

Report of the first national palliative care support bed review

| | |
|--------------|--|
| Item type | Report |
| Authors | Ryan, K; Guerin, S; O'Brien, N; Nixon, E; Cooney, F; Fitzpatrick, S; Foley, S; Larkin, P; Lee, B; Newnham, P; O'Leary, E; Peelo Kilroe, L; Rayner, S; Reaper Reynolds, S |
| Citation | National Palliative Care Support Beds Review Subgroup. Report of the first national palliative care support bed review. Dublin: HSE; 2014 |
| Publisher | Health Service Executive (HSE) |
| Downloaded | 7-Nov-2017 18:37:51 |
| Link to item | http://hdl.handle.net/10147/323551 |

Report of the First National Palliative Care Support Bed Review

Prepared by the National Clinical Programme for Palliative Care Working Group; Palliative Care Support Bed Review Subgroup in collaboration with Dr Suzanne Guerin & Mr Nolan O'Brien (*UCD Centre for Disability Studies & UCD School of Psychology*) & Dr Elizabeth Nixon (*TCD School of Psychology*)



This report should be cited as follows

Ryan K, Guerin S, O'Brien N, Nixon E, Cooney F, Fitzpatrick S, Foley S, Larkin P, Lee B, Newnham P, O'Leary E, Peelo Kilroe L, Rayner S, Reaper Reynolds S; National Palliative Care Support Beds Review Subgroup. (2014). Report of the First National Palliative Care Support Bed Review. Dublin: Health Service Executive

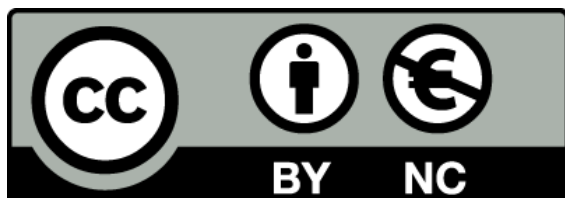
Or

National Palliative Care Support Beds Review Subgroup. (2014). Report of the First National Palliative Care Support Bed Review. Dublin: Health Service Executive

Published by:

Health Service Executive, Dublin

ISBN 978-1-906218-81-2



© Health Service Executive 2014. Report of the First National Palliative Care Support Bed Review.
This work is licensed under a Creative Commons Attribution-Non Commercial 4.0 International License.

To view a copy of this license visit <http://creativecommons.org/licenses/by-nc/4.0>

Table of Contents

| | |
|--|-----------|
| 1. BACKGROUND AND AIMS | 4 |
| 2. KEY LITERATURE | 5 |
| DEFINITION OF PALLIATIVE CARE | 5 |
| INTERNATIONAL TRENDS IN MODELS OF PALLIATIVE CARE SERVICE PROVISION..... | 6 |
| PALLIATIVE CARE SUPPORT BEDS AND THE IRISH CONTEXT..... | 7 |
| 3. SURVEY METHODOLOGY | 7 |
| PARTICIPANTS AND SAMPLING | 8 |
| MATERIALS..... | 9 |
| PROCEDURE..... | 9 |
| DATA ANALYSIS..... | 10 |
| 4. SURVEY RESULTS | 10 |
| PROVISION OF PALLIATIVE CARE SUPPORT BEDS..... | 11 |
| NUMBER AND CHARACTERISTICS OF PATIENTS ADMITTED TO PCSBs | 12 |
| FUNDING OF PALLIATIVE CARE SUPPORT BEDS..... | 14 |
| ADMISSIONS TO PALLIATIVE CARE SUPPORT BEDS..... | 14 |
| PROFESSIONS INVOLVED IN PROVISION OF CARE TO PATIENTS ADMITTED TO PCSBs..... | 17 |
| ABILITY TO CARE FOR PATIENTS WITH SPECIFIC NUTRITIONAL OR RESPIRATORY NEEDS | 20 |
| ACCOMMODATION FACILITIES..... | 21 |
| EQUIPMENT AVAILABILITY | 21 |
| POLICIES AND EDUCATION/TRAINING | 22 |
| OPEN-ENDED QUESTIONS | 23 |
| STRENGTHS OF THE PCSB SYSTEM | 24 |
| CHALLENGES FOR THE PCSB SYSTEM | 24 |
| OPPORTUNITIES FOR THE PCSB SYSTEM | 25 |
| 5. DISCUSSION OF SURVEY FINDINGS | 27 |
| 6. CASE STUDY METHODOLOGY..... | 29 |
| CASE SAMPLING | 29 |
| PARTICIPANTS | 31 |
| MATERIALS..... | 32 |
| PROCEDURE | 32 |
| 7. CASE STUDY FINDINGS..... | 33 |
| OPENING INFORMATION | 33 |
| PCSB GOVERNANCE | 34 |
| HOW IS A REFERRAL ASSESSED? | 35 |
| THE IMPORTANCE OF CLINICAL INFORMATION IN SUPPORTING THE REFERRAL PROCESS | 35 |
| INCLUSION/ EXCLUSION CRITERIA AND REASON FOR ADMISSIONS..... | 36 |
| FUNDING | 37 |
| PCSBs UTILISATION | 37 |
| DEMAND FOR PCSBs..... | 38 |
| RING-FENCED BEDS..... | 39 |
| REVIEW OF UTILISATION | 40 |
| PCSBs STAFFING, TRAINING AND SUPPORT | 40 |
| 8. CASE STUDY DISCUSSION..... | 50 |
| 9. CONSENSUS STATEMENT AND RECOMMENDATIONS FOR FUTURE DEVELOPMENT OF PALLIATIVE CARE SUPPORT BEDS | 52 |
| 10. REFERENCES | 56 |
| 11. APPENDICES | 57 |
| APPENDIX A: PALLIATIVE CARE CONSULTANTS SURVEY METHODS AND FINDINGS | 58 |
| APPENDIX B. PALLIATIVE CARE SUPPORT BED PROVIDER SURVEY QUESTIONS..... | 60 |
| APPENDIX C: NOTE ON INDIVIDUAL INTERVIEWS | 64 |
| APPENDIX D: CASE STUDY INTERVIEW SCHEDULE | 68 |
| APPENDIX E. CONSULTANT SURVEY..... | 70 |

1. Background and Aims

The concept of palliative care support beds (PCSBs) was first signaled in the National Advisory Committee on Palliative Care (NACPC) 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 services (SPC) in the direct provision of care.

The National Clinical Programme for Palliative Care 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 Group established the PCSB subgroup¹ 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.

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 gathered that the views of palliative care consultants on PCSB provision. Having completed the surveys, the Group implemented a second component, which was designed to qualitatively examine 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 were 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

¹PCSB subgroup members:

- Dr Karen Ryan (Clinical Lead, PC Programme)
- Mr. Brian Lee replaced by Ms Sinéad Fitzpatrick December 2013 (Programme Manager)
- Ms Lorna Peel Kilroe (Nursing Lead, PC Programme)
- Ms Sheilagh Reaper Reynolds (General Manager Palliative Care representing Acute Hospitals)
- 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)

PCSBs. The aim of the interviews was to identify higher level issues regarding the operation of PCSBs in health settings in Ireland.

The PCSB working group, the National Clinical Programme for Palliative Care and relevant stakeholder groups reviewed the findings. This resulted in the development of a number of recommendations about the further development of PCSBs that are presented in the final part of the report.

We wish to acknowledge and thank the Irish Hospice Foundation who kindly provided personnel and funding to support the production of this report.

2. Key Literature

On an international scale, the field of palliative care is challenged by a number of factors. Firstly, it is faced with an aging population, which increases the demand for palliative care service provision (Higginson, 2005). Secondly, there is recognition of the need to integrate palliative care into chronic disease management programmes and to ensure that specialist palliative care services provide care to people with non-malignant diseases. The increased demand for palliative care services is faced, however, with budgetary issues that pose problems at an administrative level within health services (Bainbridge, Brazil, Krueger, Ploeg& Taniguchi, 2010). These trends are evident within the Republic of Ireland as the country's healthcare service seeks to improve its performance while experiencing unprecedented financial constraints. The following review of literature aims to establish international trends in the designation of PCSBs and identify factors that point toward the need to evaluate the current usage of PCSBs in Ireland.

Definition of palliative care

In the last twenty years, the scope of palliative care has broadened to providing palliative care at an earlier stage in the disease trajectory. The original World Health Organisation definition of palliative care highlighted that idea that palliative care should be a gradually increasing component of care from diagnosis to death (WHO, 1990), and the emphasis on the early provision of palliative care concurrently with disease modifying treatment has been shown to be acceptable to clinicians, patients and their families. Early integration of palliative care eases the transition towards an eventual sole focus on palliation and also offers improved quality and efficiency of care in the earlier stages of chronic disease management. In fact, the health of the population requires good palliative care, not simply for the benefit of the person dying, but also for caregivers while in the role and after bereavement.

In 2002, The World Health Organisation (WHO) refined its earlier definition of palliative care, stating:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(World Health Organization, 2002)

While this definition is currently accepted in most European countries and is used to guide service provision, the literature surrounding specific models of palliative care provision remains somewhat disjointed. This is likely due, at least partially, to unique terminology that varies between - and sometimes within - locales.

Communication is a cornerstone of healthcare provision; a lack of consistency in use of terminology can lead to challenges in service development and provision when terms come to represent different things to different people. The National Clinical Programme for Palliative Care has noted that it is important to move towards developing common understanding between stakeholders in order to provide a firm basis for dialogue and engagement. The Programme produced a *Glossary of Terms* (revised in 2014) to promote clarity and consistency in the way in which palliative care is spoken about in Ireland, and the document includes the current WHO definition of palliative care.

