Palliative Care in Partnership Programme Overview 2019

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Palliative Care in Partnership Programme

The Palliative Care in Partnership (PCIP) programme was officially formed in Northern Ireland in September 2016, bringing together previous structures and workstreams from Living Matters, Dying Matters (2010) and the Transforming Your Palliative and End of Life Care programme (2013 – 2016) and taking cognisance of recommendations from the RQIA Review of Living Matters, Dying Matters (2016) and the key finding of the Let's Talk About Palliative Care Survey (2016).

The PCIP programme is based on the following principles:

- One structure, one regional work plan and one direction for palliative care in Northern Ireland;
- Good palliative care is everyone's business – no one service, professional, organisation or person can provide everything required to support a person at the end of their life;
- Palliative care is not just for cancer;
- Palliative care is not just about the last weeks or days of life;
- Palliative care supports the person with palliative care needs and improves the experience of those important to them; and
- Good palliative care is about supporting quality of life until the end.

The PCIP programme structure consists of:

Regional Palliative Care in Partnership Programme Board: co-chaired by the Director of Nursing and AHPs (PHA) and the Director of Commissioning (HSCB). The PCIP Programme Board encompasses 33 members representing organisations across the health and social care system and palliative and end of life stakeholders across Northern Ireland. The programme management of the programme is currently sponsored by Macmillan. Please see appendix 1 for the current PCIP Programme Board membership.

Clinical Engagement Group (CEG): provides a forum for palliative care clinicians/professionals from across Northern Ireland to share good practice and guidance, input to the development of and contribute to the progression of the regional Palliative Care in Partnership programme and work plan. Members are drawn from palliative care and professional forums and represent the key providers of palliative care in Northern Ireland namely the 5 HSC Trusts and the hospices (Foyle, Marie Curie, NI Hospice, Southern Area Hospice) and Macmillan, as well as General Practice, and District Nursing.

Palliative Care in Partnership Voices4Care Group: a forum of NI based service users, carers and interested citizens whose membership and meetings are facilitated by the All Ireland Institute for Hospice and Palliative Care Voices4Care forum. This forum enables the engagement of service users and carers in all aspects of the regional palliative care work plan and key service developments.

Palliative Care Locality Boards: There are five Palliative Care Locality Boards across Northern Ireland which are co-terminus with HSC Trust boundaries and Local Commissioning Groups and build on previous structures already in place through LMDM and TYPEOLC. The purpose of the Palliative Care Locality Boards is to promote collaborative working between key stakeholders at locality level and as a mechanism for communicating and facilitating the implementation of the regional palliative care priorities and activities at locality level. The Locality Boards are co-chaired by the HSC Trust Director with responsibility for palliative care and a nominated member of the local Integrated Care Partnership Committee or Local Commissioning Group. The Co-chairs of the Locality Boards are responsible for ensuring their membership is representative of local service provision and partnerships.

Please refer to the PCIP structure diagram in Appendix 2 for more information.

Demography and context:

Palliative Care Need:

- It is estimated that around 1% of the population are in their last year of life (c. 19,000 people in NI each year) and around 16,000 people die in NI each year[i].
- Recognised research methodologies suggest that between 75- 80% of all deaths could benefit from a palliative care approach (c. 12,000 – 12,800 people each year – ELCOS[ii] Green/yellow/red).
- In addition, it is estimated there may be a further c.150K people with a life-limiting progressive condition who could also benefit from a palliative care approach (the 'could be years' category (ELCOS Blue)).
- Palliative care is provided by all health and social care professionals working across all care settings (in the community/ the person's home, in care homes, in hospitals and in hospices).
- The majority of palliative care is provided by 'generalist' staff – GPs, District Nurses, core AHPs[1], Social Workers, hospital nurses/ doctors and care home staff.
- Specialist Palliative Care (SPC) is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues and is provided by professionals with expert knowledge, skills and competencies including Palliative Medicine Consultants, SPC Nurses, SPC AHPs, SPC Pharmacists and SPC Social Workers.

