Palliative Care Policy into Practice

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Dame Cecily Saunders, founder of the modern Hospice movement, said:

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

“How people die is as important as how long they live.”

Regional Palliative Care Programme - Palliative Care in Partnership

Department of Health
Regional Palliative Care Programme Board
PHA & HSCB Directors with responsibility for Palliative Care

Clinical Engagement Group

Palliative Care Service Team
Supported by PCIP Project Manager

Service User & Carer Reference Group

Palliative Care Locality Boards
Belfast, Northern, Southern, South Eastern & Western

Please note: These structures may be subject to organisational change

Projected Deaths and Palliative Care Need in Northern Ireland

<table>
<thead>
<tr>
<th>Year</th>
<th>Estimated Deaths</th>
<th>Projected Palliative Care Need*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td>15,401</td>
<td>11,551</td>
</tr>
<tr>
<td>2020</td>
<td>15,800</td>
<td>11,850</td>
</tr>
<tr>
<td>2030</td>
<td>17,750</td>
<td>13,313</td>
</tr>
<tr>
<td>2040</td>
<td>20,261</td>
<td>15,196</td>
</tr>
</tbody>
</table>

* Using 75% of all deaths (Gomez and Batiste et al)

Source: PHA, data on file (2017)
### Palliative Care in Hospitals

- **In Northern Ireland, 1 in 4 hospital inpatients (25%)** will die within the next year.

**Source:** PHA, data on file (2017)

### Regional Palliative Care Work Plan

To provide the regional direction so that everyone identified as likely to be in their last year of life (regardless of their condition) are:
- Allocated a keyworker
- Have the opportunity to discuss and record their advance care planning decisions
- Be supported with appropriate generalist and specialist palliative care services to die in their preferred care (where appropriate)

**Priorities**
- Identification
- Keyworker
- Advance Care Planning
- Specialist Palliative Care Services
- Good practice tools and guidance

### Palliative Care in Partnership Programme

To provide the regional direction so that everyone identified as likely to benefit from a palliative care approach (regardless of their condition) is:
- Allocated a keyworker
- Have the opportunity to discuss and record their advance care planning decisions
- Be supported with appropriate generalist and specialist palliative care services
- Bereavement

**Priorities**
- Identification
- Keyworker
- Advance Care Planning
- Specialist Palliative Care Services
- Regional best practice tools and guidance
- Communication
- Public Health Approach to Palliative Care

**PCP PRIORITY 1**

**IDENTIFICATION:** Why is it important?

- Around **15,000 people die each year** in Northern Ireland
- Estimated **11,250 of those could benefit** from palliative care approach
- Given the choice, most people want to be cared for and die at ‘home’
- **47% of people in NI die in hospital each year** and it is estimated that **40% of those have no clinical reason to do so**
Identification

• To improve identification of people with palliative and end of life care needs. Aim 1% of the population

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Number of GP Practices 2016</th>
<th>Number of GP Practice 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 0.25%</td>
<td>196</td>
<td>216</td>
</tr>
<tr>
<td>0.26 – 0.50%</td>
<td>104</td>
<td>92</td>
</tr>
<tr>
<td>0.51 – 0.75%</td>
<td>35</td>
<td>22</td>
</tr>
<tr>
<td>0.76 – 1.00%</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Above 1%</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Total number of practices: 347 341

Source: Department of Health (2017)

Early Identification Prototype aims:

• Improve identification of people who could benefit from a palliative care approach
• Build local relationships and capability to enable healthcare professionals to deliver palliative care at ‘home’
• Support people to live well for longer in their own ‘home’
• Enable people to plan and consider their end of life choices – **Advance Care Planning**
• Avoid crisis situations which lead to poor quality of life or an avoidable hospital admission

EIP is based on the findings from 2 previous projects...