International trends in models of palliative care service provision

Ahmedzai and colleagues (2004) suggested that medical practice in many developed countries (including many European nations as well as Australia/New Zealand and North America) now has a layered approach to PC that encompasses a level of care that is either 'basic' or 'specialized'. This approach is in recognition of the fact that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services. Within this classification system, fundamental palliative care is provided by every health care professional, as a part of their responsibilities to any patient with a life-limiting condition. In general, fundamental palliative care occurs in non-specialised units where the practitioners involved are not experts in palliative care, but often have received some pre- or post-registration training/education/development in palliative care. Specialised palliative care reflects those services delivered by an interdisciplinary team of experts whose core activity is limited to the provision of palliative care.

In Ireland, the split between 'fundamental' and 'specialised' palliative care is on par with other developed countries - the NCPPC *Glossary of Terms* (2014) refers to this split as 'generalist' and 'specialist' palliative care, respectively and the National Advisory Committee Report on Palliative Care (2001) provides additional detail on these services, stating that palliative care services may be structured in three levels of ascending specialisation according to the expertise of the staff providing the service (NACPC, 2001).

- **Level one** – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.
- **Level two** – General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.
- **Level three** – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Palliative care support beds and the Irish context

In Ireland, the definition of level two services has been uniquely associated with the establishment of 'level 2' or 'palliative care support' beds. In the 2001 Report published by the National Advisory Committee on Palliative Care (NACPC), these beds were recommended as a means of ensuring that an intermediate level of palliative care was available in all localised community settings (Department of Health and Children, 2001, p. 32). While the terms 'palliative care support beds' 'level 2 bed' and 'intermediate palliative care bed' have all been used interchangeably, the NCPPC *Glossary of Terms* (2014) advocates abandoning the latter two in favour of adopting a single term in order to promote clarity and consistency of terminology.

The NACPC (2001) noted that typically patients are admitted to PCSBs for respite, control of symptoms, or for end-of-life care, and recommends these beds should be available in all care settings. Despite these clarifications, it is recognised nationally that while many institutions have designated support beds for palliative care, there is no agreed upon definition of the model of care that should guide the services provided to patients admitted to the palliative care support beds. Along these lines, recent discussions, most notably those involving the Irish Hospice Foundation (Irish Hospice Foundation, 2011), have recognised the need for the establishment of standards in all aspects of the provision of intermediate palliative care. To meet this goal, research is needed to map the current landscape of generalist palliative care in Ireland. An important facet of this work will be determining how PCSBs are currently used within acute and community healthcare settings.

3. Survey Methodology

Two surveys were designed and conducted by the PCSB committee. The first (which is presented here) was a national survey of targeted key informants in organisations involved in palliative care support bed provision. The second (smaller scale) survey gathered the views of palliative care consultants. The method and results of this consultant survey are reported in Appendix A.

Participants and sampling

A purposive sampling framework was used to target locations currently providing access to palliative care support beds. This involved identifying all organisations listed as providing level 2 beds in May 2011. Figure 1 below presents a map displaying the location of all PCSB providers in the Republic of Ireland.



Figure 1. Map of Ireland showing locations providing access to PCSBs

Overall, 74 organisations were identified from routine returns on PCSB activity that were made to the Business Intelligence Unit of the HSE in May 2011. The eligible sample of organisations included a total of 187 beds and the geographical spread of the total potential sample is reported in Table 1.

Table 1. Geographical spread and number of eligible organisations

| HSE Area | Eligible Organisations | PCSBs |
|-------------------------|------------------------|-------|
| HSE Dublin Mid Leinster | 14 | 60 |
| HSE Dublin North East | 2 | 8 |
| HSE West | 30 | 67 |
| HSE South | 28 | 52 |

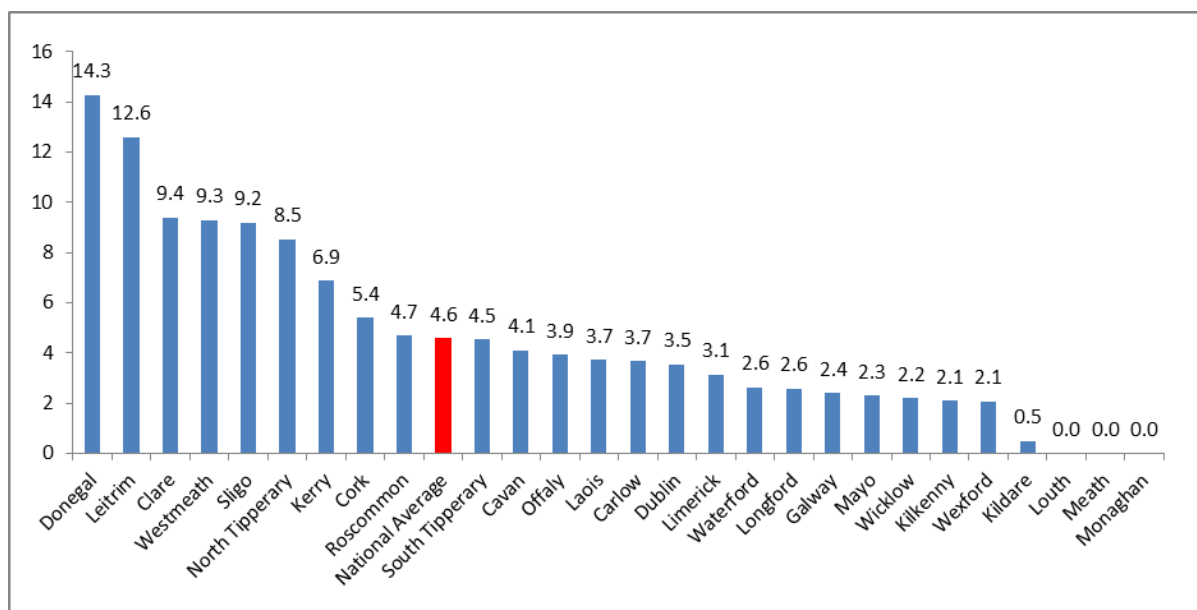


Figure 2. No of Palliative Care Support Beds per 100,000 of population, by county (HSE, 2011)

Materials

A semi-structured survey was developed to gather information on the use of PCSBs in target organisations. The survey was designed by the PCSB subgroup drawing on their knowledge of the area and the national and international literature. Specifically the survey was modelled on the one used in the report, *Mapping the Level of Intermediate Care in the HSE South* (Sub-Group Area Consultative Committee, 20098) though amended to collect national data. Questions including Likert scale responses, Yes/No questions, and open-ended questions that offered an opportunity for brief comments (The survey is available in Appendix B).

The survey gathered information including the number of and funding arrangements for PCSBs, practice regarding the access to the beds, reasons for admission, length of stay for patients and outcome following admissions. Information was also gathered on staffing and equipment provision in relation to PCSBs and the interaction with other professionals including local GPs, public health nurses and members of the local specialist palliative care team. Later sections of the survey included questions regarding governance and related policy, provision of training for staff, and open-ended questions regarding the strengths, weaknesses, opportunities and threats in the provision of PCSBs.

Procedure

Having been formed in December 2011 the PCSB subgroup met on a number of occasions and corresponded by email to develop survey. Once the draft survey had been prepared it was piloted with three randomly selected sites during late January/early February 2012, with pilot results returned by mid-February. The feasibility and usability of the survey reviewed in light of survey responses and final version agreed by the working group. The

final version of the questionnaire was then put into electronic format using Survey Builder (the HSE's online survey platform). Once the survey was finalised, an email containing a letter of invitation detailing consent and data use, along with a survey web link was distributed to all eligible organisations. These had been identified based on a list of organisations across the HSE areas that provided PCSBs. The Directors of Nursing (DONs), Acting Directors of Nursing and Nurse Managers were targeted as it was agreed that they were best placed to provide the information sought by the survey. Reminder emails were sent out to those organisations who did not return the survey, followed by a final round of follow up by phone to request that they complete and return the survey.

Data analysis

The data collected were exported from Survey Builder into a Microsoft Excel file and from there into SPSS (Statistical Package for the Social Sciences). The data were reviewed to identify and remove duplicates. Once the final dataset was established descriptive analyses were conducted to identify frequency of response to categorical data (e.g., yes/no questions, multiple choice questions, etc.) and measures of central tendency were calculated for continuous data (e.g. number of beds, number of new patients, etc.). Free text questions were analysed using content analysis based on Guerin and Hennessy (2002). Each question that allowed a free text response was treated as a section or topic and the responses to the question were reviewed to identify possible themes. These responses were then collapsed to provide mutually exclusive themes, which represented the key patterns evident in the participants' responses. Wordle™ is a tool for generating "word clouds" from text – wordles are used to represent the relative frequency of key themes as the clouds give greater prominence to words that appear more frequently in the source text. Therefore larger fonts in each wordle represent more frequent themes.

4. Survey Results

The survey documented a range of information about the number and provision of PCSB, the services provided and the staff directly involved and consulted with in the provision of care. This section reports the key findings from the analysis of this information.

Overall 70 surveys were completed (once duplicates were removed), which represented a **94.5% response rate**. A target person within each organisation completed the surveys and the most common role represented was **Director of Nursing/Matron** (including those in an acting or assistant capacity, n = 55, 77.5%). Other roles represented included Clinical Nurse Manager or Divisional Nurse Manager (n = 9, 12.7%), and Other (Director, Advanced Nurse Practitioner, General Manager, Unit Manager, Medical Officer, etc., n = 7, 9.8%).

In profiling the organisations, the sample was drawn from across all four HSE areas and the individual breakdown by region is reported in Figure 1. As is clear from the graph, there are

similar numbers of organisations from HSE West and HSE South, with fewer from HSE Dublin Mid Leinster. However this also reflects the distribution of the eligible organisations.

