Final Draft Strategy and Outcomes Framework to Support the Delivery of Patient Centred End of Life Care Adults 2021 -2026

June 2021

Northern Lincolnshire's End of Life Care Partnership

NHS North Lincolnshire CCG
NHS North East Lincolnshire CCG
Northern Lincolnshire and Goole NHS Foundation Trust
East Midlands Ambulance Service NHS Trust
Rotherham, Doncaster and South Humber NHS Foundation Trust

Northern Lincolnshire End of Life Care Partnership Strategic Framework Introduction

Partners across Northern Lincolnshire are working together to improve end of life care.

This strategy sets out how our partnership will improve how we deliver care to people who are nearing the end of life in Northern Lincolnshire.

'*End of Life care is the care that affects us all, at all ages, the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not the parochial concern of a particular group or section of society*'
(National Ambitions for Palliative and End of Life Care 2015)

As a partnership we are committed to making care as good as possible for people and those important to them at the end of life; we have worked together to develop this framework which sets out how we will achieve this by delivering the ambitions set out in the national framework for palliative and end of life care. This was published in 2015, however the ambitions hold today.

The needs of people nearing the end of life (patients) and those who matter to them, including family members, carers, friends, neighbours and members of their local communities, have been central in developing this strategy. As have the voices of the staff who deliver these services; both employees and volunteers

To ensure that this strategy focuses on what is important for our communities and truly delivers improvements we shared the draft strategy across partners and other stakeholders including with a number of community forums. We have taken into account the feedback received in finalising this framework.

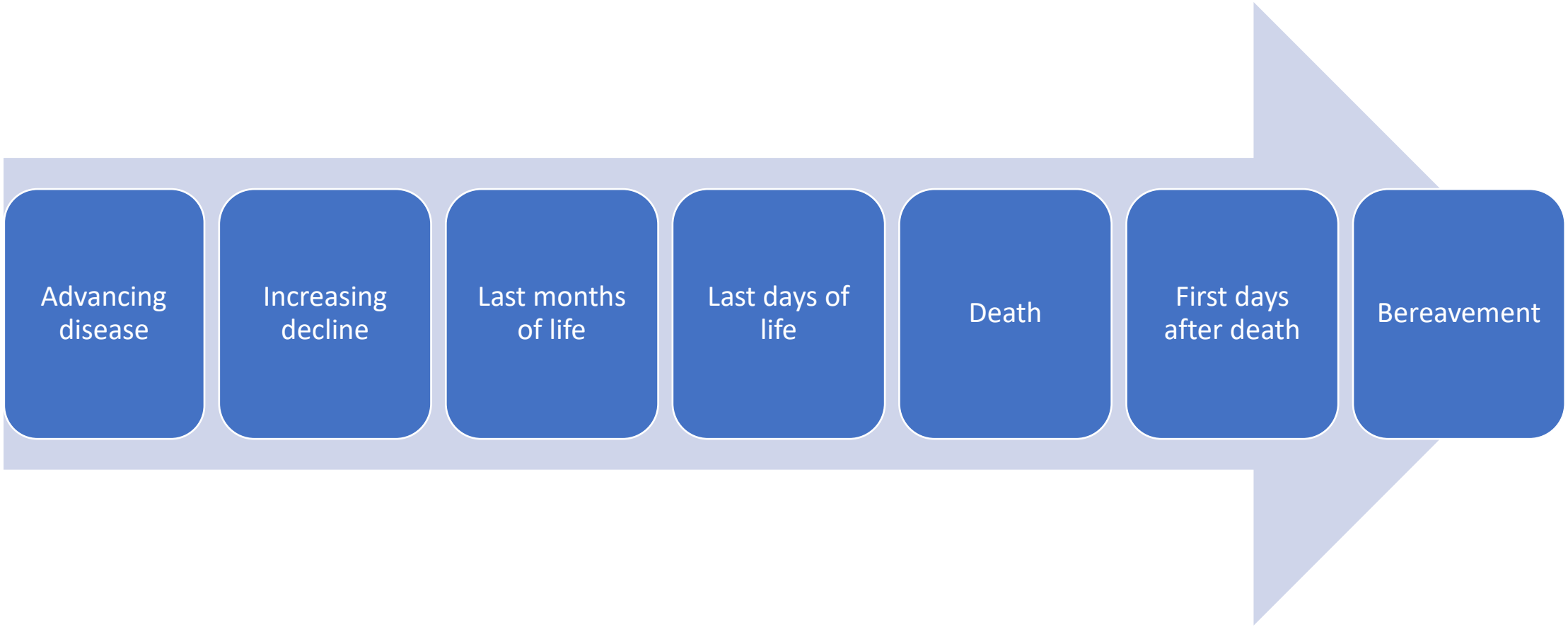
The strategy covers the period from 2021 to 2026 and our ambitions for end of life services for adults including those moving from children and young peoples services. We recognise it is an ambitious strategy and we won't be able to achieve everything at once, however we have already begun to make progress on some of the areas set out. We will be establishing delivery plans on an annual basis to deliver against the strategy. We will keep delivery of this strategy under review through changes in the organisation of health and care services.

