 people may have died without their pain properly controlled. Distress from pain and symptoms can be relieved with access to care, with early EoLC improving outcomes for life expectancy as well as quality of life (QoL). Inadequate or misguided interventions are features of poor experience. A comfortable death can help those who are bereaved to adjust to their loss and is captured in Ambition 3 which focusses on 'maximising comfort and wellbeing'. Recognising distress is supported by skilled assessment and symptom management. Locally, opportunities exist to capture and respond to all forms of distress in support of delivering holistic care.

Good end of life includes bereavement. 47% of people in the last 5 years have been bereaved, with three quarters saying they didn't get the support they required. The COVID-19 pandemic has resulted in an exceptionally difficult set of circumstances, with a UK Research and Innovation (UKRI) survey providing insights on the impact of experiences on the grieving process with additional distress making it difficult to find closure and begin to grieve. During the pandemic 56% of people had not tried to access support from a bereavement service, of those who did 56% experienced difficulties in accessing services. 13% did not know how to get support from bereavement services. Providing care for the individual includes understanding the need to support their unique set of relationships with family, carers, friends and their community to prepare for loss, grief and bereavement. This encompasses pre-bereavement and bereavement support and includes support to those affected by sudden death or trauma. Across the ICS there are over 60 commissioned services for bereavement support, but with gaps in provision for bereavement following sudden or traumatic death. |

Equality and Access

In the UK 1% of the population die nationally each year. Locally, 0.66% are captured on the EoLC register across the ICS. Access to EoLC varies impacting on healthcare use in the last 2 years of life. Locally, 85% of people attend ED at least once in the 2 years prior to death, 85% have at least 1 emergency admission and around two thirds call 111. Nationally, people from BAME communities and deprived areas report a poorer quality of end of life care, similarly for those with non-cancer conditions and those who are more vulnerable or less able to advocate for their own care. Inequities and inequalities in access to palliative and EoLC particularly exist for those with learning disabilities (LD), dementia and non-cancer conditions. For example, only 6% of people with Heart Failure with EoLC needs are referred to specialist palliative care teams. The predicted increase in older age group deaths and complexity in deterioration places further additional demand on EoLC , with a forecast of an additional 200 beds required in the ICS by 2040 based on current use.

Central to supporting equitable access to EoLC for the 1% of the population is the principle of earlier identification and advance care planning, with future aspirations to identify 2% of the population likely to die within the next year to increase likelihood of having advance care planning offered. The Gold Standards Framework (GSF) includes Prognostic Indicator Guidance (PIG) which can be used as a practical guide for clinicians enabling earlier recognition of decline for patients considered to be in their final years of life. Training and engagement with relevant clinicians across the breadth of conditions supports earlier identification and advance care planning to capture patient wishes and preferences, enabling the delivery of coordinated care and supporting a reduction in healthcare utilisation in last 2 years of life. Locally this was evidenced in a small audit in Mid Notts. It showed that there were missed opportunities to identify and diagnose terminal phase and initiate a care plan that would enable better planned care and potentially avoid admission and death in hospital.

Earlier identification is the first step to supporting access to EoLC for people in the last years of life. Ambition 2 recommends that 'Each person gets fair access to care' , regardless of 'who I am, where I live or the circumstances of my life'. This supports NHS LTP ambitions to provide personalised and coordinated care to enhance quality of care, reduce avoidable emergency admissions and enable people to die in a place they have chosen.

Access to care varies dependent on diagnosis. Locally, people with cancer are more likely to die in their own homes or in a hospice than those dying of other causes. However, a lower proportion of people with cancer die in a hospice in our ICS than in the Midlands. Nottinghamshire Hospice supported patients and all those involved in their care on 15,872 occasions in 2019, working with more than 3000 people providing care in the community. In Nottingham and Nottinghamshire there are 32 beds in the community supporting EoLC for the ICS population which is low in comparison to other regions. The Nottinghamshire JSNA states that although not specifically evidenced, anecdotally it is noted that there is lack of capacity amongst care homes and hospices in Nottinghamshire. Consideration is required to EoLC bed capacity across the ICS. Supporting people to die in the place they have chosen requires health and care professionals to deliver care in any setting and with clear understanding of how to access support based on needs. Consideration to 24 hour access for every person, referral pathways to teams such as specialist palliative care teams when this is needed and seamless transitions between services supporting timely access and coordination of care.

Care at the end of life encompasses a mix of 'health' needs and 'personal and social care' needs. Expertise in both is important for the best clinical assessment of need and the best delivery and management of hands-on care in the right environment, right through until death. This is supported by health care, social care and voluntary organisations working together to deliver all the personal, health and social care that people need to live their last days, weeks, months and years as well as possible. Ambition 1 highlights that 'people must be supported with rapid access to needs based social care' and Ambition 2 includes access to rehabilitative palliative care. Systems to respond to social care needs, with clear referral processes and access to reablement maximises independence and social participation to the extent the person wishes to achieve their personal goals. Locally, a range of community care, home first and fast track services are available. Awareness of services available, clear referral processes and sharing of advance care plans across settings supports coordination of care requirements in partnership with all involved in delivering EoLC.

5. Priorities for Change

| Whole System Approach | Caring for the dying and supporting people facing loss and grief is difficult and distressing, challenging the resilience and fortitude of those working in EoLC. Ambition 5 recommends that 'All staff are prepared to care', with every professional competent and up-to-date in the knowledge and practice appropriate to their role that enables them to play their part in good EoLC. However, staff can only provide compassionate care when they are cared for themselves. As well as training, access to support and encouragement leads to resilience and psychological safety, ensuring that all staff have the skills, competence and confidence to deliver care. People that have received training in EoLC saying it helped them to engage more sensitively and creatively with dying individuals.

Locally, current education and training arrangements are piecemeal, via numerous providers, with challenges to accessibility and engagement. For example, many staff in care homes are not trained in EoLC, but open to training to develop their confidence and practice. An opportunity exists to develop a universal offer for the system, building on guidance that each locality has a framework for the education, training and continuing professional development of all staff involved in EoLC. This incorporates the opportunity to promote the use of consistent and common educational resources. Alignment with the East Midlands End of Life Education Standards defines the knowledge and skill requirements for roles to achieve and maintain competence and considers the breadth of workforce and inclusive of paid and non-paid carers. Education, training and support allowing expertise to flourish in the culture of every organisation and every caring contact and how care can be delivered in a way that is tailored to the person.

Fragmented and disjointed care is a source of frustration and anxiety for the dying person, all those important to them and for staff caring for them. Lack of coordination between professionals and organisations causing distress, with poor communication and failure to share information a recurrent failing. Widespread adoption of GSF, ReSPECT and EPaCCS supports coordination of care. Fundamental to achieving this is access to shared records to ensure the plan guides a person centred approach, by being available to that person so that they can review, change and update it themselves. The plan should also be shared with all those who may be involved in their care. Locally, EPaCCS and ReSPECT are not used consistently across the ICS, with challenges to visibility and read/write access across numerous settings. Extending access across all health and social care, voluntary and private sector settings with consideration to the required interfaces across multiple systems to support visibility of information both by the person and all involved in their care.