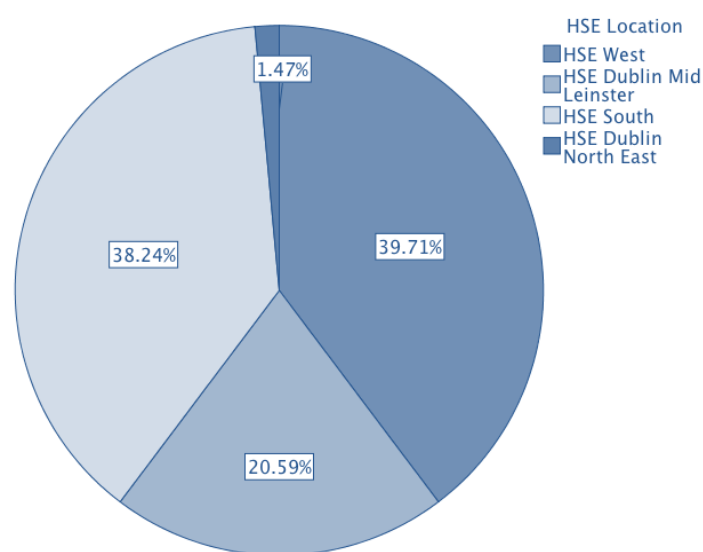


Figure 3. Regional Distribution of Respondents

The organisations ranged in size, with **total number of beds in the organisation ranging from 10 to 220²**. The mode (most frequent response) for this variable was 22 and the median (point below which 50% of the sample falls) was 38. Figure 4 below presents a histogram reporting the distribution for this variable (valid response = 64).

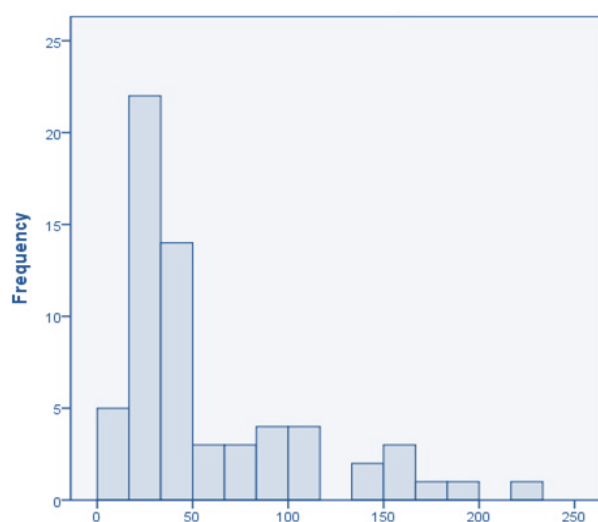


Figure 4. Total Number of Beds in the Organisations

Provision of palliative care support beds

Looking at the **number of palliative care support beds (PCSBs)** reported by respondents, this ranged from 0 – 40, and both the median score and the modal response was **two beds**.

²Note: Inconsistencies in demographic data were corrected using existing data, for example in the case of the number of beds.

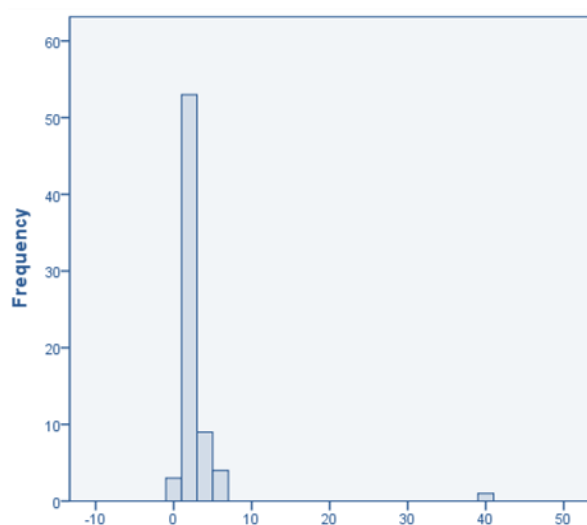


Figure 5. Number of PCSBs based on Self Report

Later in the survey, respondents were asked if the number of PCSBs had changed in recent years. While 25% of participants did not answer this question or made a general comment, **60% (n = 42) of organisations reported there had been no change in the number of beds.** Of the small number of remaining respondents there were reports of both decreases (8.6%) and increases (5.7%) in the number of beds available. It is interesting to note that in both the examination of changes over the course of 2011 and reports of longer term change there is significant stability in the number of beds available.

Participants were also asked if there were any plans to change the number of beds. A proportion did not respond (21%) and just over half (52.9%, n = 37) reported that there were no planned changes. 25% (n = 18) reported a plan to increase the number of beds, however in some cases this was pending a decision from the HSE.

Number and characteristics of patients admitted to PCSBs

Another issue examined in the survey was **the number of new patients admitted to PCSBs in the 12 months from January 1 – December 31 2011 and the results ranged from 0 to 81,** with only one organisation (1.4%) reporting no new patients in this period (median = 10). **The number of returning patients reported was between 0 and 11, with 40% of respondents reporting no returning patients in this period** (median = 0). Figure 5 below presents histograms for each of these responses. A key point here is the small number of returning patients in the organisations, which might suggest a predominant focus on end of life provision.

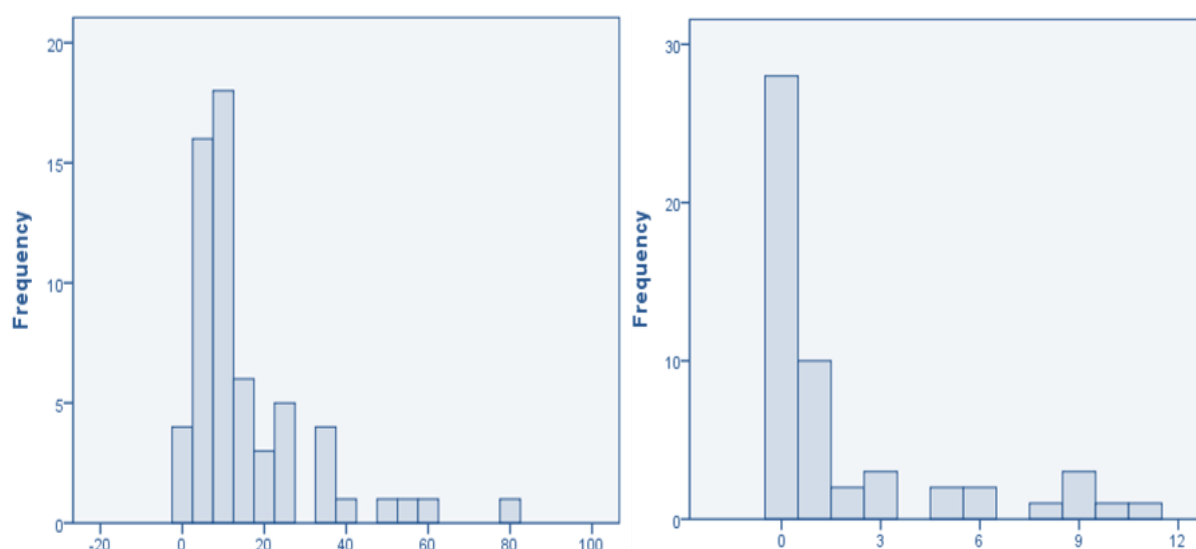


Figure 6. New (on left) and returning (on right) patients for 2011

Respondents were also asked to indicate the proportion of new patients who were diagnosed with malignant disease and what proportion had non-malignant disease. **The proportion of patients with malignant disease was reported as varying between 33% and 100%, with a median of 94%. In contrast, for non-malignant disease the range was 0% to 66%, with a median of 10%.** Again, Figure 6 below presents histograms for each of these responses.

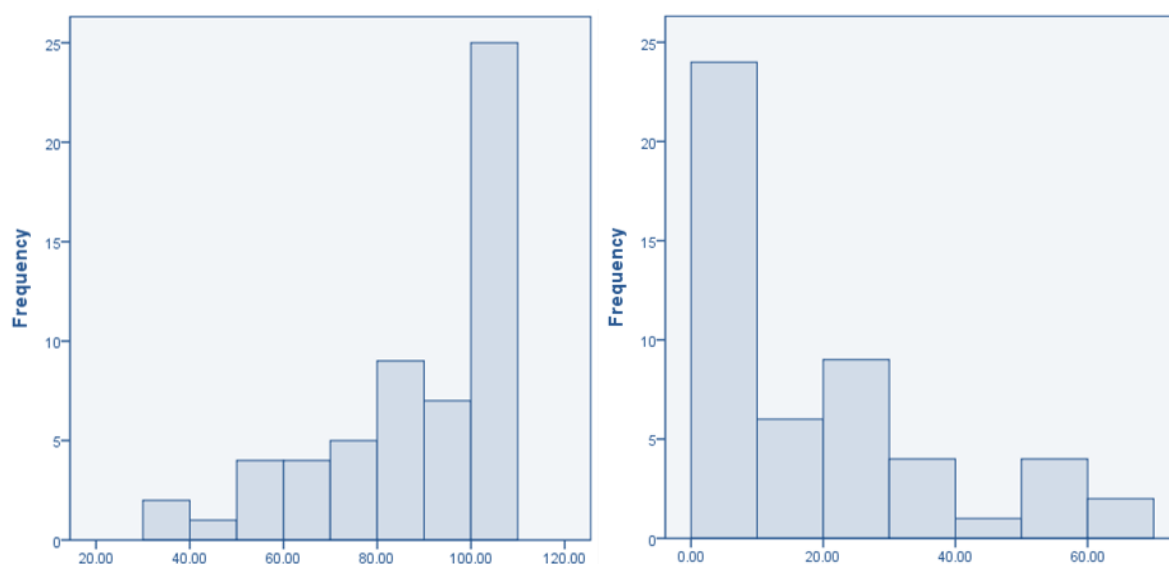


Figure 7. Proportion of new patients in 2011 presenting with malignant (on left) and non-malignant (on right) disease

A key finding here is the significantly higher levels of provision of care to patients with malignant disease. This might highlight a need to consider the provision of services for patients with non-malignant disease. However, as yet, it is unclear whether these patterns are the result of policies within the organisations or simple demand. In addition, it is noted

that missing data for these four questions ranged from 12% (number of patients) to 27% (proportion of non-malignant disease diagnosis).