Our Achievements So Far

In 2020 we have worked together as a partnership from May 2020 to begin to make improvements particularly;

- Introducing **ReSPECT** (Recommended Summary Plan for Emergency Care and Treatment). ReSPECT is a PROCESS and a FORM. It creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes. It includes as one part decisions that a patient does not wish to be resuscitated, which has previously been documented on a DNACPR form (Do Not Attempt Cardiopulmonary Resuscitation). This policy was introduced in September 2020 and we continue to offer support and training to clinicians to use.
- Implementing **Electronic Palliative Care Co-ordination Systems (EPaCCS).** EPaCCS record people's care preferences and important details about their care at the end of life. Information, available 24 hours a day, facilitates co-ordination of care between all health and care providers in involved in caring for a patient at the end-of-life. It supports appropriate treatment decisions to allow more people to experience a "good death", in the place that they wish and with the appropriate level of intervention. Access has been rolled out across most organisations and we expect that over the next few months professionals will be able to access in all settings and increasing numbers of records will be created.
- **Education and Training –**we've adopted a standard competency framework for end of life care skills across all partners and are working together to develop access to standard training for agreed priority areas. 3 initial priorities are being developed:- Clinical Practice/Direct Patient Care, Communications Skills and Symptom Management including Last Days of Life
- To support the work so far we have engaged with people who deliver end of life care to agree our ideal pathway – how we want people to be cared for through the last 12 months of life, their death and the support to those who are important to them after their death.

Northern Lincolnshire End of Life model of care



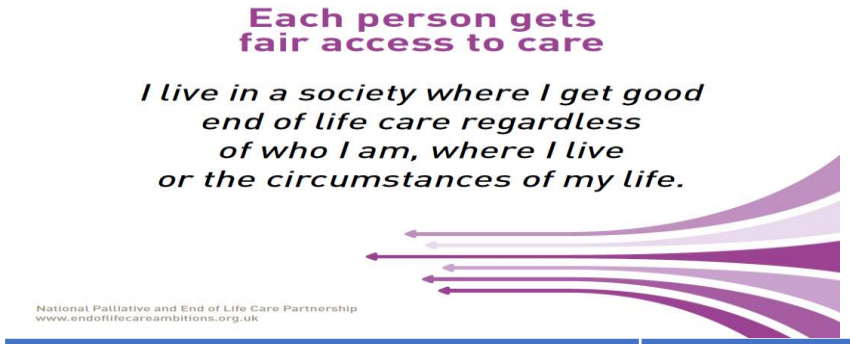
Our commitments:	
	People who are nearing the end of life and those who matter to them, are at the heart of everything we do
	We will deliver compassionate, high quality, safe, effective and responsive end of life services
	We listen to our patients and those who matter to them, our communities, our staff and our wider stakeholders to make sure our services are clinically led and designed around the needs of our population
	We will collaborate to design and deliver an integrated model of care; ensuring our patients have access to the right services and levels of care, both generalist and specialist, at the right place, at the right time, within a setting of their choice
Our principles are:	
	We prioritise high quality end of life care as an integral part of all of our services
	We work collectively across Northern Lincolnshire to deliver seamless patient-centred pathways that support people's care across all settings
	We maximise the use of resources across the system with any investment being targeted to have greatest impact for patients
	We create an environment where we deliver and share best practice with a focus on continually improving our services
	We will learn from experience and thoughts and views of those nearing end of life and those that matter to them

Each person is seen as an individual

I, and the people important to me,
have opportunities to have honest,
informed and timely conversations
and to know that I might die soon.
I am asked what matters most to me.
Those who care for me know that
and work with me to do
what's possible.