As described, coordination of care supports the delivery of person centred care and is highlighted in Ambition 4. It assures the person requiring EoLC that they can get the right help at the right time from the right people. It ensures a team surrounds them that knows their needs and plans and works together to achieve them. Consideration to access to equitable services, aligned with existing core provision, with clear lines of access and seamless transitions across health and care settings through active partnerships supports access to someone to provide support and respond at any time of the day or night. Developing partnerships creates an impetus for delivering care, with the opportunity locally to develop active partnerships to coordinate care across health, social and voluntary care providers, building on the Mid Notts Alliance model. |

Compassionate Communities	Dying, death and bereavement are not primarily health and social care events; they affect every aspect of people's lives and experience. The dying and bereaved can feel disconnected or isolated from their communities and networks of support. Ambition 6 is that 'Each community is prepared to help', with a community where everybody recognises their role in supporting each other in times of crisis and loss. Raising public awareness of the difficulties people face creates a better understanding of the help that is available and with people ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways; developing their capacity to play a significant role in supporting individuals and those important to them to achieve the best outcomes for those with pressing needs. Public campaigns, such as Dying Matters, has supported progress in raising awareness, but there remains a continued need to address and dissolve the taboo that many people feel when it comes to talking about death, dying and bereavement. Further consideration is required to ways in which to foster and support compassionate communities and to put EoLC at the heart of community health and wellbeing. This incudes access to information through a central and locally inclusive information point, with information available in a range of formats. Public Health approaches, such as the widespread adoption of the Dying Well Community Charter, can also support this ambition

Social prescribers can work with people requiring EoLC and their families to develop tailored plans and connect them to local groups and support services. Locally, there is variation in the use of social prescribing for EoLC from 2% in Nottingham City to 20% in Mid-Notts. The NHS LTP aims to widen, diversify and make social prescribing accessible to 900,000 people across the country by 2023/24. Opportunities exist locally to consolidate and grow community networks through collaboration across the ICS to support the increased impact of social prescribing in EoLC.

Around 3 million people volunteer for the health, disability and welfare organisations in England comparable to the combined NHS and social care workforce. Volunteers are a significant resource in creating good EoLC, with an average return on investment in volunteering of at least 11 times the actual cost. Volunteers in hospices ensure the highest quality EOLC and form an integral part of hospice teams, receiving training support and development. 125,000 volunteers work in hospices across the UK supporting care in wards, day services and in the community. The NHS LTP is backing the Helpforce programme with at least £2.3 million of NHS England funding to scale successful volunteering programmes across the country, part of an ambition to double the number of NHS volunteers over the next three years. Locally, opportunities exist to promote volunteering in all settings and to connect volunteers into a more integrated effort to support people, families and communities. This requires consideration to the recruitment, training and supervision to underpin the volunteer role in EoLC and to acknowledge support for informal carers acting as invisible volunteers. |

Home

Planned/Scheduled

Urgent – 24 hours

Emergency/Crisis – 4 hours

Planned/Scheduled

Person Centred Care – Advance care planning, Holistic needs, Bereavement services
- Earlier identification to plan care and anticipate needs – with clear referral pathway
- Relationship with the team, dying person and family to develop ACP and understand preferences and wishes
- Definition of who is responsible for coordinating care
- EPaCCS accessible support advance care planning e.g. care homes, domiciliary care
- Roll out of ReSPECT 2 to all care homes
- Education of HCP on all forms of distress increasing knowledge and confidence
- Patient and carer awareness of services available to address all forms of distress e.g. social, spiritual
- Access to Grief Line and bereavement support for sudden or traumatic death
- Support for person and family helps in bereavement – what to expect and relocating the person in your ongoing life
- Experience of death was not quiet or with time to say goodbye – signposting to support

Sustainable by:
- Earlier identification and signposting to support to maximise comfort

Equality and Access – Services irrespective of place and diagnosis, Social care and reablement
- Access to services for breadth of conditions e.g. LTC such as dementia
- Public awareness of services, engagement regarding planning ahead and addressing myths regarding hospice care
- Understanding the services available and the differenced between them
- Assessment of social care needs with systems, including referral process, in place for rapid access to assessment of social care needs
- Access to reablement to maximise independence and achieve personal goals
- Access to equipment and knowing how to use it
- Consideration to communication challenges e.g. hearing, to ensure equity of access

Sustainable by:
- Earlier and coordinated intervention supporting the achievement of personal goals

Whole System Approach – Education and training, Shared records, Coordination of care, Partnership working
- Universal education offer for health and care staff (paid and non-paid) across the system – includes recognising a deteriorating patient how to act appropriately and communication skills to increase confidence in having conversations
- Training mandated and defined according to role
- Empowering to provide care but knowing when to intervene to care for carer
- Visibility of EPaCCS and ReSPECT and ability to amend across all settings
- Coordination of home based care and clarity on who's responsibility to support
- So many people involved – having one person to communicate with
- Discussion of patients at MDT meetings – define approach, capacity and identified key worker
- Role of voluntary sector in connecting patients and carers into subsequent support

Sustainable by:
- Supports consistent and coordinated care, with staff confident to deliver compassionate care

Compassionate Communities – Public awareness and engagement, Social prescribers, Volunteers
- Public campaigns and facilitation of discussion regarding death and dying
- Encouraging people to talk about death and dying – improves conversations and support
- Practical support offered from community and faith groups
- Access to community networks, central and inclusive information points and resources in accessible formats e.g. media/online to support public, families and carers
- Inclusive End of Life strategy and compassionate communities charter
- Hospice café as drop in for access to support
- Culture to recognise carers as invisible volunteers with access to support
- Promote volunteer roles and embed feedback in service planning and design

Sustainable by:
- Increasing confidence within communities to help

Urgent – 24 hours

Person Centred Care
- Consistent 24/7 point of contact for patients/carers and captured in ReSPECT form
- One point of contact at any time day or night and a key person to communicate with
- Re-assessment of needs mandatory at each change in GSF status e.g. green to amber and amber to red
- Access to Hospice at Home
- Quick access to bereavement support

Sustainable by:
- Timely support to optimise comfort
- Reduces future demand on urgent care

Equality and Access
- Swift signposting and access to services to address urgent health and care needs
- Provision of support for deteriorating dementia patients e.g. Admiral Nurses
- Access to specific requirements for complex needs e.g. bariatric patients, oxygen
- Map of services and connectivity to give seamless provision

Sustainable by:
- Timely support to optimise comfort, reduces future demand

Whole System Approach
- Education to support people responding in an urgent situation
- Visibility of EPaCCS and ReSPECT for all urgent care services Robust and responsive care coordination with go to place e.g. Gold Line used by GSF centres

Sustainable by:
- Coordination of care

Emergency/Crisis – 4 hours

Person Centred Care
- Consistent point of contact for patients/carer captured in ReSPECT form
- Re-assessment of needs mandatory at each change in GSF status e.g. green to amber and amber to red
- ReSPECT captures emergency recommendations
- Crisis team (MH) accessible for bereaved

Sustainable by:
- Timely support to optimise comfort
- Reduces future demand on emergency care

Equality and Access
- Swift signposting and access to services to address urgent health and care needs e.g. C4C
- Provision of support for deteriorating dementia patients e.g. Admiral Nurses
- Access to specific requirements for complex needs e.g. bariatric patients, oxygen
- Map of services and connectivity to give seamless provision

Sustainable by:
- Timely support to optimise comfort, reduces future demand

Whole System Approach
- Education to support people responding in an emergency situation
- Visibility of EPaCCS and ReSPECT for all responding in an emergency situation
- EMAS anticipatory medicines protocol included in ReSPECT to allow provision of medication where already prescribed
- Quick access to medication to help the person stay at home

Sustainable by:
- Coordination of care

Colour KEY to information source: Steering Group/ Workshop 1 Evidence Document/ Guideline Patient Focus Groups