**LOTHIAN EARLY IDENTIFICATION PROJECT (2015)**
Edinburgh University & Marie Curie
Method: Developed a computer based algorithm (based on SPICT indicators) to search primary care records and identify patients who may be suitable for a palliative care approach and who were not already on the Palliative Care Register.
Findings: Clinicians judged that 30-60% of the patients identified by the algorithm could benefit from a palliative care approach.
Algorithm used became Anticip app

In 2015 Mason, Boyd, Murray showed it is possible to significantly improve the identification of patients for palliative care needs assessment using a computerised search [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4529733](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4529733) and, this year have presented new findings that GP practices can use computer searching to generate lists of patients for review and care planning [https://bjgp.org/content/early/2018/03/26/bjgp18X695729](https://bjgp.org/content/early/2018/03/26/bjgp18X695729)

**PENINSULA PROJECT (2014-15)**
South Eastern Health & Social Care Trust
Method: Piloted monthly practice MDT meetings to discuss and proactively plan for patients who would benefit from a palliative care approach with a view to improving patient experience and avoiding unnecessary hospital admissions.
Findings: 82% of patients received palliative care in their place of choice, 57% reduction in emergency hospital admissions.
Source: HSCB

Early Identification Prototype

**POSSIBLE ACTIONS TO BE TAKEN:**

• Add to Palliative Care Register
• Start Key Information Summary
• Allocate Palliative Care Keyworker
• Initiate Advance Care Planning discussions
• DNACPR / ADRT discussions
• Discuss with Specialist professional (if involved in current care)
• Schedule visit for assessment
• Refer for review by Social Work/ AHP
• Refer to Specialist Palliative Care Team
• Consider referral to other support services – e.g. respite, sitting services
• Medication reviews
I suggest moving the slide that defines QoF before this as you use the QoF acronym here.

Dominic, 22/01/2018
**Early identification Prototype:**
Moving forward

- Prototype currently running in 46 GP practices using Vision system
- Initially 6 months – with Transformation funding able to extend to 9 months (to Mar 19)
- Collate & evaluate findings, refine Local Enhanced Service accordingly
- Plans to enable AnticiPal on EMIS clinical systems
- Recruit up to 100 additional practices for Phase 2 (2019/20)

**Palliative Care Keyworker:**

**Definition:** 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. This should include co-ordinating care across interfaces (within and between professionals, teams and care settings) and promoting continuity of care.

- 4 operational elements of the keyworker function:
  - Identification
  - Contact & co-ordinating care
  - Care in the last weeks/days of life
  - Bereavement follow up

In the community the Keyworker agreed regionally as ‘typically the District Nurse’ – role shared with registered nurse for Nursing Home residents.

**Advance Care Planning:**

- Communicating wishes and preferences to other care providers through:
  - Advance Care Planning Summary
  - Key Information Summary

**Specialist Palliative Care Services:**

- **Specialist Palliative Care for ‘complex and unresolved needs’:**
  - Fatigue
  - Breathlessness
  - Anxiety
  - Unintentional weight loss
  - Dysphagia
  - Communication Difficulties
  - Lymphoedema
  - Emotional & psychological needs

- **Specialist Palliative Care Workforce Review** currently underway, looking at the SPC Professionals to meet the population needs to 2024 and associated training requirements.

**Regionally agreed Palliative Care Tools & Guidance**

- SPICT: Supportive & Palliative Care Indicators Tool
- ELCOX 2017
- Prompts to aid ELCOX
- Palliative Care Aide Memoire (based on NISAT)
- Palliative Care Keyworker Role & Function
- Your Life, Your Choices - Plan ahead
- Advance Care Planning Summary
- Specialist Palliative Care Referral Guidance & Service Directory
- NICE NG31: Care of dying adults in the last days of life
- RPPM End of Life Guidance (2018)
- PANG: Palliative Care Adult Network Guidelines
- Management of Symptoms in Palliative Care: Role of SPC AHPs

**Awaiting approval/updating:**
- DNACPR Policy for NI
- Revision Advance Care Planning Operational Guidance for Healthcare professionals

**What I Have observes about how research can be translated to Policy and Practice**

- Influence with Heart and the Head
- Engage early
- New knowledge is important but need to align to current priorities and work
- Timing
- It’s all about the people!
Thank you
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