[1] Core Allied Health Professionals include Physiotherapists, Occupational Therapists, Dietitians, Speech & Language Therapists and Paramedics

- Given the aging population of Northern Ireland, it is predicted that palliative care needs will increase by 41% by 2050[iii].

Preferred place of care:

- Given the choice, most people would prefer to die 'at home' (in their own home or care home).
- In 2017, 47% of all deaths happened in hospital (down from 51% in 2007); a further 19% of all deaths occurred in care homes (up from 15% in 2007).[iv]
- A study of hospital inpatients on 5 Feb 2015 found that 25% had died within the following year.
- Approximately 1/3 of all deaths in acute hospitals are patients aged over 85 years old.
- If palliative care needs of patients can be identified earlier and appropriate community services and supports are in place then inappropriate acute hospital admissions and those resulting in death may be significantly reduced in the future.

PALLIATIVE CARE IN PARTNERSHIP PRIORITIES

The key aim of the Palliative Care in Partnership programme is to provide regional direction so that everyone **identified** as likely to benefit from a palliative care approach (regardless of their condition):

- Is allocated a palliative care **keyworker**
- Has the opportunity to discuss and record their **advance care planning** decisions; and
- Is supported with appropriate **generalist and specialist palliative care services** to be cared for in their preferred place (whenever it is safe and appropriate to do so).

The programme aim is underpinned by:

- Regional good practice tools and guidance
- Communication
- A public health approach to palliative care

Priority 1: Early Identification	
Aim:	To improve the early identification of people who would benefit from a palliative care approach (regardless of their condition).
Programme activities:	**Early Identification Prototype in Primary Care** This prototype uses the AnticiPal algorithm run directly on the GP clinical system to produce a list of patients 'who might benefit from a palliative care approach'. These patients are then discussed between the GP and local District Nurse at a monthly MDT meeting and if agreed as having palliative

	care needs then appropriate actions are taken. Findings from Phase 1 (18/19): • 70% increase in the number of patients on the QOF palliative care register of participating practices • All participating practices increased their palliative care identification rate • District Nursing reported the prototype was useful for identifying patients with palliative care needs earlier and found the ability to discuss and plan with the GPs beneficial. Phase 2 (19/20) is currently under way with 43 practices participating. The AnticiPal algorithm is currently only available to Vision practices; the programme is in discussions with EMIS Web and Merlok about making AnticiPal available on other clinical platforms and future integration of the algorithm into GPIP. **Identification in Emergency Departments** Retrospective audits conducted on hospital admissions through Emergency Departments in both South Eastern & Belfast Trusts have found that around 30% of those admitted had palliative care needs. The programme aims to encourage/facilitate similar audits in EDs in the other Trust areas and there are plans in SET for a further more in depth project to study a larger cohort of patients with the aim of understanding: - the reasons why these patients attended ED and how/if those attendances might have been prevented and if future attendances/unscheduled admissions can be avoided - learning which could inform future service developments - testing in reach/ turn around services which could support these patients who would benefit from a palliative care approach. **Identification in Care Homes** The average length of stay for a resident in a nursing home is 18 months which leads to the conclusion that the majority of nursing home residents could benefit from a palliative care approach. Yet a survey of Care Home Managers in one HSC Trust found that only 18% of residents were considered as having palliative care needs. The PCIP Programme is working with the Care Home Transformation project to provide support and information to care homes across NI. Recent activities have included the distribution of the 'Your Life Your Choices- Plan Ahead' booklets to all care homes across NI and producing a Palliative Care Toolkit for Care Homes (please see priorities 3 & 4 respectively for more information).