Finally, **the vast majority of the sample (90%, n = 63) reported that patients under 65 years of age can access PCSBs in their organisation.** This is despite the fact that many PCSBs are located in organisations that predominantly provide care for older persons.

Funding of palliative care support beds

The survey also examined the funding model for these beds. Overall **82.9% (n = 58) of respondents reported that the beds were completely funded by the HSE**, an additional 8.6% (n = 6) reported they were partially funded by the HSE.

Admissions to palliative care support beds

Just over half of the sample (54.3%, n = 38) reported that the use of these beds was ring-fenced and that only patients with palliative care needs were permitted to use the beds.

Respondents were asked in a free text question to state what they viewed the purpose of the PCSBs to be. Figure 8 presents the responses as a wordle. The most commonly held views regarding the purposes of the beds are seen to be respite, assessment and convalescence/ rehabilitation.



Figure 8. Themes relating to the most common purposes for PCSBs

Respondents were asked in a separate question to report how frequently admissions to PCSBs were for the following reasons: symptom control, end of life care, respite and rehabilitation.

Figure 9 below reports the reasons for admission to PCSBs reported in the survey. Interestingly, the reported reasons for admission vary quite significantly to the previous descriptors given by the respondents as to what they perceive the purpose of the PCSBs to be. For example, respondents most commonly stated that they considered respite to be the purpose of PCSBs, yet only 34.3% reported that they frequently or very frequently provided this service. This is potentially an important mismatch and needs to be explored further.

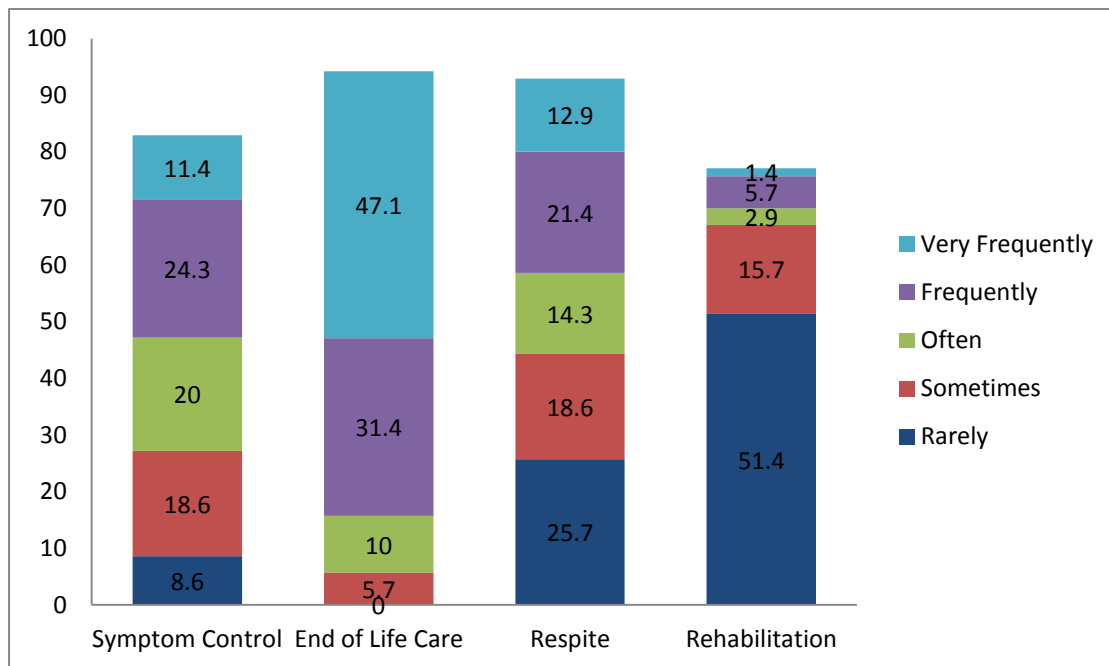


Figure 9. Percentage of organisations reporting their frequency of types of care

Just under one third of respondents (31.4 %, n = 22) reported that there were other important reasons for admission, which are reported in Figure 10 below and include contextual factors such as family issues (*'To support family that can no longer cope with their loved one at home'*) and community circumstances (*'People cannot manage at home on minimal support in the community'*) and issues regarding access to care (*'Unit is open for day service only. Full service never funded by HSE'*).



Figure 10. Themes for other reasons for admission

Figure 11 below reports the source of admissions to PCSB reported in the survey. The frequencies here represent the number of organisations reporting that their admissions constituted a specific proportion. For example, **45.7% of respondents reported that the majority of their admissions came from community settings** whereas **47.1% indicated that the majority came from the acute hospital setting**. There appeared to be significant variability in pattern of referrals from specialist palliative care units with only 8.6% of

respondents indicating that the majority of referrals came from this source (which may reflect the fact that there is marked regional variability in specialist palliative care bed provision). However the high proportion of missing data on this particular question should be noted and this limits the generalisability of these particular findings.

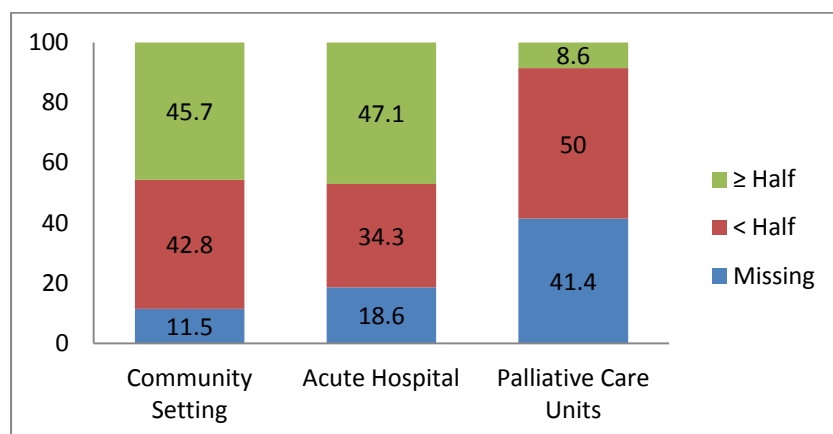


Figure 11. Source of admissions to PCSB (% of participants)

The survey also examined the average length of stay of patients admitted to PCSB (see Figure 12 below). It is clear that **the vast majority of organisations reported stays of between two weeks and three months**. This would appear to suggest that the beds are being used for patients with time-limited diagnoses rather than for long stay patients.

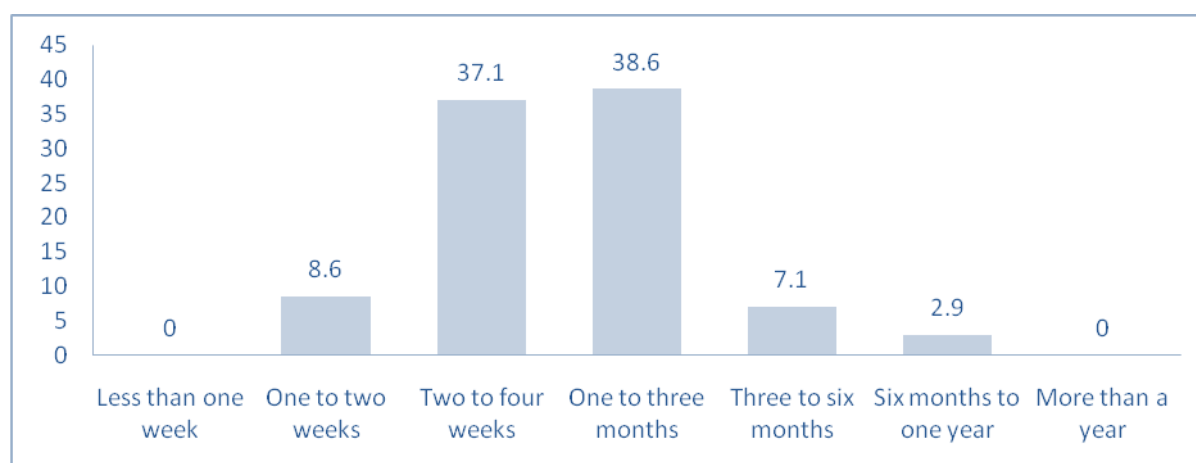


Figure 12. Average length of stay in PCSB (% of participants)

Figure 13 below reports the outcomes of admissions to PCSB reported in the survey. The figures here represent the proportion of organisations reporting that particular outcomes occurred for a specific proportion of admissions. For example, **a clear majority of respondents reported that more than half of their patients died while in the setting**, while two thirds reported that less than half were discharged home. This finding is in line with previous patterns that suggested that patients were commonly admitted to PCSBs for end of life care, with discharge home being a less common outcome.

