

# Report of the First National Palliative Care Support Bed Review

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## Executive Summary

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## Background and aims:

The concept of palliative care support beds (PCSBs) was first signaled in the National Advisory Committee on Palliative Care Report (Department of Health and Children, 2001). They were proposed as a means of providing an intermediate level of in-patient palliative care for patients in a local environment, typically in designated centres for older people. However, specific guidance on issues such as organisation and governance was not provided. As a result, a pattern has emerged where palliative care support beds have developed largely in response to local need and opportunity. Although in 2011, 179 PCSBs were reported to exist there is much regional variation in organisation and capacity- including such notable issues as differences in physical environment, access and discharge criteria, staff training and the level of involvement of specialist palliative care (SPC) services in the direct provision of care.

The National Clinical Programme for Palliative Care (NCPPC) Working Group identified the need to conduct a review of the organisation and function of PCSBs in Ireland in order to provide strategic direction on the future of the services provided. The review is important because it describes services that are otherwise relatively hidden from view in our conventional perception of palliative care provision. The Group established the PCSB subgroup<sup>1</sup> in December 2011 with the following aims:

- To describe the current organisation and function of the palliative care support beds,
- To conduct further analysis of the contribution/ value the beds offer to the system,
- Produce recommendations about the development of palliative care support beds.

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<sup>1</sup>PCSB subgroup members:

- Dr Karen Ryan (Clinical Lead, National Clinical Programme Palliative Care)
- Mr. Brian Lee replaced by Sinéad Fitzpatrick (Programme Manager)
- Ms Lorna Peelo-Kilroe, (Nursing Lead, National Clinical Programme Palliative Care)
- Ms Sheilagh Reaper Reynolds (General Manager PC Acute Hospitals Division)
- Ms Eileen O’Leary (Regional Support, Palliative Care, HSE South, Grade VIII)
- Dr Fionnuala Cooney (Public Health Specialist, HSE West)
- Ms Sharon Foley (CEO, Irish Hospice Foundation)
- Prof. Philip Larkin (Professor of Palliative Care, UCD)
- Ms Pauline Newnham (Director of Nursing, Our Lady’s Hospice)
- Ms Samantha Rayner (National Specialist, Services for Older Persons HSE)

## Methods:

A comprehensive survey of organisations involved in PCSB provision was carried out in order to describe the current organisation and function of the PCSBs. This was supplemented by a second survey to gather the views of palliative care consultants on PCSB provision. Having completed the surveys, the Group implemented a second component, which was designed to examine qualitatively the operation of PCSBs across the country. The second component included case studies in a number of locations and interviews conducted with senior managers within the health services.

The aim of the case studies was to document at a local level the implementation of these resources from a range of perspectives, to explore the strengths and limitations of the system and to identify the barriers and solutions to the provision of palliative care via the PCSBs. The aim of the interviews was to identify higher level issues regarding the operation of PCSBs in health settings in Ireland.

## Key findings from the Mapping Exercise:

- Over 90% of organisations involved in the provision of PCSBs responded to the survey and senior (typically nursing) staff within these organisations generally provided the information.
- The organisations ranged in overall size and location.
  - The largest number of PCSBs reported in one organisation was 40.
  - The majority had two or fewer PCSBs.
  - There was a marked lack of PCSBs in Dublin North East (DNE) in comparison to other areas of the country.
- The reporting of available bed suggests stability in the number of beds, with limited numbers of increases/decreases reported. A need for an increased number of beds was articulated.
- The provision of PCSBs is largely funded by the HSE, however a number of organisations reported that additional funding was required and obtained from fundraising, charitable donations and other sources.
- Just over half of the organisations reported that PCSBs were ring fenced for use by patients with palliative care needs only. The lack of a consensus guiding the process by which patients should be admitted to PCSBs however meant that some respondents considered that beds were, at times, used 'inappropriately'.
- The beds are primarily used for end of life care, but use for symptom control admissions and respite is also common. The beds are rarely used for rehabilitation purposes. Marked variability in use between organisations was observed. The palliative medicine consultant group commented that a consensus

on referral criteria did not currently exist and that this impacted negatively on the functioning of the beds.