Priority 2: Palliative Care Keyworker	
Aim:	To ensure everyone identified as likely to be in their last year of life has an allocated Palliative Care Keyworker who is appropriately trained and that operational processes and communication is in place 24/7 across care settings.
Programme activities:	**Palliative Care Keyworker Role & Competencies (2017)** The palliative care keyworker is an identified individual with responsibility for planning and co-ordinating care for patients who (as a minimum) have been identified as likely to be in their last year of life. The role includes co-ordinating care across interfaces (within and between professionals, teams and care settings) and promoting continuity of care. The four operational elements of the keyworker role are: • Identification • Contact & co-ordinating care • Care in the last weeks/days of life • Bereavement follow up In 2017, the PCIP Programme Board endorsed the Palliative Care Keyworker Role & Competencies which indicates that the keyworker will typically be the District Nurse. Since 2017, HSC Trusts have been progressing operational plans to ensure District Nursing is equipped for the role and training, processes and policies are in place to support the role in practice. Operationally HSC Trusts are at various stages of implementation of the Palliative Care Keyworker role. Delivering Care Phase 3 includes capacity for District Nursing to fulfil the Palliative Care Keyworker role. A recent QI Project looking at the role of Districts Nurses as the Palliative Care keyworker has returned encouraging results regarding the percentage of patients dying in their preferred place and a reduction in the number of patients dying in hospital compared to the regional average of 47%. The programme would be keen to explore these findings further with a larger cohort of patients and in other localities.

Priority 3: Advance Care Planning	
Aim:	To ensure everyone identified as likely to benefit from a palliative care approach has the opportunity to discuss and document an Advance Care Planning Summary which will facilitate the sharing of their preferences for care across settings (via a Key Information Summary).
Programme activities:	**Your Life, Your Choices – Plan Ahead** This public facing booklet produced in partnership with Macmillan and the Public Health Agency contains information regarding planning ahead and considering end of life care preferences. The booklet has been endorsed by

	the programme board and is used widely by our stakeholders. **Key Information Summary** The Palliative Care in Partnership Programme provided input to the development of the Key Information Summary to ensure fields relating to patients preferences for end of life care were included to enable the sharing of information across care settings. **Regional DNACPR Policy & Advance Care Planning Operational Guidance for Healthcare Professionals** A regional ***DNACPR Policy for Northern Ireland*** enabling DNACPR decisions to apply to patients across care setting has been drafted and has been submitted to the Department of Health for consideration. Similarly, ***Advance Care Planning Operational Guidance for Healthcare Professionals*** has been drafted by the programme and is awaiting endorsement of the regional DNACPR Policy before being finalised and disseminated. **Advance Care Planning Level 2 Training** In partnership with the Clinical Education Centre the programme stakeholders developed Advance Care Planning Level 2 training course and resources aimed at health care professionals across care settings to equip them to have advance care planning discussions with patients and understand the process for documenting and sharing decisions across the system.

Priority 4: Provision of palliative care services across Northern Ireland	
Aim:	To continue to improve equity and the provision of generalist and specialist palliative care services in all care settings across Northern Ireland.
Programme activities:	Over the last number of years the programme has concentrated on ensuring equity of access to palliative care services across Northern Ireland regardless of the person's conditions or the care setting in which they are being cared for. Throughout our work plan the programme considers the 4 main settings where people with palliative care needs will be cared for namely, in their own home, in a care home, in hospital or in a hospice. **<u>Generalist Palliative Care Services</u>** The majority of palliative care is provided by 'generalist' health care professionals (the patient's usual healthcare professionals) such as GPs, District Nurses, AHPs, Social Workers, pharmacists and hospital based doctors and nurses and nurses in care homes. As detailed previously, the programme is working to improve generalist palliative care service through early identification of people who would benefit from a palliative care approach in GP practices, the implementation of