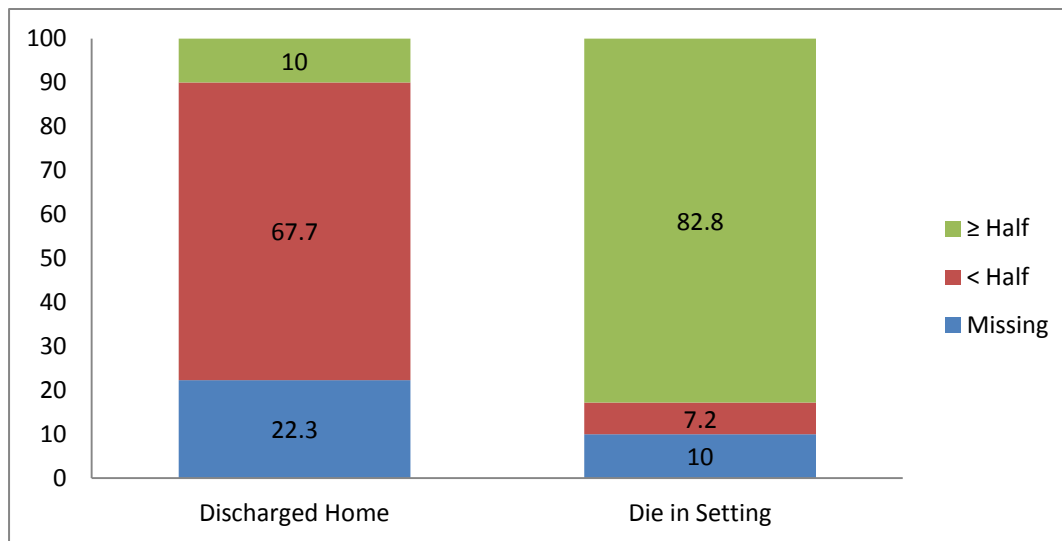


Figure 13. Outcome of admissions to PCSB (% of participants)

Professions involved in provision of care to patients admitted to PCSBs

In examining aspects of staffing and the professionals involved in the provision of PCSBs participants were asked to indicate who has decision making authority for admissions to PCSBs. Figure 14 below reports the findings from this question and **highlights the role of the Director of Nursing in this process**. However it also shows the number of people involved. A count was conducted to determine how many separate professionals had authority for decision-making. In just under a quarter of settings (24.3%, n = 17) only one of the named professionals had authority, while **in 70% of settings between two and six of the professionals were involved**. Interestingly **in four settings none of the local clinical professionals had decision-making authority**. In examining the 'other' responses it was noted that two participants had indicated that all of the professionals listed were involved and two others had indicated that staff in the acute hospital setting were responsible.

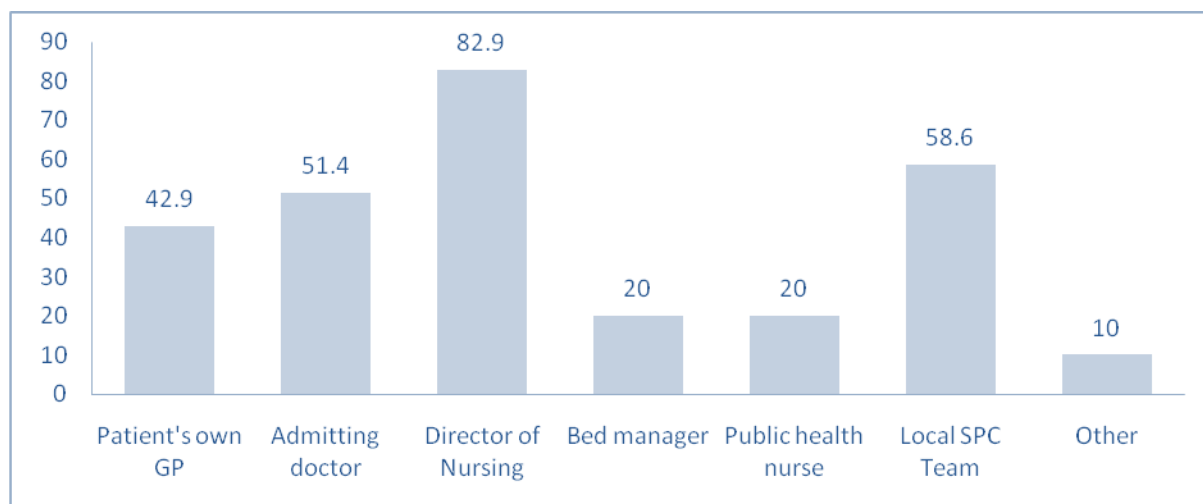


Figure 14. Professionals with decision-making authority for admissions (SPC - specialist palliative care)

Participants were asked to indicate the doctor responsible for the care of patients admitted to PCSBs (see Figure 15). The results **showed the person most commonly responsible was a GP attached to the organisation, followed by the patient's own GP**. The role of the GP reflects the intended model of GP-directed care. Unfortunately unlike the previous question, respondents did not indicate who the other admitting professionals were.

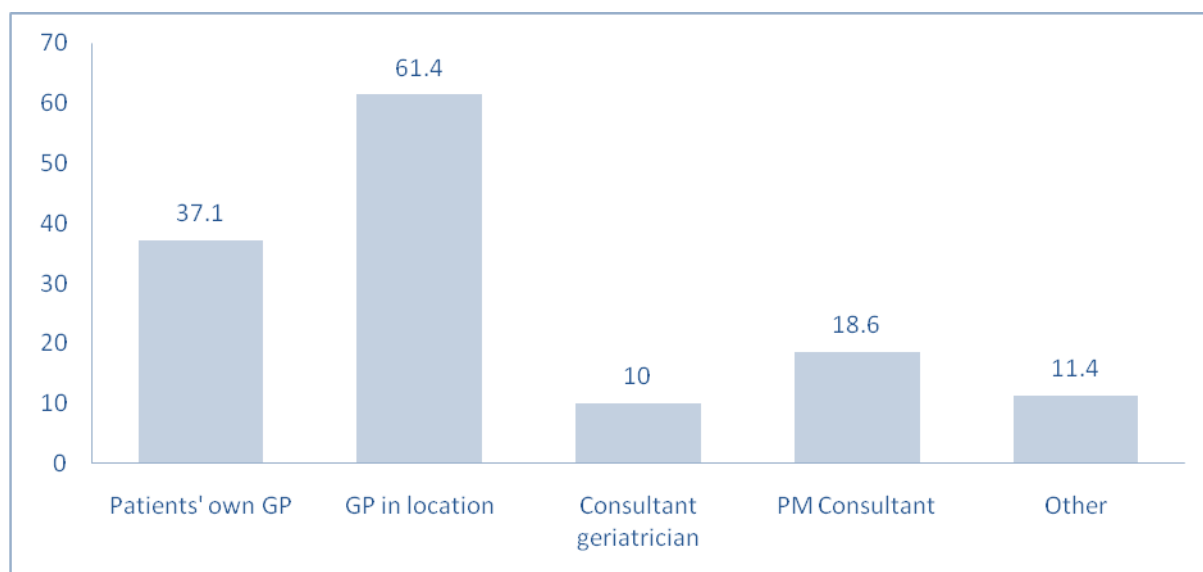


Figure 15. Professionals responsible for care of patients admitted to PCSBs (PM- Palliative Medicine)

The next section of the survey explored the provision of care to patients in PCSBs. Respondents were asked to report on the disciplines other than doctors, nurses and healthcare assistants involved in provision of care to patients in PCSB. Figure 16 below shows that **physiotherapy and chaplaincy services were most common**, however all four disciplines were reported by more than half of the sample.

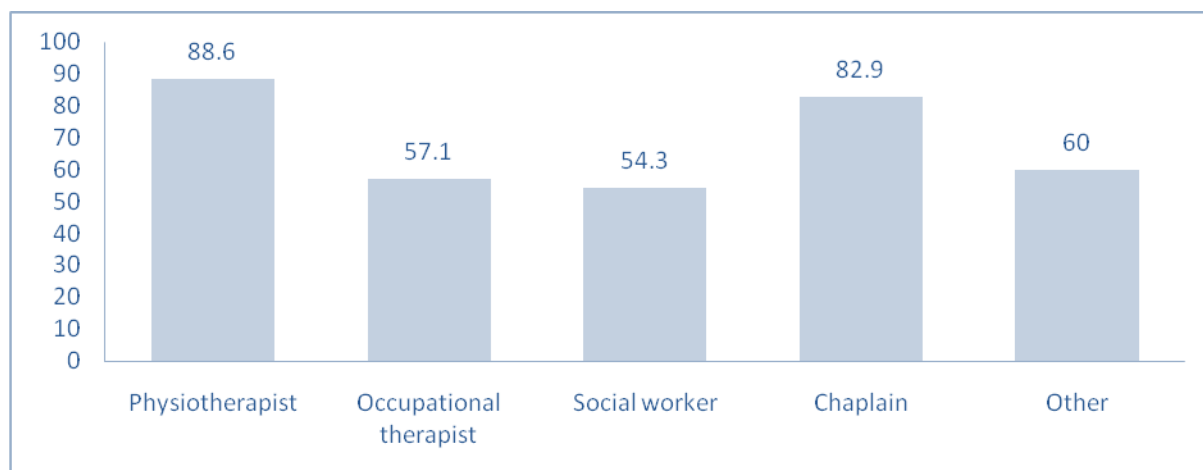


Figure 16. Other disciplines involved in PCSB care provision

Examining the ‘other’ disciplines reported by participants, the figure below highlights the frequency of reported involvement of specialist palliative care staff, chiropody, dietitians and speech and language therapy. In addition **58.6% (n = 41) reported that they had access to bereavement support for families if necessary.**



Figure 17. Other disciplines reported to be involved in care provision

Almost all of the respondents (95.7%, n = 67) reported that the specialist palliative care team provide care to patients. Exploring this further, almost three quarters of the respondents (n = 52) indicated that there were formal arrangements in place to ensure that all patients admitted to PCSBs were reviewed by a member of the specialist palliative team, while 21.4% (n = 15) indicated that this occurred only when it was requested by staff. Finally, Figure 18 below reports which members of the specialist team were available to visit patients in PCSBs, with the specialist palliative care nurse and the palliative care consultant being highest and rather limited availability of other disciplines noted.