NOTE: In further developing and implementing the proposals set out above as part of our focus, each partner organisation within the ICS will continue to ensure that they comply with their statutory duties and system/organisational governance processes, particularly (but not limited to) those relating to patient and public involvement; equality and inequality analysis

6. Proposed future care system

Neighbourhood

Planned/Scheduled

Person Centred Care – Advance care planning, Holistic needs, Bereavement services
- Early identification and referral processes across all health conditions e.g. LTC
- Consider needs and wants across different cultures in diverse society
- Consistent access to EPaCCS to support identification of patients & provision of care
- Sharing and visibility of EPaCCS and ReSPECT to support coordination of care
- Services available for all holistic needs with awareness of where to go and confidence in care planning to support holistic approach inclusive of all needs
- End of life support worker embedded across all GP practices
- MDT meetings within PCN to invite local community assets to support holistic needs – oversight and role of social prescribers to bring services together
- Road map to all bereavement services, with quick access and coordination of support
- Grief line – supporting in intense moment of grief with self-referral possible
- Combining with volunteers who can support signposting/provision of information
- Talking about bereavement before and contact with team after bereavement

Sustainable by:
- Earlier identification and signposting to patient wishes to optimise comfort

Equality and Access – Services irrespective of place and diagnosis, Social care and reablement
- Population learning –how access services, why didn't with LA supporting promotion to enhance access to all communities e.g. BAME
- Services for all health conditions with clear referral process between services including specialist palliative care and proactive/flexible use of Fast Track
- Access to specialist palliative care for people with LTC
- MDT inclusive of all conditions with key worker role to coordinate
- Support from community hospice e.g. telephone/befriending, day therapy, identifying exacerbations quickly and accessing community care
- Links across 3rd sector and PC - supported by social prescriber role

Sustainable by:
- Consistent access to care based on patient wishes

Whole System Approach – Education and training, Shared records, Coordination of care, Partnership working
- EPaCCS accessible across all services including social care with visibility of information
- One live record easily accessible to all and with patient access to aspects e.g. ReSPECT
- PKB to share information between the person, their carers and the team
- Palliative care MDT informed through data sharing
- Education and support for all professionals using EPaCCS and ReSPECT process
- Universal education offer across different formats e-learning/F2F –includes communication skills at core, intermediate and advanced levels, symptom control
- Training for people in care homes
- Team giving the same information regarding range of care available
- Clear lines of access and seamless transitions across settings through active partnerships across health, social and voluntary care

Sustainable by:
- Supports consistent and coordinated care, with staff confident to care

Compassionate Communities – Public awareness and engagement, Social prescribers, Volunteers
- Increase public awareness of care planning
- Recruitment/training/supervision for volunteers – developing skills and experience
- Soul midwife to support person dying and their loved ones in last weeks and days of life
- Enhanced Social prescribing offer
- Training and support for social prescribers
- Volunteers and social prescribers linking with health and care –trust between agencies

Sustainable by:
- Increasing confidence in communities to help

Urgent – 24 hours

Person Centred Care
- Grief line 24/7
- Advance care plan accessible and visible e.g. OOH, 111
- Access to holistic support in an urgent situation –map of services and connectivity to give seamless provision
- Education and support to urgent care services regarding EPaCCS and ReSPECT

Sustainable by:
- Timely support to optimise comfort
- Reduces future demand on urgent care

Equality and Access
- Single points of access across 24hrs - with seamless signposting to support across health and care
- IT system which shows the services a person is known to and direct to these
- Ability and capacity to adapt and influence advance care plan in an urgent situation with links to advice from acute care as required

Sustainable by:
- Early signposting to support
- Coordination of care based on patient wishes

Whole System Approach
- EPaCCS visible and accessible to support urgent response with one live record across all settings to coordinate care
- Education and support for all professionals in urgent care e.g. EPaCCS, ReSPECT, communication skills, symptom control
- Co-ordination of care– one number across ICS in and out of hours to co-ordinate queries, organise reviews etc.

Sustainable by:
- Supports consistent and coordinated care, with staff confident to care

Emergency/Crisis – 4 hours

Person Centred Care
- Access to holistic support in an emergency
- EPaCCS and ReSPECT visible to services responding in an emergency
- Education and support to services regarding EPaCCS, ReSPECT, symptom control

Sustainable by:
- Timely support to optimise comfort
- Reduces future demand on emergency care

Equality and Access
- Single point of access to health and care support to provide wrap around care and onward referral
- Consistent access to palliative care services to respond quickly

Sustainable by:
- Swift signposting to support
- Coordination of care based on patient wishes

Whole System Approach
- EPaCCS visible and accessible to support urgent response with one live record across all settings to coordinate care
- Education and support for all professionals responding in an emergency e.g. EPaCCS, ReSPECT, communication skills, symptom control
- Co-ordination of care– one number across ICS to contact in an emergency situation

Sustainable by:
- Supports consistent and coordinated care, with staff confident to care

Colour KEY to information source: Steering Group/ Workshop 1 Evidence Document/ Guideline Patient Focus Groups

NOTE: In further developing and implementing the proposals set out above as part of our focus, each partner organisation within the ICS will continue to ensure that they comply with their statutory duties and system/organisational governance processes, particularly (but not limited to) those relating to patient and public involvement; equality and inequality analysis

6. Proposed future care system

Acute

Planned/Scheduled	Urgent – 24 hours	Emergency/Crisis – 4 hours

Planned/Scheduled

Person Centred Care – Advance care planning, Holistic needs, Bereavement services
- Increased advance care planning from non-cancer specialties with access to EPaCCS
- Universal tool around the indicators to support early identification e.g. GSF
- Non-cancer specialist colleagues to engage with tool and how they can apply it
- Culture change issues linked to holistic view of life as a 'life span' not only about 'healing'
- Support to MDT over time to overcome barriers and enable earlier conversations to make a meaningful impact
- Mentoring from palliative care for non-cancer services

Sustainable by:
- Earlier identification and signposting to support based on the needs of the person

Equality and Access – Services irrespective of place and diagnosis, Social care and reablement
- Directory for HCP to increase awareness of services available to signpost to
- HCP awareness of options available regarding place of death – linked with cultural change
- Access and referral process to specialist palliative care services
- Targeting key areas for development and improvement.
- Equality of access on and at discharge to support fast track provision

Sustainable by:
- Equitable access to support aligned with individual wishes

Whole System Approach – Education and training, Shared records, Coordination of care, Partnership working
- Education of identification approach and engagement with this (GSF or other) to support capturing specific information
- Education on how to identify deteriorating patient
- Enhanced and consistent education including communication skills, advance care planning, tools to communicate to patients and community
- Defining level of communication skills training to role and time to attend
- Support for undergraduate training – so the training happens when you are at the outset of your career
- Coaching, mentoring and reflective working to build on education, enhance skills and provide support
- Access to electronic record, sharing cross-system record and completed as accurately as possible
- Interoperability of systems to support sharing of cross-system record

Sustainable by:
- Supports consistent and coordinated care, with staff confident to care

Compassionate Communities – Public awareness and engagement, Social prescribers, Volunteers
- Volunteer availability to non-cancer planned clinics
- System for connecting charity organisations into planned clinic settings
- Role for acute hospital in connecting voluntary sector to support EoLC patients in planned settings

Sustainable by:
- Signposting to support based on the needs of the person

Urgent – 24 hours

Person Centred Care
- Specialist advice available with an emerging situation not identified in care plan

Sustainable by:
- Reduces admissions by signposting to care

Equality and Access
- Specialist advice available with support to community teams as required