	the District Nurse as the Palliative Care Keyworker and the promotion of Advance Care Planning. In addition the following activities have also contributed to the improvement of generalist palliative care services across Northern Ireland: • **Marie Curie Rapid Response Service** The Marie Curie Rapid Response service is now available in all Trust areas across Northern Ireland. This service enables Marie Curie nurses who are co-located in the GP OOH service or with the Trust OOH nursing service to offer home visits or telephone advice and provide urgent interventions to prevent avoidable hospital admissions. From April to September 2019, the Marie Curie Rapid Response Service supported 1940 people across Northern Ireland in their own home. • **Northern Ireland Ambulance Service** The programme has worked with NIAS to implement: - ***Treat and Refer Protocol*** (out of hours) where NIAS staff can refer patients with known palliative care needs to the Marie Curie Rapid Response service as an alternative to transferring them to ED. - Information Markers for people identified as palliative - Call prioritisation for transferring patients 'home for the last days of life' - Palliative care education and guidance for NIAS staff. • **Discharging patients with palliative care needs from hospital** The guiding principles to enable the effective discharge planning of patients from acute hospitals and transitional settings (***Getting patients on the right road to discharge***) developed collaboratively between HSCB, PHA, the 5 HSC Trusts and DoH includes a section on discharge planning for people with palliative and end of life care needs. The accompanying ***'Transition Plan for Care and Support'*** includes fields to record information pertinent to the palliative care needs of the patient being discharged. The guidance also includes a '***Home for the last days of life'*** protocol to enable quick discharges for patients who wish to spend their last days at home. • **Palliative Pharmacy Service Improvement Project** In partnership with Macmillan, the Palliative Pharmacy Service Improvement Project ran from 2017 to 2019. The project aimed to improve existing Pharmacy services and develop ways of working that would make a significant contribution to patients with palliative and end of life care needs. A ranges of resources and service improvements were implemented through the project including:

- Standardised regional palliative stock list
- Standardised procedures for discharging patients on syringe drivers and 'as required' injections
- Regional Standard Operating Procedure (SOP) for discharging palliative care patients
- Regional '***Guidance for the management of symptoms in adults in the last days of life'***
- Pilot of anticipatory prescribing 'Just in Case' boxes
- Education and training for the Community Pharmacy Palliative Care Network.

- **Palliative Care and Project ECHO[v]**

  Palliative care focused Project ECHO networks include:
  - Palliative pharmacy
  - Community District Nursing
  - Marie Cure registered nurses
  - Dementia
  - Cardiology/AF
  - Paediatric Palliative Care
  - Nursing Homes
  - Support for Carers.

- **Palliative Care in Care Homes**

  The number of people dying is care homes has increased by 38% in the last 10 years and now accounts for around 20% of all deaths in Northern Ireland. As the average length of stay in a nursing home is around 18 months it is reasonable to assume that the majority of people in nursing homes would benefit from a palliative care approach.

  The PCIP Programme is working with the Care Home Transformation Project and key stakeholders in the care home sector to promote the priorities of the PCIP Programme including the importance of early identification of palliative care needs, the benefits of advance care planning for their residents and support services available to provide additional assessment, symptom management and care as appropriate.

  In 2017, the PCIP Programme facilitated a Task & Finish Group to identify the challenges when caring for residents at the end of their lives in a care home, these included:

  i. Access to palliative care advice and drugs during out of hours periods
  ii. Timely access and support from GPs with regards to advance care planning and anticipatory prescribing
  iii. Access to palliative care education and learning opportunities for care home staff.

- **National Audit of Care at the End of Life (NACEL)**

  The five HSC Trusts in Northern Ireland are currently participating in Year 2 of the National Audit for Care at the End of Life (NACEL) managed by the NHS Benchmarking Network. The audit aims to improve the quality of care of people at the end of life (last days) in acute and community hospitals. In March 2019, following Year 1 of the audit, NACEL made 6 recommendations for Northern Ireland which are currently being progressed through the regional PCIP work plan. Recommendations from Year 2 of the audit, which includes a case note review element, are due from NACEL in March 2020.

- **Palliative Care Toolkits for Professionals**
  Based on the regional palliative and end of life care tools and guidance developed and endorsed in Northern Ireland the programme has developed 'Toolkits' for General Practice and Care Homes. These tools kits have been widely shared with GP practices participating in the Early Identification Prototype and with Care Homes through collaboration with the Care Home Transformation Project.