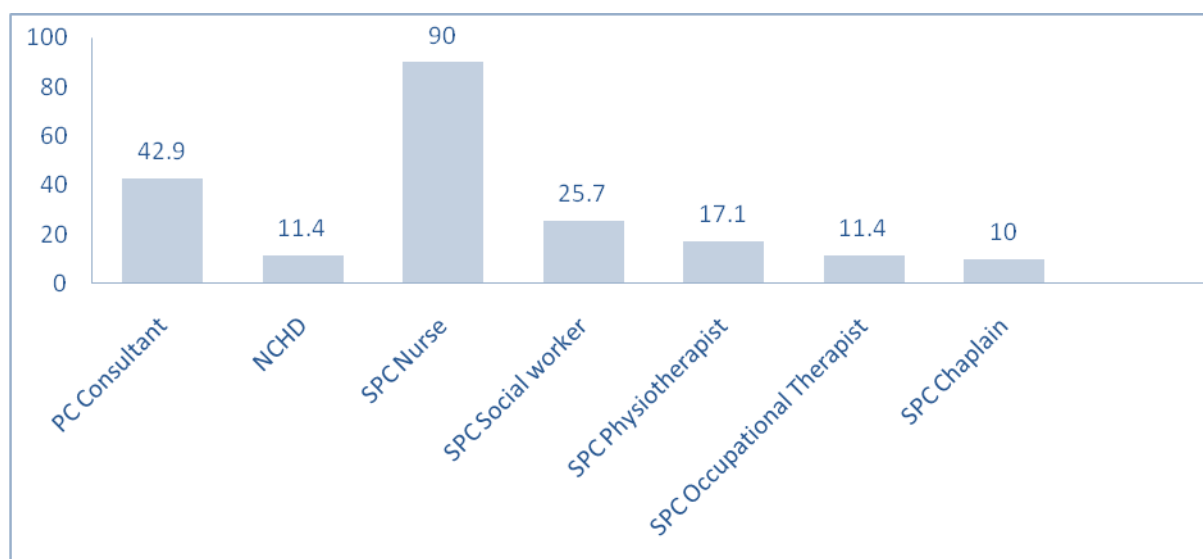


Figure 18. Members of the specialist team available to visit patients in PCSBs

Ability to care for patients with specific nutritional or respiratory needs

The survey included a number of questions that explored aspects of services available in the context of PCSBs (i.e. ability to provide PEG feeding, NG feeding, non-invasive positive pressure ventilation (NIPPV) or care for patients with a tracheostomy). Figure 19 below reports the needs that the participant organisations reported they were able to meet, with PEG feeding reported by almost all of the organisations and almost half of the sample reporting that NIPPV could be provided. A count was conducted to identify the number of needs being met in the settings. **Just over one third of respondents (34.3%, n = 24) had indicated that they have the ability to meet all four needs**, with 90% (n = 63) reporting they met two or more of the four needs. Three organisations reported that they were not able to meet any of these needs.

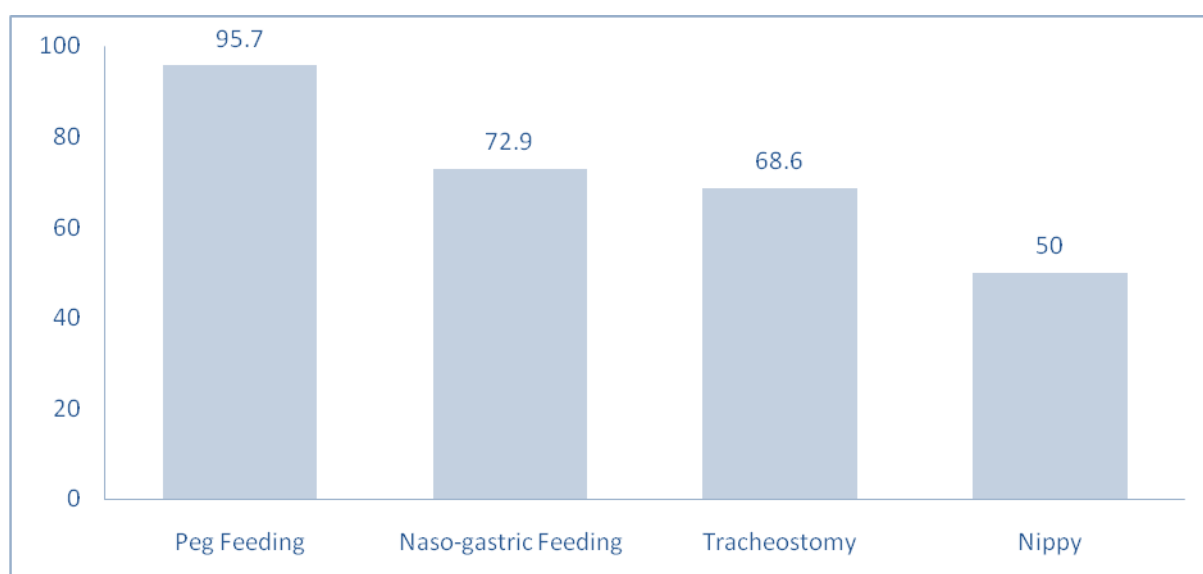


Figure 19. Needs met as part of PCSB provision

Accommodation facilities

The participants also reported on the accommodation facilities available to patients in PCSBs (see Figure 20). The figure suggests that accommodation was available in the form of a single room (with or without en-suite) more often than a bed in a multi-bedded room. Facilities for relatives were also widely available; however en-suite accommodation for relatives was reported as 'always available' by fewer than one in four organisations. It should be noted that there were notable levels of missing data across these questions.

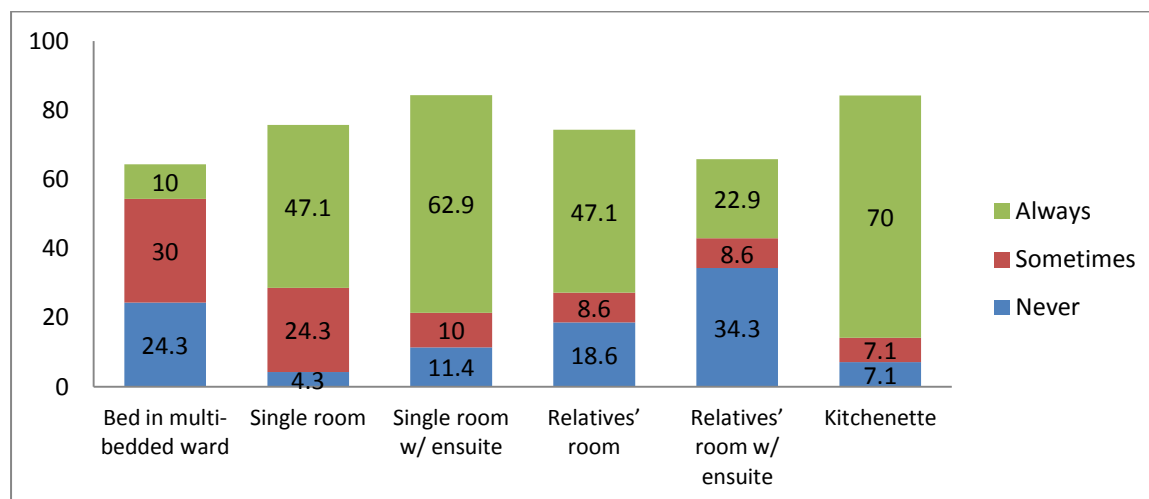


Figure 20. Accommodation facilities available to patients in PCSBs

Equipment availability

Participants reported on the equipment available for use with patients in PCSBs (see Figure 21). The graph highlights the range of equipment that was available in almost all settings. A count was conducted to identify the number of types of equipment available to patients and almost all of the organisations had five or six of the pieces (95.7%, n = 67). However, the remaining three organisations reported having none of the listed equipment. While this is a small percentage, taken together with the previous finding that a small number of organisations were not able to meet medical care needs, this is potentially problematic for the effective provision of care in these settings.

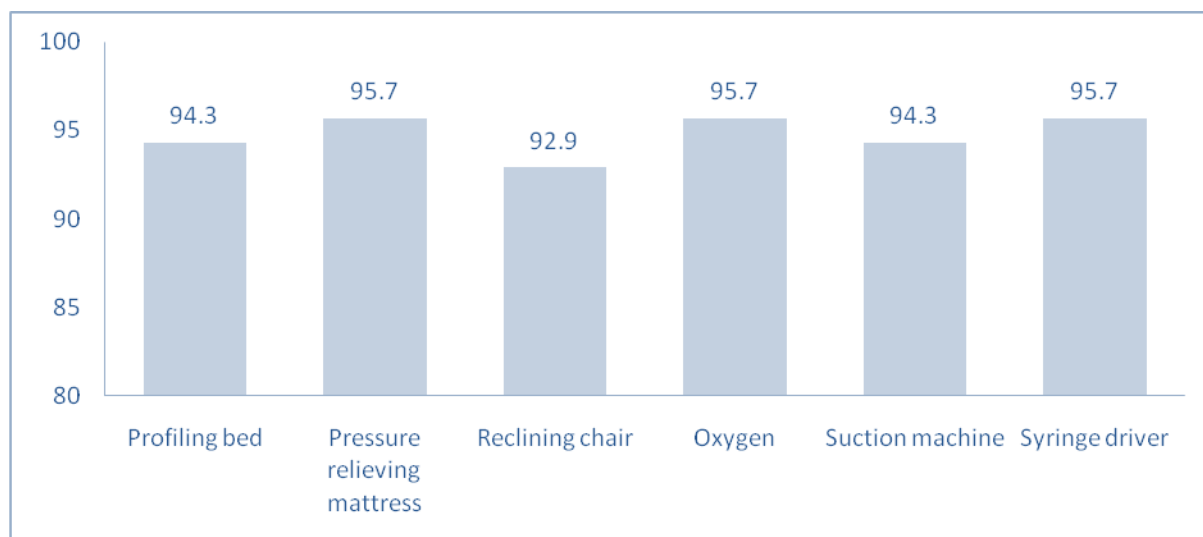


Figure 21. Equipment available as part of PCSB provision

Policies and education/training

The penultimate section of the report considers the policies governing PCSBs, audit and feedback procedures, and staff training and education. **More than half of the organisations (58.6%, n = 41) indicated that they had a policy detailing access to PCSBs** and a similar proportion **(52.9%, n = 37) had a policy relating to communication with patients with life-limiting conditions**. A significant majority of respondents indicated their organisations had a **policy relating to end of life care (84.3%, n = 59)**, while **just under two thirds (62.9%, n = 44) reported having a policy relating to nutrition and fluids at the end of life**. By comparison **just under one-third (30%, n = 21) had a policy relating to Do Not Attempt Resuscitation**.