Sustainable by:
- Access to expertise
- Reduces admissions

Whole System Approach
- Access to electronic record for all urgent care settings, sharing cross-system record and completed as accurately as possible

Sustainable by:
- Coordination of care
- Reduces admissions

Compassionate Communities
- Access to information and signposting to support

Sustainable by:
- Signposting to support based on the needs of the person

Colour KEY to information source: Steering Group/ Workshop
1 Evidence Document/ Guideline Patient Focus Groups

NOTE: In further developing and implementing the proposals set out above as part of our focus, each partner organisation within the ICS will continue to ensure that they comply with their statutory duties and system/organisational governance processes, particularly (but not limited to) those relating to patient and public involvement; equality and inequality analysis

Emergency/Crisis – 4 hours

Person Centred Care
- Access to Same Day Emergency Care (SDEC) for complex care issues e.g. feeding tube/catheter/tracheostomy
- Support or actions when plans say not to convey and situation not identified in plan
- Outreach services can reach into the community to troubleshoot

Sustainable by:
- Reduces admissions by signposting to care

Equality and Access
- Specialist advice available with support to community teams as required

Sustainable by:
- Access to expertise
- Reduces admissions

Whole System Approach
- Access to electronic record for all emergency care settings, sharing cross-system record and completed as accurately as possible

Sustainable by:
- Coordination of care
- Reduces admissions

Compassionate Communities
- Volunteers in frailty assessment areas proving support for carers in this setting
- Access to information and signposting to support

Sustainable by:
- Signposting to support based on the needs of the person

Future Care System – Summary

Integrated Care System — Nottingham & Nottinghamshire

Availability

Level of Care

		Acute/ MH Hospital	Neighbourhood	Home
4 hours or less	**24/7**	• Access to SDEC for complex care issues • Consistent point of contact e.g. Gold Line to respond quickly • Specialist advice available - coordination of response with community teams • Fast track to include local EoLC services and used proactively and flexibly • EPaCCS and ReSPECT accessible in all settings • Volunteers in frailty assessment areas supporting carers • Access to information on services available to signpost to support	• Consistent point of contact e.g. Gold Line to respond quickly and coordinate response based on needs • Awareness and coordination of information and services to support timely access to wrap around care e.g. hospice support • EPaCCS and ReSPECT visible to services • Education and support to services responding	• Consistent point of contact e.g. Gold Line to respond quickly • Visibility of EPaCCS and ReSPECT • Swift signposting to services to address needs e.g. C4C • Death Doula role to support patient and family • Re-assessment of needs with change in GSF status • Self- referral to Grief Line for bereavement support and signpost to further support and information e.g. Crisis MH • Support and education of carers in an emergency situation • Education of people responding e.g. EMAS • EMAS anticipatory prescribing protocol
Urgent Care/ within 24 hours	**7 days**	• Consistent point of contact e.g. Gold Line • Awareness of information and services to support timely access to care, including specialist advice and signposting to community support • Fast track to include local EoLC services and used proactively and flexibly • EPaCCS and ReSPECT accessible in all urgent care settings • Education to support completion of EPaCCS and ReSPECT • Access to information and signposting to support	• Consistent point of contact e.g. Gold Line • Awareness of information and services to support timely access to wrap around care e.g. hospice support • EPaCCS visible in support response e.g. OOH services • Education and support linked to EPaCCS, ReSPECT and symptom control	• Consistent point of contact e.g. Gold Line • Awareness of information and services to support wrap around care e.g. Hospice at night, DN, C4C • EPaCCS and ReSPECT visible to services • Re-assessment of needs with change in GSF status • Self- referral to Grief Line for bereavement support and signpost to further support and information – including Crisis MH Team where appropriate • Education and support e.g. 111
Scheduled	**Appt based**	• Universal tool e.g. GSF to identify early • Access to EPaCCS to non-cancer specialities with visibility across settings • Access and referral pathway to advice and support, including specialist palliative care teams • Fast track to include local EoLC services and used proactively and flexibly • Clear lines of access and seamless transitions across settings • Dedicated EoLC beds to support patient choice • Website for health and care professionals to support signposting • Holistic view of life as 'life span' to enable earlier conversations and education of HCP earlier education from undergraduate training • Defined and consistent education e.g. communication skills, symptom control, deteriorating patient, advance care planning • Coaching and mentoring from palliative care specialists • Volunteer available in non-cancer planned clinics and system for connecting to voluntary and charity organisations	• Earlier identification and referral pathway to plan and anticipate needs • Equitable access to EPaCCS and ReSPECT and visibility across all health conditions/settings • Key worker role to coordinate care - patient and family aware of point of contact • Services to support holistic needs e.g. physical, social, spiritual, inclusive of all health conditions • Referral pathway to specialist palliative care services • Clear lines of access and seamless transitions across settings • MDT meetings within PCN and care navigator to ensure all patients identified as per GSF • Social prescriber role to bring services together, including third sector • Community hospice support identifying exacerbations and signposting to community care • Palliative care beds for symptom control and respite • Website for health and care professionals - services available and how to access (including bereavement support) • Consistent education for HCP, including communication skills, deteriorating patient, holistic needs, EPaCCS and ReSPECT process • Volunteers and social prescribers linking with HCP • Volunteer training and access to supervision	• Earlier identification and referral pathway to plan and anticipate needs • EPaCCS and ReSPECT accessible in all settings e.g. care homes • Patient and carers aware of services available to address all forms of distress e.g. social, spiritual • Key worker role to coordinate care - patient and family aware of point of contact • Soul Midwife role to support patient and family in last days of life • Breadth of services available, including long term conditions e.g. dementia with consideration to communication challenges to support equity of access • Respite provision at home including virtual palliative care beds • Assessment of social care needs with referral processes for rapid access • Reablement to maximise independence to achieve personal goals • Self- referral to Grief Line for bereavement support and signpost to further support and information • Consistent education for health and care staff, including communication skills, deteriorating patient, holistic needs, EPaCCS and ReSPECT • Consistent education and mentoring of patients and carers in their own home on fundamentals of care giving e.g. mouth care, manual handling • Public awareness of death and dying, with public campaigns and conversations across all cultural and faith groups • Website for health and care professionals and the public • Volunteers connecting patients and carers into subsequent support

7. Transformation Proposal

Website for end of life care rolled out across the ICS:
•Repository of information for end of life care
•Accessible to health and care professional and the public
•Supports public awareness campaigns

Med Priority

A central repository of information for EoLC provides a single point of access for the public, patients, carers and professionals to access the most up to date information which encompasses all aspects of EoLC. It provides timely information of services available to help navigate people to the right care at the right time. Enhancing awareness of death and dying and increasing confidence in conversations is a key component of the strategy; a website for the system can support public campaigns about living and dying well and provides information and tools to develop their capacity to play a significant role in supporting individuals and those important to them to achieve the best outcomes. A universal education offer for healthcare professionals and carers supports a consistent approach to developing knowledge, skills and confidence. A website can support widespread access to education materials and online delivery enhancing engagement and uptake.
A website is at the advanced stage of development. To enable roll-out consideration and support if required to populate, maintain and audit content and use to ensure it remains an up to date resource for the system.

Impact & Benefit
•Single point of access to information which is easy to navigate for professionals and the population
•Enables navigation to the right care at the right time
•Supports communication and education strategy
Alignment – To support the development of a repository of information for end of life care for the ICS alignment and delivery should be at an ICS level to support a consistent approach.