<u>Specialist Palliative Care Services</u>

Patients will be referred to Specialist Palliative Care (SPC) services when the patient has complex/unresolved symptoms or care needs which can't be resolved by their usual healthcare professionals.

Specialist Palliative Care is provided by specialist personnel with expert knowledge, skills and competencies working as a multi-professional team and should be available to patients across care settings.

There are nine providers of specialist palliative care services across Northern Ireland namely the 5 HSC Trusts (including the Macmillan SPC Unit in Antrim) and the 4 independent hospices (Foyle Hospice, Marie Curie Hospice, Northern Ireland Hospice and Southern Area Hospice).

- **Specialist Palliative Care Workforce Planning Review**

  Under the governance of the PCIP Clinical Engagement Group the programme undertook an interdisciplinary specialist palliative care workforce planning review. This was the first interdisciplinary workforce review undertaken in Northern Ireland and covered 8 professional disciplines – Palliative Medicine Consultants, SPC Nurses, SPC Physiotherapists, SPC Occupational Therapists, SPC Dietitians, SPC Speech & Language Therapists, SPC Pharmacists and SPC Social Workers. The final report, which makes recommendations regarding education and training for each of the respective SPC professions to meet the population needs to 2024, was endorsed by the PCIP Programme Board in April 2019 and has been submitted to the Department of Health for consideration at the Workforce Strategy

	Programme Board. • **Enhancing Specialist Palliative Care Services** Service scoping undertaken by the TYEPLOC programme in 2015/16 highlighted an inequity of access to some SPC professions across localities and across care settings. Further assessment of the current SPC staff working across NI, undertaken as part of the SPC Workforce Planning Review identified variations in the SPC professionals (particularly AHP, Social Work and Pharmacy) available to meet the current demand for services in localities. Through Transformation Funding each Trust was allocated funding to enhance existing SPC teams and to uplift the local teams to a baseline of SPC staff representation. Different configuration of services and service providers in each locality led to a range of new SPC posts being recruited across NI (15 WTE posts). • **Provision of Out of Hours Specialist Palliative Care Advice to Healthcare Professionals** Currently in Northern Ireland, health and social care professionals, patients or those looking after people with palliative care needs can avail of specialist palliative care advice in-hours from local specialist palliative care teams/providers in each locality area. However, there is currently no formalised arrangement for providing specialist palliative care advice out of hours (Weekdays 18.00 to 08.00, 24hrs at weekends and on Bank Holidays). Specialist Palliative Care advice out of hours is usually available on an adhoc basis from the local hospice providers and there is variation across the region regarding the advice they provide and to who (i.e. to healthcare professionals, patients and those caring for them or only to healthcare professionals). In Jan 2019, under the auspices of the PCIP Clinical Engagement Group a Task & Finish Group was established to scope the needs of SPC advice for professionals during out of hours periods and to explore existing arrangements in NI and best practices from other countries to develop a preferred model moving forward. Phase 1 of this project identified the issue of providing advice to health care professionals caring for people with palliative care needs as more complex than initially indicated and highlighted a range of varying processes, advice givers and responses times across Northern Ireland both in hours and out of hours. As a result, the Terms of Reference for the Task & Finish Group has been widened to look at the *'provision of palliative care advice to professional 24/7'.* This work is ongoing.

REGIONAL GOOD PRACTICE TOOLS & GUIDANCE

A range of good practice tools and guidance have been regionally endorsed by the Palliative Care in Partnership programme board for use by healthcare professionals in Northern Ireland. The current list of these tools can be found in Appendix 3.

PUBLIC HEALTH APPROACH TO PALLIATIVE CARE

Working with the PCIP Programme, the Department of Health are leading on the development of a framework to support a public health approach to palliative care in Northern Ireland.

A Public Health Approach to Palliative Care Innovation lab workshop held in May 2019 sought to define what is meant by a public health approach to Palliative Care in Northern Ireland. A definition was developed and has subsequently received the endorsement of the Palliative Care in Partnership Board.