Audit and feedback processes within the participating organisations were also examined. **Fewer than one in five respondents (18.6%, n = 13) indicated that any aspect of the palliative care of patients in PCSBs had been the subject of an audit**. It was indicated that the audits conducted had examined issues such as service usage and implementation of particular practices (e.g. The End of Life Pathway, The Liverpool Care Pathway, HIQA standards). In addition **just under one third of participants (28.6%, n = 20) reported that the organisation formally seeks feedback from patients and/or families on their experience of PCSBs**.

Following this staff training and education was examined. Figure 22 below reports the responses regarding experience of palliative care education among staff in the last two years, with nurses showing the most frequent experience, followed by healthcare assistants. However given the high proportion of responses submitted by Directors of Nursing or Nurse Managers it is possible that this group are less aware of training/education completed by doctors. As a result the low percentage reported for doctors should be interpreted with caution.

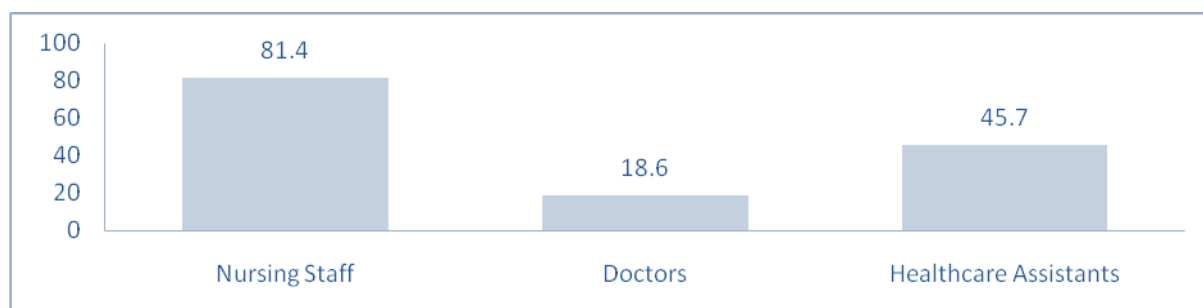


Figure 22. Reported recent experience of palliative care education among staff

Building on this general question, respondents indicated the proportions of staff who had taken part in relevant training/education at different levels. The responses for nursing staff and healthcare assistants taking part in different types of training/education are reported in Figure 23 below. However due to the concern regarding reporting of training/education for doctors this group is excluded.

It is clear from the figure that for both groups the most common type of training/education received was a short palliative care programme, in addition the finding that training/education was more common among nurses holds for each type of training/education reported. However the graph also highlights the number of organisations who did not respond to these questions. While this might be interpreted as reflecting that the training/education had not taken place, an alternative interpretation is that this information was not readily available to the individual completing the survey.

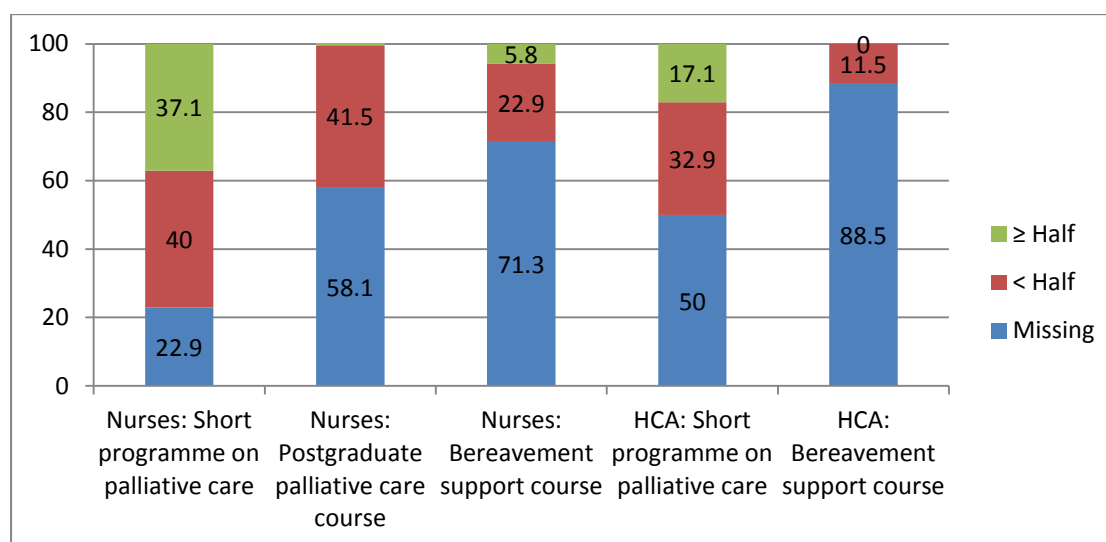


Figure 23. Proportion of nursing & healthcare assistants (HCA) completing training

Open-ended questions

At the end of the survey participants were presented with a series of open-ended questions examining the strengths, challenges, opportunities and threats of/for palliative care support

bed provision. Responses to these questions were very varied and content analysis was used to identify key themes.

Strengths of the PCSB system

A number of themes were identified in response to this question. One of the most common themes was the benefit of the PCSBs being in a **local setting** with representative comments including *'being able to offer patients and families care and support in their local area'* and *'patients can be nursed as near to home as possible'*. Being close to home conferred advantages to families and one staff member reported that *'relatives can be with their loved ones on a continuous basis if required'*.

Staff comments also suggested that the theme of **partnerships in care** was recognised as a particular strength of the palliative care support bed system. Respondents commented on the strengths of the PCSBs in terms of links with home carers and the links with specialist palliative care staff. As one participant commented, the PCSB system *'provides good communication links and support with the palliative care team'*. Although this was noted as a strength of the PCSB system, some additional commentary suggested that the links between services could be further strengthened and improved. As one participant commented *'there is only a part time specialist palliative care presence in the hospital, a consultant who also works in' [number of other locations]*.

Respondents also commented on the **quality of the staff** as a strength, as seen in comments such as *'Highly competent staff with vast amounts of experience in End of Life Care'* and *'staff give 110% to palliative patients'*. Related to this was the contribution of PCSBs to staff development and education (*provision of education and support to nursing staff*).

A number of less common themes grouped together under the broader theme of **the nature of care**, and subthemes including the holistic nature of care (*suitable environment to promote holistic approach for patient*), the integration of care and the specialist nature of the care provided (*access to specialist medicine within the units for these patients*). Within this broader theme the suggestion that symptom control, end of life care and treatment monitoring were mentioned as particular strengths.

Challenges for the PCSB system

Staff were asked to consider challenges in and to the provision of PCSBs and again the figure below highlights the key themes. Unsurprisingly, the key issues relate to **resources**, which included staffing (provision and turnover) and funding. Aspects of this theme included the impact of the current recruitment moratorium, and indeed the wider economic situation in Ireland. The complexity of these issues is captured in the following quotes:

"While the building of the beds was funded by [organisation removed], no additional funding or staff WTE was allocated for this type of patient, this has

resulted in the availability of these beds been threatened with decreasing staffing levels as a result of the ban on recruitment and reduction in overall allocation of budgets.”

Two related themes identified as challenges were **demand for beds** and **bed availability and access** (including admission practices and procedure). A number of comments referred to increasing demand for PCSBs for example, *‘More and more patients are diagnosed daily with cancer, so more beds will be needed in this area’*. In terms of availability of beds, issues related to the length of time a patient may occupy a bed (*‘Some of these illnesses may have a long care trajectory and occupy a bed for a long time’*) and the demands of other illness groups (*‘We don’t always have access to the beds due to service demands and bed blocked awaiting long term placement’*).

Other common themes included the need for, or challenge of, **staff education and training** (*‘More training required, only in-service on-site training’*). Finally, a number of comments related to the **quality of facilities**, as represented in the following quote from one respondent who referred to the challenge of *‘Old building, no en-suite facility, no relatives room’*.

Opportunities for the PCSB system

Compared to the strengths and limitations of the PCSB system, there was less discussion of the opportunities and indeed less consistency in the issues raised. From reviewing the comments, it appears that responses to this question took one of two different positions; (i) suggestions for the development of the PCSB system and (ii) the factors that might contribute towards the development of the system.

In terms of opportunities for the development of the system a number of comments focused on the **provision of PCSBs**. Subthemes within this broader theme included suggestions such as extending the care groups to include non-malignant conditions and younger patients. Comments also referred to the potential to examine the locations in which PCSBs are made available including using district hospitals and locations where beds have been closed. One respondent noted there is *‘Huge opportunity where beds are closed temporarily or long-term. Most elderly people will require palliative care input at end of life’*. Other comments suggested changes in the structure of PCSB provision including smaller units.

However the dominant topic appeared to be factors that might contribute to the development of PCSBs and a number of themes were identified. Not surprisingly a common theme was **resources**, with subthemes including the need for greater public funding, the contribution of local fundraising and also the need for more flexibility in budgets. Linking

back to the challenges discussed earlier, maintaining staffing was seen as one way to promote the development of PCSBs, as can be seen in the following quote:

‘Use the expertise of nurses currently in the system and do not reduce the ratio of nurses to [health care assistants]. You ultimately reduce the knowledge available to delivering optimal care to patients. If the expertise isn’t there palliative care patients will not be admitted to facilities’.