ICS wide adoption of early identification and advance care planning across all health and care settings using GSF, ReSPECT and EPaCCS to deliver a consistent approach:
• Education to support individualised care planning based on needs
• Digital and non-digital solutions to achieve system wide read/write functionality to ensure an up-to-date record accessible to the patient e.g. PKB
• Focus on care homes, non-cancer specialities and urgent and emergency services

High Priority

More needs to be done to identify people with emerging EoLC needs. Widespread adoption of GSF PIG, with education of clinicians on its use, supports earlier conversations with patients and their carers and is the first step in accessing appropriate and timely care aligned with wishes and preferences. Targeting non-cancer conditions and those who are more vulnerable or less able to advocate for their own care will enhance equity of access and address health inequalities in the delivery of EoLC. EHealthScope has the functionality to identify patients for EPaCCS and advance care plan development, with opportunities to incorporate an identification search tool within the GP electronic record, such as EARLY, to increase identification.
As well as supporting earlier identification, EPaCCS helps to plan care and anticipate needs, capturing preferences and wishes in an advance care plan to enhance access and coordination of care. The ReSPECT process captures personalised recommendations in a future emergency and can be captured in EPaCCS. Locally, EPaCCS, inclusive of ReSPECT, is only in widespread use in primary and community care. ReSPECT forms are completed in acute care, but only available in paper form and therefore not visible and accessible to all. Extending use across all care settings and including, EMAS, 111, care homes, social care and secondary care provide further opportunity to coordinate care to support better outcomes and experience and reduce admissions and emergency attendances. Connected Notts has been instrumental across the ICS in improving sharing of information to enhance visibility and access to coordinate care. Developing a read/write interface for solution for EPaCCS will enable a seamless information sharing platform with the patient, with opportunities to link with PKB functionality.
Education of the workforce to have honest conversations between the person nearing EoL and those important to them. Training which includes the development of individualised advance care plan supports capturing an individuals preferences for care and personal goals, including their preferred place of care and death. Recording and reviewing on a regular basis supporting the delivery of care in a coordinated way, with clear expectations to help people reaching EoL to take control.
Impact & Benefit
•Early identification using agreed prognostic indicators
•Timely access to personalised care leading to better outcomes for the patient and support/experience for families and carers
•Reduced subsequent mental health problems
•Supports shared decision-making and patient choice
•Reduced admissions, emergency attendances and complaints, with enhanced job satisfaction
Alignment – Ensuring adoption of early identification and advance care planning across the system is delivered with a consistent approach alignment and delivery should be at an ICS level.

End of Life Care ICS Clinical and Community Services Strategy FINAL V3.2

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Personalisation in end of life care through consistent access to a single point of contact e.g. Gold Line, with an identified key worker to coordinate timely health and care provision and implementation of personal priorities: •Signposting to MDT •Coordinating access to social prescribers, soul midwife and volunteers to connect patients and carers into subsequent support •Supporting assessment of social care needs & reablement **High Priority**	Consistent identification and advance care planning is a key step to achieving personalisation in EoLC. Fragmented care is a source of frustration and anxiety for the dying person and for all those important to them. Providing assurance to the person requiring EoLC and their carers that they can get the right help at the right time from the right people significantly reduces distress caused. Access to a single point of access 24 hours a day, such as a Gold Line as available in GSF centres, helps navigate people to the right support at any time of the day or night. Coordination of care supports the delivery of personalised care. It ensures a team surrounds them that knows their needs and works together to achieve them. An MDT supports the delivery of coordinated care by brining everyone involved in care together. Identifying a key worker from the existing workforce helps build the bridge to the MDT, developing a relationship with the person with EoLC needs and their loved ones to communicate care needs aligned with their wishes. Optimising personalisation in EoLC can be enhanced by a number of roles. Social prescribers, volunteers and soul midwives can work with people requiring EoLC and their families to tailor plans and connect and provide support. Increasing access to these roles in EoLC can enhance outcomes and experience. Social care and reablement services are fundamental to delivering personal care needs with Awareness of services available, clear referral processes and sharing of advance care plans across settings supports coordination of care requirements in partnership with all involved in delivering EoLC. **Impact & Benefit** •Improved outcomes and experience through navigation to the right care with seamless transitions •Reduces inappropriate referrals and emergency attendances •Better use of PHB budgets through delivery of flexible packages of care **Alignment –** Supporting personalisation in end of life aligned should be at an ICS level to deliver a consistent approach, with more local delivery at an PCN level
Equitable services, aligned with existing core provision, with clear lines of access and seamless transitions across health and care settings **through active partnerships,** including: •Services available to support condition management, holistic needs and wrap around care •Access to specialist palliative care teams and hospice support, including respite care •End of life care beds in acute, hospice and 'virtual beds' in the home and care homes •Fast track used proactively and flexibly and includes local services **Med Priority**	Personalisation in EoLC is supported by coordination of care. Equitable services across health and care enables the person with EoLC needs to access the right support at any time of the day or night. A number of services already exist that support people with EoLC needs, including hospice care, fast track, services that support long term conditions and provide wrap around care. Developing a clear understanding of services available, with clear lines of access supports the flexible and proactive provision of the right care at the right time. Developing active partnerships across the system will further enhance coordination of care by supporting seamless transitions to the right support in a timely way. Active partnerships have been developed in the system, such as the Mid Notts Alliance, with opportunities to extend across the ICS. Optimising access to existing services supports understanding any gaps in EoLC provision, such as respite care, specialist palliative care teams and bed capacity across the system, including specialist palliative care and end of life care beds. Access is inconsistent across settings and requires consideration to achieve equity of access, with opportunities to consider the development of 'virtual beds' to complement existing provision. Achieving equity of access supports the ambition of enabling people to die in their chosen place of death. **Impact & Benefit** •Improved outcomes and experience •Better use of PHB budgets through delivery of flexible packages of care •Timely access to support •Patient choice offered and care aligned with wishes •Enhances flexible offer to increase overall capacity **Alignment –** In order to improve pathways for non 2WW referrals alignment should be at an ICS level to support pathway agreement across the system and a consistent approach, with local delivery at a PCN level

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Integrated Care System
Nottingham & Nottinghamshire

Universal education offer for end of life care for the ICS:
•Mandated for everyone working with people requiring end of life care with defined levels based on roles
•Education of patients and their carers
•Supports consistent approach to communication, identification , advance care planning and holistic care

High Priority

Developing a universal education offer for the ICS supports the delivery of consistent and coordinated care developed through active partnerships. The ambition of 'all staff are prepared to care' increasing knowledge, skills and confidence, but also ensuring staff are supported and cared for in the delivery of compassionate care.

East Midlands End of Life Education Standards for EoLC defines education and support requirements for all the workforce involved and is inclusive of all carers, both paid and unpaid. Consideration of skills and competence dependent on role provides an opportunity to incorporate EoLC training within mandatory training. A universal offer supports a consistent approach to core components of training such as, communication skills, identification and advance care planning and addressing holistic needs. A blended approach consisting of e-learning, virtual and F2F, simulation suite and role play meets the needs of all staff and ensures easy access. Delivery and coordination of training achieved by a dedicated facilitator.

The website for EoLC provides a platform for sharing education material to ensure consistent resources are developed and used to underpin the education offer. Delivery of education should be considered in a range of formats to enhance engagement and uptake. Technological solutions are also accessible e.g. Project ECHO (Extension of Community Health Outcomes) as a virtual platform for knowledge sharing and to develop communities of practice to provide support.