The agreed definition is as follows:

> ***A public health approach to palliative care recognises the role of society and community in enabling and supporting people living with life-limiting conditions, and those important to them, to live well with flexible, holistic and person-centred care based on positive and collaborative partnership.***
>
> ***A public health approach to palliative care will involve working collaboratively to:***
>
> - ***Increase awareness, understanding and discussion around palliative care through education and information;***
> - ***Create and enhance networks across communities and sectors to support people living with a life limiting illness and those important to them;***
> - ***Encourage people to think about and plan for their future physical, emotional, social, financial and spiritual needs.***

Following on from this initial engagement, further work bringing together representatives from a wider range of stakeholders, including NI Departments, district councils, the voluntary and community sector, employers, funeral directors, faith groups and the education sector will happen at 2 strategic Insight Labs scheduled for November 2019. These events will offer the opportunity to develop a framework for implementing a public health approach to palliative care and identify how, through a cross-sectoral partnership approach, this might be taken forward in Northern Ireland.

AREAS FOR FUTURE FOCUS

1. The algorithm (AnticiPal) used for early identification in primary care is currently only available on one GP clinical system (Vision) limiting the scale and spread potential. The programme is actively progressing making AnticiPal available on other clinical platforms and future integration with GPIP.

2. Historically palliative care has been perceived for those only with cancer. Awareness and education that palliative care is for all conditions and the benefits a palliative care approach can offer is required for health and social care professionals across care settings to ensure that those patients who should be identified across all conditions are being identified.

3. HSC Trusts are at different stages of implementing the Palliative Care Keyworker Role, in particular, due to differences in the service provision of 24 hr District Nursing across localities there is difficulty in fulfilling the arrangements for providing co-ordination of care for patients with palliative care needs 24/7.

4. Lack of confidence/perceived time for professionals to have meaningful advance care planning discussions with patients.

5. Disjointed systems for sharing information across care settings and between providers caring for patients with palliative care needs.

6. Delay in regional DNACPR guidance and potential implications of the Mental Capacity Act implementation of advance care planning process.

7. Addressing the reluctance of some professionals to identify/refer patients for palliative care resulting in late identification (i.e. only when the patient is deemed to be dying) and hence removing the opportunity for meaningful advance care planning.

8. Changing public perceptions of 'palliative care' which are often associated with 'only for cancer' and 'only for the last weeks/ days of life' and promoting the benefits of advance care planning to maximise the opportunity for peoples wishes to be understood and followed and to minimise unnecessary stress and confusion in the future.

9. Provision of sustainable training mechanisms to equip all health and social care professionals across care settings to provide high quality palliative and end of life care.

10. Need for the standardisation of services across localities with equitable availability in all care settings. SPC professionals are still predominately rooted in hospitals or hospices despite evidence suggesting that most people want to be cared for in their own home. Encouragingly, recent service developments in some localities are aimed at changing this dynamic but ideally access to all members of the SPC team across care settings should be the norm.

11. Improving access to palliative care medications in out of hours periods and the need to increase anticipatory prescribing across care settings for patients at the end of life.