- The majority of patients accessing PCSBs had malignant disease. The median proportion of new patients with non-malignant disease accessing PCSBs was reported as 10%. However, some organisations reported that as many as two-thirds of new admissions had non-malignant disease, indicating variability in practice.
- The vast majority of organisations reported that length of stay was between two weeks and three months.
- The provision of care to patients in PCSBs involves a range of disciplines both within the setting and via teams such as specialist palliative care services.
  - The Director of Nursing (DoN) in the setting, the local specialist palliative care (SPC) team, the admitting doctor and the patients' own General Practitioner (GP) were commonly reported as responsible for decision making, with GPs regularly reported as responsible for care. Significant variability in these processes was observed, however.
  - The central importance of the GP to the provision of care was recognised.
  - The significant role that the SPC team also plays in supporting the functioning of PCSBs was evident. Organisational survey responses indicated that three quarters of respondents felt that there were procedures in place by which all patients would be reviewed by the team. However, it should be noted that the consultant survey demonstrated marked difference in opinion around governance and just under one third of participants reported that there were formal arrangements in place to ensure that a member of the palliative care team reviewed every individual referred to a PCSB.
  - The palliative care clinical nurse specialist (CNS) was reported as being the member of the SPC team who visited in 90% of responses; the palliative care consultant in 42.9% (and palliative care non consultant hospital doctor in 11.4%); the palliative care social worker in 25.7%; the palliative care physiotherapist in 17.1%; the palliative care occupational therapist in 11.4% and the palliative care chaplain in 10%.
  - Marked variability was observed in the range of disciplines available to provide care to patients admitted to PCSBs. Physiotherapists were available in 88.6% of organisations, chaplains in 82.9%, occupational therapists in 57.1% and social workers in 54.3%.
  - Only 58.6% reported that they had access to bereavement support for families if necessary.
  - Particular challenges were noted in ensuring adequate out-of-hours service provision.

- There is relative consistency in the range of equipment available to patients admitted to PCSBs. However, there is greater variability noted in the ability of organisations to provide support such as percutaneous enteroscopic gastrostomy (PEG) feeding or non invasive positive pressure ventilation (NIPPV).
- In comparison to the consistency of service and equipment provision reported, there was much greater variation in the presence of required policies such as do not attempt resuscitation (DNAR) policy.
- In relation to staff training/education there is some concern with the validity of the patterns reported, given the high level of missing data returned in this section of the survey. While the temptation may be to assume that where respondents have not indicated training/education among key groups it indicates that no training/training took place, it is more likely that respondents do not have access to accurate information in this area. Further investigation is required.
- While stakeholder opinion on the quality of care provided in PCSBs was reassuring, the absence of a consistent mechanism for feedback or outcome measurement means that it is difficult to assess the standard of patient or family experience across all services.
- A number of insights are evident from a review of the themes that emerged from the qualitative data:
  - The provision of PCSBs is seen as bringing multiple benefits for patients, families and professionals around the country, with staff commenting on the ready accessibility of beds in local settings and the connections that have developed around them. There was some concern articulated that there was a relative lack of integration with the wider healthcare system that limited PCSB value and effectiveness.
  - Respondents were also positive about the competence of the staff involved in PCSB provision. A concern was expressed by respondents that a lack of continuing training and development would undermine the competence of staff.
  - A perspective was voiced that the PCSBs act as a 'beacon' within an organisation and serve to have a ripple effect on the quality of palliative care provision in other parts of the organisation. The value that the local community place on the principles of palliative care provision and the knock on impact that this can have on the perception of the ethos and overall care provided within an organisation was noted.
  - Respondents clearly see the potential for the further development of the PCSB provision; however in the opinion of respondents, issues of resourcing may threaten these developments.