Impact & Benefit
•Improved outcomes and experience with confidence in conversations regarding EoLC
•Earlier identification by having timely conversations
•Enhanced skills, knowledge and confidence
• Supports personalisation and advance care planning
•Reducing inequalities through workforce education

Alignment – To ensure a consistent and equitable approach and to achieve the ambition of a universal education offer alignment and delivery should be at an ICS level

Everybody to be offered **timely bereavement support** dependent on needs:
•Key worker to support pre-bereavement assessment to identify support proactively
•Self-referral via Grief Line
•Signposting for complex needs e.g. Crisis MH Team

Med Priority

Providing care for the individual includes understanding the need to support their unique set of relationships with family, carers, friends and their community to provide timely pre-bereavement and bereavement support. An identified key worker can support pre-bereavement assessments to prepare people for loss and proactively identify and signpost to support at the right time for the person. Access to timely bereavement support following death also supports people following loss, grief and bereavement, with opportunities to self-refer at a time appropriate for the person.

Across the ICS there are over 60 commissioned services for bereavement support. Opportunities exist to review existing provision to ensure it encompasses defined components of bereavement support and is inclusive of support for people with complex needs. Gaps in provision exist, including support following sudden or traumatic death which should be considered in a future offer.

Impact & Benefit
•Global offer for all bereaved people
•Identifying those who need help
•Navigating and coordination to right level of support

Alignment – Delivering a consistent offer across the system requires alignment and delivery at an ICS level

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Transformation Proposals	Priority (High/ Med/ Low)	Alignment (ICS/ ICP/ PCN)		Workforce	Technology	Estate/ Configuration	Culture	Finance/ Commissioning	Benefits (*Less than £20,000 per QALY is cost effective)
		Consistency	Delivery						
Website for end of life care rolled out across the ICS: •Repository of information for end of life care •Accessible to health and care professional and the public •Supports public awareness campaigns	MED	ICS	ICS	•Education to support public and population awareness of website •Consideration to IT skills to maintain functionality •Workforce to populate, maintain content and audit use and impact on navigation	•IT support to maintain functionality, with required licenses in place		•To support a single point to information to support EoLC	•Funding and commissioning of workforce to maintain content and licenses	•Single point of access to information which is easy to navigate for professionals and the population •Enables navigation to the right care at the right time •Supports communication and education strategy
ICS wide adoption of early identification and advance care planning across all health and care settings using GSF, ReSPECT and EPaCCS to deliver a consistent approach: • Education to support individualised care planning based on needs • Digital and non-digital solutions to achieve system wide read/write functionality to ensure an up-to-date record accessible to the patient e.g. PKB • Focus on care homes, non-cancer specialities and urgent and emergency services	HIGH	ICS	ICS	•Advance Care Planning Nurse for all areas to support completion of process and training of workforce •Education of staff (health and care) to support completion of EPaCCS and ReSPECT to develop skills and confidence to ensure they are timely, anticipate needs, support escalation and are re-assessed and recorded accurately	•EHealthScope to identify people with EOLC needs requiring EPaCCS and ACP •Technology which allows visibility and the ability to access and maintain version control across all settings		•Creating a culture where it is everyone's responsibility to enable two-way conversations with patient and their families. •Raising awareness with patient and families earlier to capture wishes •Timely completion of EPaCCS embedded in practice	•Commissioning people to complete the ReSPECT process -currently seen as an add on	•Early identification using agreed prognostic indicators •Timely access to personalised care •Better outcomes for the patient and support/experience for families and carers •Reduced subsequent mental health problems •Supports shared decision-making and patient choice •Reduced admissions and emergency attendances •Increased job satisfaction •Reduction in complaints
Personalisation in end of life care through consistent access to a single point of contact e.g. Gold Line, with an identified key worker to coordinate timely health and care provision and implementation of personal priorities: •Signposting to MDT •Coordinating access to social prescribers, soul midwife and volunteers to connect patients and carers into subsequent support •Supporting assessment of social care needs & reablement	HIGH	ICS	PCN	•Define key worker role and scope requirements for consistent access - opportunity for hub model •Scope and define other roles e.g. social prescribers and soul midwife •Scope access to social care assessment and reablement to identify gaps •Training of health and care staff – quality assured to support conversations	•Develop a Gold Line for the ICS available 24/7 •Technology to support virtual connections for MDT •Use of GPRCC to identify people as per GSF and assign key worker •Visibility of information across health and care		•Culture change to ensure personalisation principles, with the patient taking the lead to make informed choices •Cross-system working across all settings and providers to coordinate end of life care	•Funding and commissioning of roles and training offer	•Improved outcomes and experience •Supports navigation to the right care with seamless transitions •Reduces inappropriate referrals •Better use of PHB budgets through delivery of flexible packages of care •Reduced emergency attendances

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7. End of Life Care Transformation Proposal

Transformation Proposals	Priority (High/Med/Low)	Alignment (ICS/ ICP/ PCN)		Workforce	Technology	Estate/ Configuration	Culture	Finance/ Commissioning	Benefits (*Less than £20,000 per QALY is cost effective)
		Consistency	Delivery						
Equitable services, aligned with existing core provision**,** with clear lines of access and seamless transitions across health and care settings **through active partnerships,** including**:** •Services available to support condition management, holistic needs and wrap around care •Access to specialist palliative care teams and hospice support, including respite care •End of life care beds in acute, hospice and 'virtual beds' in the home and care homes •Fast track used proactively and flexibly and includes local services	MED	ICS	ICS	•Mapping existing services supporting end of life care to pool knowledge and resource and identify gaps •Defining referral pathways across services to identify gaps in capacity •Education of workforce, including those supporting condition management to support defining pathway to specialist palliative care	•Technology to support referral pathways •Shared access to record/ visibility across all settings •Virtual expert e.g. Project ECHO to support partnerships and shared decision-making •Consideration to platforms such as Coordinate My Care	•Defining difference between specialist palliative care and hospice beds to determine capacity required to offer equity of access aligned with people's wishes	•Person's wishes central in deciding the right support, at the right time by the right team •Joint working to develop active partnerships and consistent recognition of the right support by the right team	•Commissioning of services where gaps identified •Funding for technology to support partnership approach •Funding for Fast Track aligned with local services – timely funding requests	•Improved outcomes and experience •Better use of PHB budgets through delivery of flexible packages of care •Timely access to support •Patient choice offered and care aligned with wishes •Enhances flexible offer to increase overall capacity
Universal education offer for end of life care for the ICS: •Mandated for everyone working with people requiring end of life care with defined levels based on roles •Education of patients and their carers •Supports consistent approach to communication, identification , advance care planning and holistic care	HIGH	ICS	ICS	•Develop a training portfolio for the system with defined competencies for all roles •Workforce capacity to deliver training and develop train the trainer roles •Dedicated facilitator to support delivery and coordination •Quality and assurance and qualification within offer	•Technology to support delivery and quality assurance •Platform e.g. Project ECHO to support training delivery with capacity to deliver across the ICS •Access to equipment to support delivery e.g. laptops	•Access to rooms for F2F training aligned with virtual offer	•Everyone's responsibility to educate, share knowledge and develop skills and behaviours •Promoting conversations earlier with the public regarding death and dying	•Funding and commissioning to deliver education offer to NHS Standard Contract and a consistent approach	•Improved outcomes and experience with confidence in conversations regarding EoLC •Earlier identification by having timely conversations •Enhanced skills, knowledge and confidence •Supports personalisation and advance care planning •Reducing inequalities through workforce education
Everybody to be offered **timely bereavement support** dependent on needs: •Key worker to support pre-bereavement assessment to identify support proactively •Self-referral via Grief Line •Signposting for complex needs e.g. Crisis MH Team	MED	ICS	ICS	•Mapping current services against 4 levels of pre-bereavement and bereavement support •Training of workforce to offer bereavement support and signpost as required •Support and mentoring for staff	•Grief line accessible and awareness when to offer F2F and group support •Awareness of websites offering support and when to signpost		•Overcoming fear of talking about death and dying across all levels of support e.g. faith, emotional support •Supporting communities to support within themselves earlier – don't need permission to talk about their grief	•Standardise commissioning across levels 1 to 4 and access to IAPT •Public engagement to support service offer	•Global offer for all bereaved people •Identifying those who need help •Navigating and coordination to right level of support