Appendix 1

Regional Palliative Care in Partnership Programme Board Membership

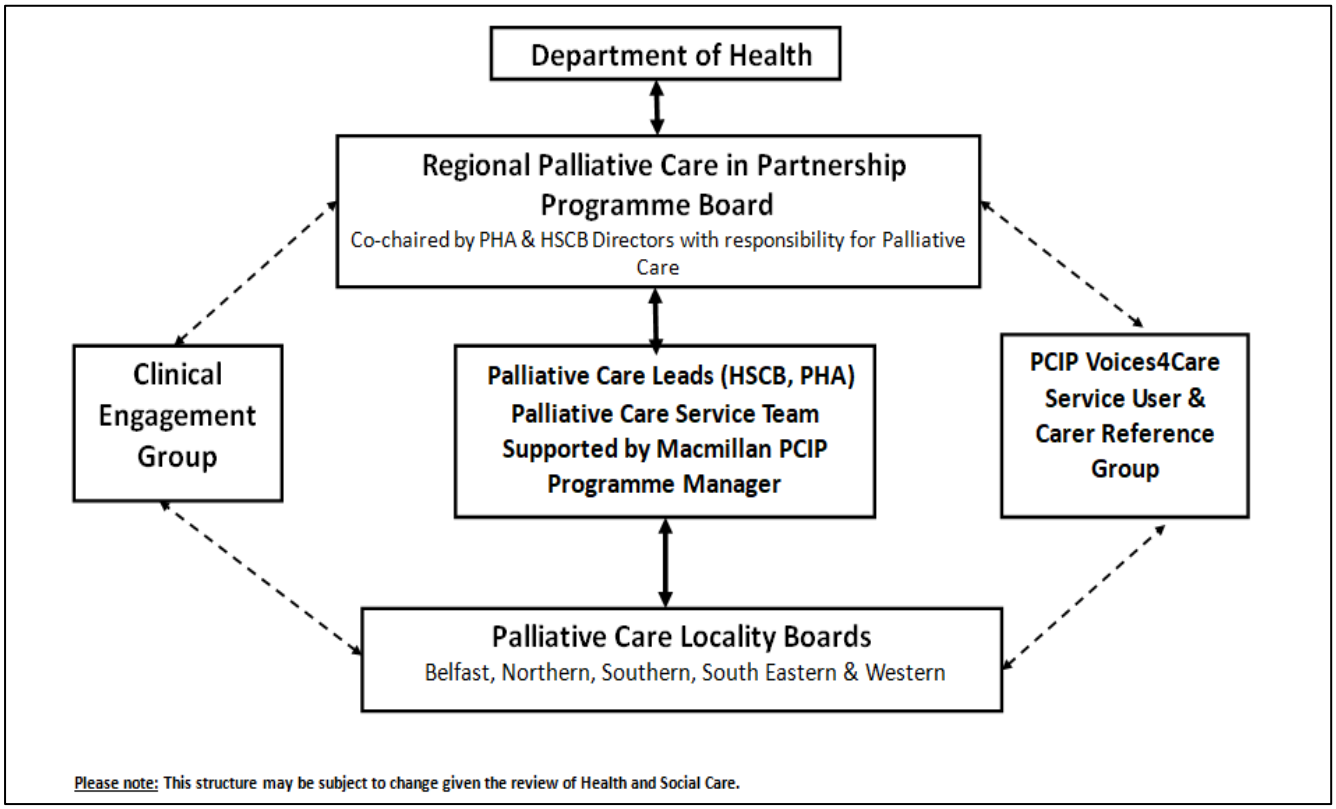
	Organisation/Role	Members
1	Public Health Agency (Co-chair)	Briege Quinn (Interim)
2	Health & Social Care Board (Co-chair)	Miriam McCarthy
3	Macmillan (Sponsorship)	Heather Monteverde
4	Palliative Care Commissioning Lead (HSCB)	Paul Turley
5	Palliative Care Clinical Lead (PHA)	TBC
6	Department of Health	Chris Matthews
7	Belfast HSC Trust	Marie Heaney
8	Northern HSC Trust	Phil Hughes
9	South Eastern HSC Trust	Nicki Patterson
10	Southern HSC Trust	Melanie McClements
11	Western HSC Trust	Bob Brown
12	NI Ambulance Service	Brian McNeill
13 14	Clinical Engagement Group	Bernie Corcoran TBC
15	Service User and Carer Group	As nominated
16 17 18	Integrated Care Partnerships	Martin Hayes Dr Grainne Bonnar Roberta Tasker
19	Macmillan	Paula Kealey
20	Marie Curie	Eamon O'Kane/ Joan Regan
21	Northern Ireland Hospice	Heather Weir
22	Foyle Hospice	Paul McIvor
23	Southern Area Hospice	Liz Cuddy
24	Independent Health Care Providers	Pauline Shepherd
25	Royal College of General Practitioners	Shauna Fannin
26	NIGPC	Brian Patterson
27	Integrated Care (HSCB)	Sloan Harper
28	All Ireland Institute for Hospice and Palliative Care	Karen Charnley
29	Patient & Client Council	TBC
30	RCN Independent Sector Nurse Manager Network	Connie Mitchell

31	Community Planning (HSCB)	Louise McMahon
32	Bereavement Network	Paul McCloskey
33	Macmillan GP Facilitators	Dr Graeme Crawford
	Palliative Care in Partnership Macmillan Programme Manager	Diane Walker

Please note: This structure may be subject to change given the review of Health and Social Care.