- The variation and lack of standardisation in the organisation of PCSBs contrasts with the strong identity that has been established for hospice (SPC in-patient unit) beds.
- The value of, and indeed apparent need for, a close working relationship between SPC and PCSB staff was made clear. It appeared that geographical proximity enhanced the quality of that relationship.

## Consensus Statement and Recommendations for Future Development of Palliative Care Support Beds

PCSB services should be regarded as services that meet all the following criteria;

- They are targeted at people with life-limiting conditions whose palliative care needs are primarily of an intermediate level of complexity,
- Types of care ordinarily provided are clinical management of palliative care issues by GP or consultant-led team<sup>2</sup>, rehabilitation, respite, end of life care for those who cannot or do not wish to be managed in home or hospital settings,
- Have a planned outcome of maximising quality of life or ensuring quality care at the end of life in a local environment,
- Prevent unnecessary acute hospital admission, support timely discharge from hospital and maximise independent living,
- Involve cross-professional working, with a single assessment framework, shared professional records and policies, procedures and guidelines and appropriate use of a single discharge planning process.

*Palliative care support beds are a form of intermediate care that is distinct from, and serves a different purpose to, long term care.*

### Key message 1:

It appears that PCSBs have a role in improving patient outcomes, experience and assisting with hospital flow; however there is variation in the organisation, scope and functionality of PCSB beds across the country. It is not yet known whether differences in organisation and operation of PCSB beds are associated with differences in accessibility, efficiency and quality of outcomes.

### Recommendations:

1. The National Clinical Programme for Palliative Care, across the appropriate Divisions, should develop a Palliative Care Admission and Management

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<sup>2</sup> Consultant may be a Palliative Medicine physician or from another specialty, typically Medicine for the Elderly

Model of Care to guide processes for referral, admission, integration with specialist palliative care services, management and discharge. The Model of Care should be based on existing knowledge of best practice.

2. Best practice in providing care in the PCSB setting should be shared more effectively. A number of local initiatives are under way that aim to improve the quality of care provided to patients and their families through articulation of models of care, better integration and joint working with SPC services. The National Clinical Programme for Palliative Care and relevant Divisions should ensure that successful initiatives are promoted more widely.
3. A key priority for future planning processes should be to strengthen the evidence base for PCSB provision including:
  - A comparative needs assessment of PCSB
  - A comprehensive evaluation of PCSBs that includes examination of structure, process, outcomes, and cost effectiveness.

#### **Key message 2:**

An integrated model of palliative care provision is strongly supported by staff, who consider that PCSBs could be more effectively integrated with the healthcare system.

#### **Recommendations:**

4. Existing HSE reporting structures should be utilised to maintain a register of PCSBs and a national annual audit of PCSB service provision should be conducted (modeled on the UK annual Intermediate Care Audit).
5. The HSE, across the appropriate Divisions, should drive service change across PCSB systems by bringing together existing PCSB providers, exchanging best practice ideas and aligning their services with those of the wider hospital, community and specialist palliative care service providers.

#### **Key message 3:**

Appropriate staffing is integral to effective PCSB operation. There is a need to ensure a balanced workforce in order to provide a quality, safe and effective service.

#### **Recommendations:**

6. Health and social care workers should be competent in palliative care approach skills; key staff should be competent in generalist palliative care skills as set out in the HSE Palliative Care Competence Framework.
7. The Education Centres of specialist palliative care units should support PCSB provision with a planned programme of education and training.



8. The staffing of PCSBs should be considered in any future workforce planning exercises involving Community Short Stay Beds.

**Key message 4:**

There are a number of factors impacting on equity of access to PCSBs including diagnosis, age, availability and geography.

**Recommendation:**

9. The HSE across the appropriate Divisions in conjunction with key stakeholders should examine the barriers to access to PCSBs and take action to facilitate equity.

**Key message 5:**

Ready access to key relevant metrics is essential if systems are to plan an integrated approach to PCSB care, understand its impact and further develop services.

**Recommendation 10:**

10. Key metrics in PCSB provision should be developed by the National Clinical Programme for Palliative Care.