Workforce	Enhancing the future health and social care for end of life care services, requires the following main considerations for workforce: • A universal education offer to support consistent and widespread training of health and care professionals and paid and non-paid carers to empower all staff to be prepared to care for people at end of life • Cross system working to develop capacity to support education offer, with a dedicated facilitator to oversee and coordinate delivery • Workforce to populate, maintain and audit End of Life Care Website for the ICS • Advance Care Planning Nurses to support completion of plans and education of workforce • Define and develop a key worker role from existing workforce • Scope and define social prescriber, volunteer and soul midwife roles in support of end of life care • Working closely with social care colleagues to address any gaps to support social care assessments and access to reablement • Cross system partnerships developed across all providers and settings to coordinate care
Technology	The main areas in which technology can effect transformation for end of life care include: • IT infrastructure and licenses to support widespread use of the End of Life Care Website for the ICS • EHealthScope to support earlier identification of EOLC needs • Enhanced use of technology e.g. PKB and with required interfaces to support widespread adoption and visibility of EPaCCS, GSF and ReSPECT with read/write access including the patient • Gold Line for the ICS available 24/7 • Use of GPRCC with GSF PIG to support earlier identification of people requiring end of life care • IT equipment and functionality to support delivery and quality assurance of the universal education offer, with consideration of use of platforms such as Project ECHO to support virtual connections to a community of practice for end of life care • Enhanced use of technology to aid virtual delivery and connections between the patient and MDT
Estate	• Specialist palliative care and end of life care beds accessible across the system to provide choice irrespective of diagnosis • Space to deliver education offer
Culture	• ICS wide central repository of information to act as a single point of access for all information for end of life care • Where it is everyone's responsibility to enable two-way conversations with the person and their families earlier to capture wishes and preferences • Widespread adoption of EPaCCS embedded in practice • Personalisation principles embedded with the person taking the lead to make informed choices • Cross-system working across all settings and providers to develop active partnerships to coordinate end of life care • Person's wishes central in deciding the right support, at the right time by the right team • Everyone's responsibility to educate, share knowledge and develop skills and behaviours • Promoting conversations earlier with the public to increase awareness about death and dying • Overcoming fear of talking about death and dying across all levels of support e.g. faith, emotional support • Support communities to support within themselves earlier – don't need permission to talk about their grief

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Integrated Care System Nottingham & Nottinghamshire

Bridge to the Future

End of Life Care Services Future Vision:

From…		Phase 1 1st year	Phase 2 2-3 years	Phase 3 5 years +		To…
• Inequitable access and uptake to EPaCCS and ReSPECT process to support advance care planning • Inconsistent access to responsive services to address all forms of distress • Inequitable access to timely pre-bereavement and bereavement care	Person Centred Care	•Identify gaps (CH, NEMS, 111, EMAS, PCN, SC) in access to EPaCCS/ReSPECT and develop a plan to roll out training and develop named trainer in each organisation to deliver EPaCCS training •Develop mechanism and common language to assess for distress •Scope commissioning of bereavement services and co-produce a road-map of defined services for all bereavement	•Roll out to all areas to ensure consistent access •Deliver EPaCCS training to support system use and completion to support individualised plans and how to act •Implement agreed mechanism and offer training to support •Agree a consistent commissioning approach to implement coordinated support to consistent standards across defined components	•Ongoing evaluation of uptake and use of EPaCCS and ReSPECT to ensure a system approach to capturing EoL advance care plans •Ongoing use of EPaCCS and ReSPECT to inform and adapt training to deliver individualised approach •Auditing quality against all forms of distress and all settings •Delivery of a coordinated and easy to access bereavement service		• Equitable access and consistent approach to ReSPECT process and development of individualised advance care plans • Consistent and equitable access to timely services to address holistic needs • Equitable access to all levels of pre-bereavement and bereavement support, with widespread understanding of services available
• Inequitable referral and access to services to support EoLC • Lack of awareness and coordination of services available to support proactive and flexible use • Limited flexibility in access to specialist palliative and EoLC beds to offer patient choice	Equity and Access	•Scope IT solution to support referral for EoLC and strategy for consistent identification e.g. GSF and signposting •Scope and define key worker and care coordinator role - formalising from existing staff •Understand inequity – referral to EoLC or service provision – and identify gaps •Populate website and agree ongoing maintenance •Scope bed capacity by type	•Implement IT solution to support consistent referral and signposting and educate/raise awareness •Develop and educate key worker •Ensure pathways are functioning and address identified gaps to exploit care options •Campaign to raise awareness across HCP and population •Review process to ensure navigation to right service/right time •Develop plans for bed capacity	•IT systems in place supporting timely referral, access and signposting •Embed a consistent approach to key worker and care coordinator role •Comprehensive and consistent service offer with seamless transitions •Website maintenance, audit and sustainable license access •Bed capacity aligned with service offer and supports patient choice		• Equitable referral and access to services to support EoLC, including self-referral • Widespread awareness of services available to support timely EoLC , with processes to support coordination of care • Sufficient access to specialist palliative care and EoLC beds, to agreed quality marker e.g. GSF accredited, to offer and enable patient choice aligned with their wishes
• Inconsistent and fragmented approach to education • Lack of interfaces to support visibility of information • Inconsistent single point of contact to coordinate care • Lack of referral pathways to support seamless transitions across health and care	Whole System Approach	•Scope current delivery against education strategy in EM to define future offer and inclusion in mandatory training. Workforce to lead and coordinate •Scope with IT leads what is visible across settings (EPaCCS and ReSPECT) with option appraisal e.g. PKB •Scope current GSF provision to support single point of contact •Review current pathways	•Implement training and agree quality markers for education delivery – link to role and build into toolkit •Implement interim IT solution across settings – develop longer term ambition for read/write interface •Roll out single point of access Gold Line •Deliver a consistent approach and single pathway to navigate access	•Ongoing evaluation of education provision, adapting content and a process of quality assurance implemented •Embed interface solution to enable seamless information sharing platform with the patient •Ongoing evaluation of Gold Line and how referrals managed •Continuous review of pathways and navigation across settings adapting approach as required		• Universal education offer for the ICS to support equitable access and consistency across health and care • Robust interfaces between systems and optimised use of shared care systems • Consistent single point of contact to coordinate care • Developed referral pathways to support seamless transitions across health and care
• Lack of awareness and confidence in discussing death and dying • Inconsistent access to roles to support patients and their families • Inconsistent education and mentoring to support carers and communities	Compassionate Communities	•Embrace opportunity to bring conversation to forefront with widespread engagement of perception and how to deliver this •Review work to date and identify which VCSEs and roles exist (volunteers, soul midwife) and develop workforce plan •Develop education plan aligned with universal offer to support delivery to carers and communities and education of workforce as a first step	•Develop a plan based on feedback to support delivery of a strong and consistent message •Implement plans to deliver consistent workforce plan to identified gaps and ensure proposals moving forward together to improve the offer •Deliver plans to improve education of workforce and communities in two pronged approach to improve conversations about death and dying more openly	•Constantly review and improve all of the actions to ensure this reflects compassionate communities and openness about death and dying •Gaps in workforce filled and ongoing review to reflect how improving support for carers and communities in a sustainable way •Ongoing review and monitoring of the effectiveness of education delivered to provide appropriate support and improved conversations		• Widespread awareness and confidence in discussing death and dying • Consistent access to roles to support patients and their families e.g. social prescribers, soul midwife • Consistent education and mentoring to support carers and communities