Appendix 2

Regional Palliative Care in Partnership Structure



Appendix 3

REGIONAL PALLIATIVE CARE TOOL KIT

The documents in this tool kit have been regionally endorsed by the Palliative Care in Partnership programme board for use by healthcare professionals in Northern Ireland.

SPICT – Supportive & Palliative Care Indicators Tool	The indicator tool which the Anticipal App (originally developed and tested by University of Edinburgh in based on). https://www.spict.org.uk/
ELCOS Final 2017	Overview of the End of Life Care Operational System (ELCOS). Updated in 2017.
Prompts to Aid ELCOS	Prompts to aid practitioners in the development of an individualised care plan. Updated 2017.
Palliative Care Aide Memoire (NI)	Prompts to be used when assessing and reviewing patients with palliative care needs across conditions. Based on NISAT domains.
Palliative Care Keyworker Role	The role of the Palliative Care Keyworker (2017)
Your Life Your Choices: Plan Ahead	Patient facing booklet about how people can plan ahead and make choices about their own future care. Updated for NI in late 2016. Copies can be downloaded from or booklets ordered from the Macmillan website: https://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx You will need to set up a Be Macmillan account to order stock.
Advance Care Planning Summary	Record of discussions regarding a person's wishes and preferences for care at the end of life.
Key Information Summary	Information about the Key Information Summary as part of the Electronic Care Record can be found here https://www.nidirect.gov.uk/articles/northern-ireland-electronic-care-record-niecr#toc-2 Or please refer to Appendix 1 of the 'Introduction to the Key Information Summary' (KIS) NI LES
Specialist Palliative Care Referral Guidance & Service Directory	Information on when and where to refer a person with specialist palliative care needs. Updated 2018.
NICE NG31	NICE Guideline: Care of Dying Adults in the last days of life. Published Dec 2015.
RPMG End of Life Guidance	Guidance for the management of common symptoms in adults in the last days of life. Updated 2018.
PANG: Palliative Care Adult Network Guidelines	These guidelines have been adopted as the preferred guidelines for general palliative care within Northern Ireland via the Palliative Care Network, and can be accessed online. You will need to register to access the guidelines.

	http://book.pallcare.info/
Community Pharmacy Palliative Care Network	Network of pharmacies spread throughout Northern Ireland who provide specialist community pharmacy palliative care services. They can supply medicines from the palliative stock list or be contacted for advice.
Guidance of the management of symptoms in adults with Heart Failure at the end of Life	This booklet provides guidance to healthcare professionals on managing commonly experienced symptoms for heart failure patients in the last weeks to days of life.
Heart of Living and Dying – A facilitators guide.	The Heart of Living and Dying is a 2 hour group process which offers members of the public the opportunity to have an advance care planning type conversation about what matters to them in their living and dying.

Many of these documents can be downloaded from the All- Ireland Institute for Hospice & Palliative Care Professional Hub

http://www.professionalpalliativehub.com/guidelines/northern-ireland-palliative-care-tools-guidance

[i] NISRA Death Statistics: 16,036 deaths in 2017, 15,923 deaths in 2018
[ii] End of Life Care Operational System, Elder 2017
[iii] NISRA Population Projections 2018 – 2068 (based on 75% pall care need of projected deaths in 2019 compared to 2050).
[iv] NISRA Death Statistics 'Recorded Place of Death 2001 – 2017'
[vv] https://echonorthernireland.co.uk/