Locally our patients and those important to them have told us that it's really important that they have the opportunity to talk about and plan their care; however we know from our patient feedback that this does not happen all the time.

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
Delivering a system wide approach to consistently identifying people who are nearing the end of their life Our staff will have the skills to support patients and those important to them to have an honest and sensitive conversation about their needs and wishes as they approach the end of their life The outcomes of end of life conversations will be clearly recorded in a plan and communicated electronically to relevant providers of care	Putting in place training for staff and systematic recording of conversations to agree an end of life plan in line with their needs and wishes	People who are nearing end of life will be identified so the needs of patients and their loved ones will be actively explored, respected and met as far as possible	More people will be supported to die in their preferred place of death and are likely to die in their usual place of residence More people will be included on palliative care registers and have an EPaCC's in place with more providers inputting to EPaCC's Referrals to palliative care services will increase More staff will have undertaken enhanced communication skills training There will be fewer people dying within 24 hours of an admission (to hospital, hospice, care home) There will be fewer people with an admission of less than 1 day that ends in death (to hospital) There will be less emergency admissions in last year/3 months of life More staff will have undertaken training re the ReSPECT process



Locally there is still some variation in access to care. Access can depend on a number of factors including diagnosis and where people live.

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
We will deliver high quality care across all providers in a setting as close to home as possible	Putting in place a commissioning framework that supports equitable, sustainable and integrated delivery with community & primary care focussed provision	More people irrespective of diagnosis, geographical location and culture will be supported in a setting of their choice at the end of their life	Thematic analysis of patient/carer/ staff feedback Themes from reviewing case notes, complaints etc. More people cared for in preferred place of care More people dying in preferred place of death and in usual place of residence Regular reviewing of data re population health outcomes
We will offer equitable culturally sensitive access irrespective of geographical location	Identifying differences in access and experience across geographies, demographics and disease to identify areas for focus to reduce health inequalities		
People (Patients and the public) can access clear information, signposting and guidance whenever they need it	Agreeing a communication strategy and supporting materials	People will have the information that they need to make informed choices about their care	

Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Providing care that keeps people as comfortable as possible is important however we know from reviewing our feedback that there is still more that we can do to support people in their chosen place of death all the time through the consistent provision of specialist services

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
All patients will have a care plan that meets their needs and anticipates rapid changes in symptoms; there are services in place to support this for example anticipatory prescribing of end of life medications	Patients with an agreed advanced care plan that includes anticipatory elements for symptom change and ReSPECT forms which is shared across providers through EPaCC's	People will benefit from high quality care to ensure that their symptoms are proactively anticipated and managed 24/7	More people will be supported to die in their preferred place of death and are likely to die in their usual place of residence Referrals to palliative care services will increase There will be fewer people dying within 24 hours of an admission (to hospital, hospice, care home) There will be fewer people with an admission of less than 1 day that ends in death (to hospital) There will be less emergency admissions in last year/3 months of life
7 day access to specialist palliative care advice and interventions	Services are in place to support delivery including anticipatory prescribing and 7 day in hours access to specialist palliative care advice and interventions and access to 24/7 advice		

Its really important for our patients and those important to them that all the staff who are caring for them talk to each other to make sure that their care is coordinated

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
Designing and implementing key principles around multidisciplinary/multiagency management of patients, supported by a key worker approach to ensure that care plans are reviewed regularly and coordinated across care settings	Key working and MDTs are in place across settings	Patients care is coordinated between and across services	More people will be supported to die in their preferred place of death and are likely to die in their usual place of residence More people will be included on palliative care registers and have an EPaCCS in place with more providers inputting to EPaCCS Referrals to palliative care services will increase There will be fewer people dying within 24 hours of an admission (to hospital, hospice, care home) There will be less emergency admissions in last year/3 months of life
Approach underpinned by a clearly articulated operational pathway document explaining what services are available at different points in the pathway and how they interface to deliver coordinated care	Agreeing a communication strategy and supporting materials (see also ambition 2)	Patients and staff understand what provision is available at which points in the pathway	Thematic review of patient complaints and incidents Monitoring themes from patient family and carer feedback