Conclusions	The review of End of Life Care services as part of the development of a Clinical and Community Services Strategy for Nottingham and Nottinghamshire ICS has been undertaken using a co-design model where patients, carers, key stakeholders and voluntary sector groups, have collaboratively worked together to shape a vision for the future care system. The work has progressed well working remotely and holding virtual meetings. The four key themes for improvement identified are: Person Centred Care (with ICS wide adoption of GSF, ReSPECT and EPaCCS to deliver a consistent approach across all settings, personalisation in end of life care through consistent access to a single point of contact and an identified key worker to coordinate care and everybody to be offered timely bereavement support dependent on needs); Equality and Access (Equitable services aligned with existing core provision with clear lines of access and seamless transitions across health and care settings including: services to support condition management and holistic needs, access to specialist palliative care teams and hospice support, including respite care, end of life care beds and proactive and flexible use of Fast Track); Whole System Approach (with access to a website for end of life care rolled out across the ICS, a universal education offer mandated for everyone working with people requiring end of life care including education for patients and their carers and digital and non digital solutions to achieve system wide read/write functionality to ensure up-to-date advance care plans); Compassionate Communities (through access to information and public awareness campaigns, coordinating access to social prescribers, soul midwives and volunteers to connect people to support and education of the public, patients and carers). The review describes a future care system in optimal care settings and with care provided at different levels of urgency and envisages 3 high priority programmes to transform care: **High** – ICS wide adoption of early identification and advance care planning across all health and care settings using GSF, ReSPECT and EPaCCS to deliver a consistent approach: **High** – Personalisation in end of life care through consistent access to a single point of contact e.g. Gold Line, with an identified key worker to coordinate timely health and care provision and implementation of personal priorities **High** – Universal education offer for end of life care for the ICS: To achieve these there are a range of enabling requirements for the ICS across workforce, technology, estate, culture and financial systems. Collectively these initiatives can help transform and provide long term health improvement and sustainability in the area of end of life care services in the Nottingham and Nottinghamshire ICS.
Next Steps	This strategy sets the future direction of development for end of life care in the ICS and it is proposed it will shape future work of the ICS in a number of ways: • The identified priorities and programmes should be used to inform commissioning ICS, ICP and PCN activity • The enabling activities require development and inclusion in the relevant ICS workstreams to inform their work programmes • The impact on estate and configuration changes require inclusion in a programme of pre-consultation business case development alongside the service changes recommended from other reviews • The aggregate impact of the collective suite of service reviews should be used to shape focus of future service provision in acute/ MH and community settings in the ICS

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AHP	Allied Health Professional	LTC	Long Term Conditions
App	Application	LTP	Long Term Plan
BAME	Black, Asian and Minority Ethnic	MDT	Multi-Disciplinary Team
C4C	Call for Care	MH	Mental Healthcare
CCSS	Clinical and Community Services Strategy	Mid Notts.	Mansfield & Ashfield, Newark & Sherwood
CMC	Coordinate My Care	NEMS	Nottingham Emergency Medical S
CNS	Clinical Nurse Specialist	NHFT	Nottinghamshire Healthcare Foundation Trust
DoS	Directory of Service	NHS	National Health Service
EBP	Evidence Based Practice	NHSE/I	National Health Service England and Improvement
ECHO	Extension of Community Healthcare Outcomes	NICE	National Institute for Health and Care Excellence
ED	Emergency Department	NUH	Nottingham University Hospitals
EoL	End of Life	OOH	Out of Hours
EoLC	End of Life Care	OP	Outpatient
EMAS	East Midlands Ambulance Service	PC	Primary Care
EMIS	Egton Medical Information Systems	PCN	Primary Care Network
EPaCCS	Electronic Palliative Care Coordination System	PHE	Public Health England
F2F	Face to Face	PHM	Population Health Management
GP	General Practitioner	PID	Project Initiation Document
GPRCC	General Practitioner Repository for Clinical Care	PIG	Prognostic Indicator Guidance
GSF	Gold Standard Framework	PKB	Patient Knows Best
H&SC	Health and Social Care	PN	Practice Nurse
HCP	Healthcare Professional	QoL	Quality of Life
FU	Follow up	QIPP	Quality, Innovation, Productivity and Prevention
IAPT	Improving Access to Psychological Therapies	QALY	Quality Adjusted Life Year
IP	Inpatient	ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
IT	Information Technology	SC	Secondary Care
ICP	Integrated Care Partnership	SDEC	Same Day Emergency Care
ICS	Integrated Care System	SFH	Sherwood Forest Hospitals
LA	Local Authorities	UK	United Kingdom
LD	Learning Disability	UKRI	UK Research and Innovation
LoS	Length of Stay	VCSE	Voluntary Community and Social Enterprise

Data Sources	Ambitions for Palliative and End of Life Care: A National Framework for local action 2015-2020 Helpforce Local Data from NUH, SFH, Social Care, CCGs, EPaCCS National Audit of Care at the End of Life National Heart Failure Audit NHS England NHS Long Term Plan Nottinghamshire Joint Strategic Needs Assessment (JSNA) End of Life Care for Adults The Strategy Unit Health Service Use in the Last Two Years of Life Nottingham and Nottinghamshire UK Research and Innovation

The table below shows the results of the completed Ambitions Self-assessment for each ICP within Nottingham and Nottinghamshire ICS:

	Mid-Notts						South Notts						City					
	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5
Ambition 1: Each Person Seen as an Individual	10.5%	5.3%	5.3%	21.1%	26.3%	21.1%	5.3%	15.8%	10.5%	26.3%	31.6%	0.0%	0.0%	21.1%	15.8%	47.4%	5.3%	0.0%
Ambition 2: Each person gets fair access to care	0.0%	16.7%	50.0%	16.7%	16.7%	0.0%	0.0%	16.7%	33.3%	16.7%	33.3%	0.0%	16.7%	50.0%	16.7%	0.0%	16.7%	0.0%
Ambition 3: Maximising comfort and wellbeing	0.0%	12.5%	6.3%	25.0%	18.8%	37.5%	0.0%	12.5%	12.5%	6.3%	37.5%	31.3%	0.0%	25.0%	0.0%	18.8%	25.0%	31.3%
Ambition 4: Care is coordinated	8.7%	4.3%	13.0%	26.1%	13.0%	34.8%	8.7%	8.7%	0.0%	17.4%	26.1%	34.8%	0.0%	8.7%	8.7%	21.7%	26.1%	30.4%
Ambition 5: All staff are prepared to care	0.0%	28.6%	0.0%	42.9%	28.6%	0.0%	0.0%	14.3%	14.3%	0.0%	42.9%	28.6%	0.0%	14.3%	0.0%	42.9%	28.6%	14.3%
Ambition 6: Each community is prepared to help	0.0%	50.0%	25.0%	25.0%	0.0%	0.0%	0.0%	75.0%	0.0%	25.0%	0.0%	0.0%	0.0%	75.0%	25.0%	0.0%	0.0%	0.0%