Our staff tell us that having the right knowledge and skills is critical for them to feel confident in delivering high quality end of life care

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
Developing and delivering a multi professional, system-wide competency framework and ongoing support/supervision mechanism	Delivery and agreement of competency framework and associated training across all providers	People receive care from staff who have the right knowledge and skills whatever the care setting and are confident and competent in delivering end of life care	Thematic analysis of patient/carer/staff feedback/ along with complaints and case reviews. Staff feedback – how prepared do they feel to care? Clinical staff feedback
End of Life education is appropriately reflected in organisational mandatory training and continued professional development	Embedding training in End of Life in mandatory training and CPD within all staff groups and organisations		
Development and delivery of inclusive clinical engagement approach	Development and delivery of inclusive clinical engagement strategy		

It is vital that we improve engagement with all within our population to increase awareness of service provision and aid in the improvement of these services and better support our communities

We will deliver this by	Through	What difference will we make for patients?	How will we know if we have made a difference?
A robust approach to patient and community engagement to understand their needs	Development and delivery of patient engagement approach and strategy	People will be supported through a holistic approach to end of life care that meets the needs of our populations Those who are important to patients will be supported during and after their loved one's end of life	Thematic analysis of patient/carer/staff feedback/ along with complaints and case reviews Increased referrals to bereavement services
Building capacity and capability within our communities to support the health and well being of those nearing the end of their life and the people important to them.	Clear communication to enable people and communities to understand and access support Working with the Voluntary and Community Sector to build capacity and capability to support Development of bereavement services		
Signposting patients and those important to them to resources and services which can support them in their preparation for death and following bereavement			

What outcomes for patients will we work towards? Summary

- People who are nearing end of life will be identified so the needs of patients and their loved ones will be actively explored, respected and met as far as possible
- More people irrespective of diagnosis, geographical location and culture will be supported in a setting of their choice at the end of their life
- People will have the information that they need to make informed choices about their care
- People will benefit from high quality care to ensure that their symptoms are proactively anticipated and managed 24/7
- Patients care is coordinated between and across services
- Patients and staff understand what provision is available at which points in the pathway
- People receive care from staff who have the right knowledge and skills whatever the care setting and are confident and competent in delivering end of life care
- People will be supported through a holistic approach to end of life care that meets the needs of our populations
- Those who are important to patients will be supported during and after their loved one’s end of life

Next Steps

We have already begun to take forward some of the areas identified in this plan, in addition to those set out in our achievements so far.

There are some areas where we have started to develop more detailed plans such as taking forward reviewing our model of care against our ideal pathway and the delivery of integrated care across core health services and specialist palliative care services.

We also want to do further work on our outcomes framework to make sure that we are monitoring and tracking those things that will tell us whether we are providing the right care in the right place at the right time.

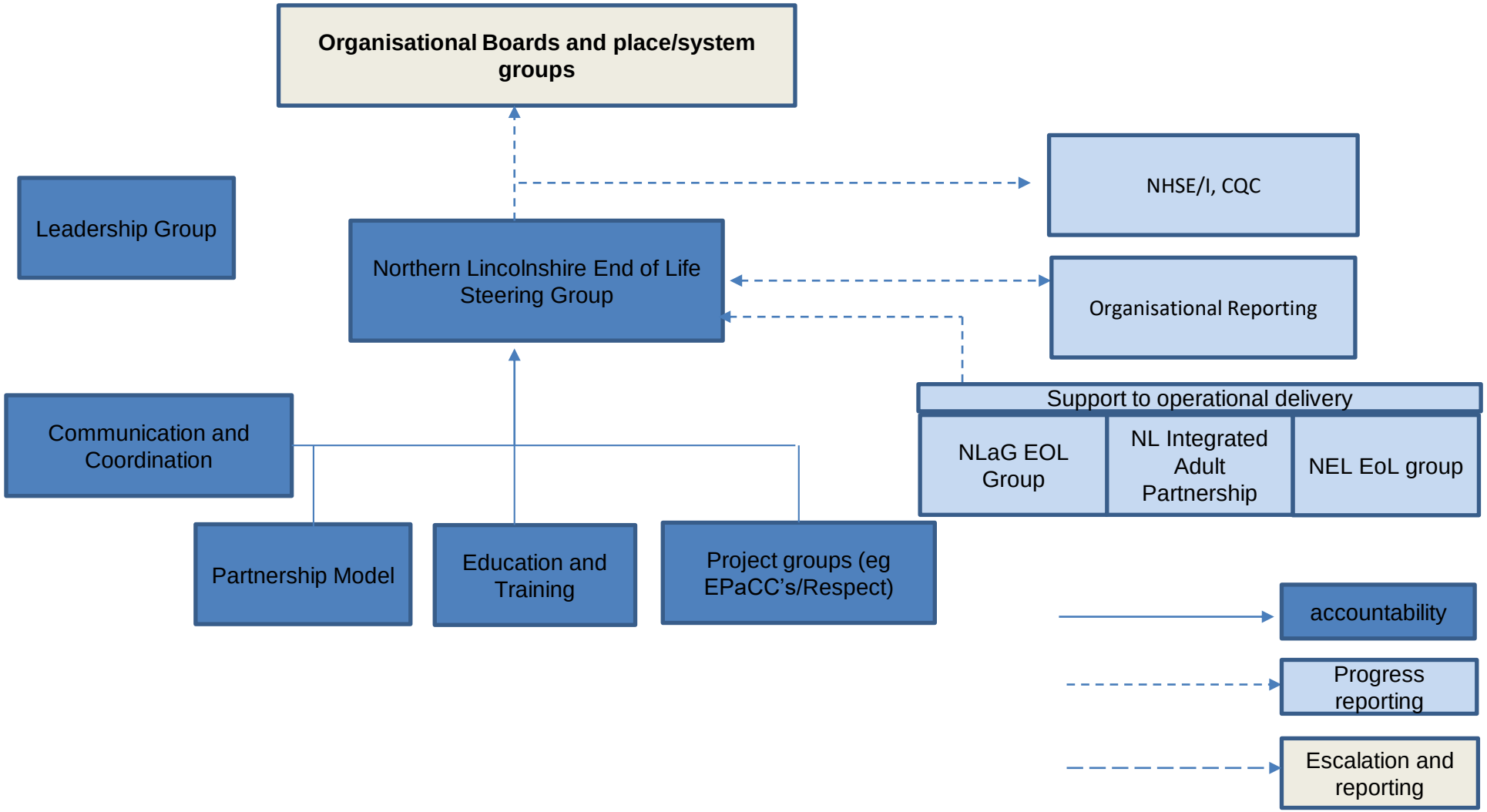
We are now developing delivery plans for each ambition and will agree a priority work plan for 2021/22

Appendices

- Governance
- Glossary and Definitions

Northern Lincolnshire End of Life Governance

(amended 9 September 2020)



Partnership Working Principles

- Patients are at the centre of our work and decisions
- Shared purpose to improve care for people at end of life
- Individual and collective responsibility to achieve the outcomes
- All those involved inform and influence decisions
- Full and active participation by members and their organisations
- Mutual understanding of risks and challenges in each organisation
- Respect for all members
- Listen to the views and concerns of others and take on board to help find a solution
- Constructively challenge
- Mutual accountability for improvement
- Culture of participation and accountability
- Focus on outcomes not organisations

Glossary and Definitions

ACP	Advance Care Planning
CH	Care Home
CNS	Clinical Nurse Specialist
CPG	Care Plus Group
CQC	Care Quality Commission
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DPoW	Diana Princess of Wales Hospital
EoL	End of Life
EPaCCS	Electronic Palliative Care Co-ordination Systems
GSF	Gold Standards Framework
GP	General Practitioner
HASR	Humber Acute Service Review
HCV	Humber, Coast & Vale
MDT	Multidisciplinary Team
NEL	North East Lincolnshire
NHSE/I	NHS England / Improvement
NL	North Lincolnshire
NLaG	North Lincolnshire and Goole NHS Foundation Trust
RDaSH	Rotherham Doncaster and South Humber NHS Foundation Trust (MH provider)
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SAFE	Specialist Assessment for the Frail and Elderly
SGH	Scunthorpe General Hospital
SRO	Senior Responsible Officer