A very common theme in this topic related to the development of **links with others**. This included a number of subthemes describing communication and cooperation with other agencies (e.g. named hospitals and primary care networks), and links with organisations such as the Irish Hospice Foundation, the Hospice Friendly Hospitals (HFH) programme and other voluntary bodies. A number of the issues discussed in response to this question are captured in the following quote from one respondent:

‘The opportunities are limited if we do not use a multi-agency approach there is huge potential. [Use] the district hospital as they are ideally located within the community. Primary Care teams involved as part of the care of these palliative care patients. Not everyone working in isolation’.

Another subtheme related to improving links with specialist services, with one respondent noting the opportunity *‘To bring the specialist services to local communities on a regular basis rather than on need’*.

A final theme that highlights an area that can contribute to the development of PCSBs stresses the **provision of education and training**. Generally respondents referred to the opportunities that would come from staff training and development, with one respondent referring to *‘Extending the role of the Nurse – excellent opportunities available – further short courses and specialised education required for example a day on Graseby pump’*. It was noted that there were opportunities for third level and HFH training, though the issue of public education was also raised, for example in the following quote, *‘Inform the public on the fact that palliative care has a broader scope outside terminal malignancy care, but includes much non-malignant diagnosis’*.

Threats to the PCSB system

The final specific question asked respondents to indicate the threats to further development and the themes that emerged in this section were unsurprisingly similar to the section on challenges. The dominant theme again was **resources**, with respondents discussing the impact of funding and staffing on the development of PCSBs. One individual noted *‘Reduction in funding to services resulting in reduced staffing levels and lack of funding of education and development of staff’* as a challenge. The resource implications were

operationalized in the theme of ***bed and hospital closures*** that were seen as a common threat. Another representation of resource implications was ***changes in access to training and education***, which was associated with reductions in staffing and the limited opportunities for staff release (*'Removal of dedicated time and support for training'*).

5. Discussion of Survey Findings

Over 90% of organisations involved in the provision of PCSBs responded to the survey, ranging widely in overall size and location and indicating unequal access. The largest number of PCSBs reported in one organisation was 40, however the vast majority had two or fewer PCSBs. The following characteristics associated with bed use were noted:

- The beds were reported as primarily being used for end of life care, but use for symptom control admissions and respite also occurs. The beds appeared to be rarely used for rehabilitation purposes, although a significant number of respondents commented that there was a need for such use.
- The majority of patients accessing PCSBs had a primary diagnosis of malignant disease. The median proportion of new patients with a primary diagnosis of 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 majority of organisations reported that lengths of stays were between two weeks and three months.
- The question on source of referral produced a wide range of responses suggesting the operation of very different service models.

Although there was consensus around the appropriateness and value of using the PCSBs to provide end of life of care in a local environment, respondents indicated greater variability in opinion and practice around the use of the beds for symptom control, respite and rehabilitation. Indeed, 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. This opinion was not articulated by non-specialist palliative care stakeholders. While some variation in practice is appropriate in order to ensure that the beds meet local contextual needs, we need to consider whether inconsistent service provision means that patients may not be able to access the most appropriate care service to meet their need or whether there is significant variation in the case mix that organisations provide for.

There appeared to be a relative lack of formal articulation of processes governing admission criteria or assessment of need and the lack of a consensus guiding the process by which patients should be admitted to PCSBs meant that some respondents considered that beds

were, at times, used 'inappropriately'. Lack of service standardisation can lead to healthcare professional and patient confusion over what services are available and how to access them, potentially contributing to fragmentation, delay and inappropriate utilisation. The majority of patients accessing PCSBs have a primary diagnosis of malignancy, despite the fact that providers saying that they are open to providing care to patients with primary non-malignant diagnoses. It is possible that referrers are unaware of that patients with non-malignant disease may be admitted to PCSBs. It is worth considering whether national, or at least regional, clarity on the purpose, admission criteria and admission processes of PCSBs would lead to improvements in accessibility and efficiency in the operation of PCSBs. The National Clinical Programme for Palliative Care could make a valuable contribution by developing a Palliative Care Admission and Management 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.

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. 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. It was noted that that current staffing levels were leading to pressure in meeting patient needs. 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.

However, staffing decisions cannot be made effectively without having good quality data on:

- Patient mix (acuity/dependency) and service demands,
- Current staffing (establishment, staff in post),
- Factors that impinge on daily staffing levels (absence, vacancies, turnover),
- Evidence of the effectiveness of staffing – quality patient outcomes/staff-sensitive indicators.

Such information is not currently available and needs to be collected in order to develop an objective and rational approach to staffing PCSBs.

The significant role that the SPC team 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 (n = 7) reported that there were formal arrangements in place to ensure that every individual referred to a PCSB was reviewed by a member of the palliative care team. The palliative care 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 NCHD in 11.4%); the palliative care social worker in 25.7%; the palliative care physiotherapists in 17.1%; the palliative care occupational therapist in 11.4% and the palliative care chaplain in 10%. Effective partnership working between PCSB and SPC services at operational and strategic levels appears to be one of the most important levers in facilitating the effective operation of PCSB services. There is an urgent need to determine the best model of care for integration between PCSB and SPC services. The model should ensure that PCSBs operate as an integrated component of the area's specialist palliative care service (particularly in their relationship with local Palliative Medicine Consultant and community SPC team member consultations).

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 PEG feeding or 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 DNAR. This is an issue that should be addressed.

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. Respondents were generally positive about the competence of staff involved in PCSB provision, however a concern was expressed by respondents that a lack of continuing training and development would undermine the competence of staff.

6. Case Study Methodology

Case studies were conducted in six sites around the country, five of which were selected based on a stratified sampling procedure, while the sixth was purposively selected to represent PCSB provision in a specialist palliative care setting. The sampling procedure and case characteristics are detailed below. For the purpose of this piece a case was defined as a setting that provided care via PCSBs. The aim was to document practice in each of the sites selected, and to conduct a cross case analysis (Khan & VanWynsberghe, 2008) to identify commonalities and differences across the sites.

Case sampling

It was decided to use a stratified sampling strategy (Vogt & Johnson, 2011) to identify appropriate cases. In agreeing the sampling strategy a number of variables were discussed as possible strata for the sampling frame. These included the geographical location of the organisation, the number of PCSBs available in the setting, whether the PCSBs in a particular site were ring-fenced or not and the proportion of malignant/non-malignant cases using the PCSBs. Analysis of the survey data had identified the following patterns in relation to the criteria considered:

- 38% of organisations are in HSE West, 37% in HSE South, 20% in HSE Dublin Mid Leinster and 1% in HSE Dublin North East.
- 80% of settings have two or fewer PCSBs, while 20% have more than two.
- 54% of organisations reported that the PCSBs are ring-fenced.
- In relation to malignant disease settings were classified based on whether they had no non-malignant cases, 25% or few cases and more than 25% of cases, with the survey showing a balanced distribution of 27%, 23% and 21% across these three possible classifications (excluding settings where this information had not been reported).

It was agreed in discussion with the Working Group that two key criteria were whether PCSBs were ring-fenced and the proportion of malignant and non-malignant cases served (given the possible implications of this for care provision). Having identified the key criteria the participating organisations were assigned to their relevant categories (organisations for which responses to these questions were not included were excluded at this point). A cross-tabulation was carried out using the survey data to identify settings that met these criteria and this is represented in Table 2 below.

Table 2. Cross tabulation of key sampling criteria

| | | Proportion of Non-Malignant | | | Total |
|-------------------|-------|-----------------------------|-------|------|-------|
| | | None | ≤ 25% | >25% | |
| Ring-fenced PCSBs | NO | 10 | 5 | 10 | 25 |
| | YES | 9 | 10 | 4 | 23 |
| | Total | 19 | 15 | 14 | 48 |

It was decided to randomly select cases from within each strata and the website www.random.org was used to generate randomly ordered lists of the settings in each of the selection categories. Three organisations were chosen within each category. This would allow for replacement where potential cases declined to participate. In addition to the six sites selected using this strategy, it was agreed that one setting that had a high number of PCSBs and represented a specialist palliative care setting would be included as a unique case. As a result the sampling strategy aimed to identify seven case studies in total.

The sampling approach also had to consider the key respondents to target in each setting. It was proposed that four individuals in each setting would be contacted, representing both professionals working within the setting and those working in parallel and engaging with the setting. The key respondents selected for inclusion in the interview were:

- Director of Nursing/ designated deputy (i.e., an individual with operational responsibility within the setting) – *Internal Respondent*;

- A nurse on the ward containing the PCSB (i.e., an experienced RGN, somebody with direct experience of working with these beds) – *Internal Respondent*;
- A GP (non-specialist medical clinician) involved in referral to or assessment for PCSB – *External Respondent*;
- A member of the local specialist palliative care team (SPCT), to include either a palliative care nurse or consultant – *External Respondent*.

Participants

Participants were ultimately sampled across six case study sites. Unfortunately despite securing consent from the required seven sites (with only one category requiring selection of a second site meeting the target criteria) only six sets of interviews were completed. In the case of one site the key contact did not respond to contact from the researcher following the initial expression of interest.

The six sites were spread across the country, with three in Leinster and one in each of Ulster, Munster and Connacht. The specific HSE area is not reported to avoid identifying the locations. Four locations had **more than two designated PCSBs**, while the other two had **two or fewer**. One site had been designated as **serving no non-malignant cases**, two sites had been designated as **serving ≤25% non-malignant cases** and the remaining two had been designated as **serving >25% non-malignant cases**.

In total **19 interviews were conducted across the six sites**, and Table 3 documents the individuals interviewed in each site. The sample was predominantly female; however no reference will be made to gender to protect the anonymity of participants. Overall 11 individuals were working within the site (Director of Nursing/Ward Nurse), with eight individuals working alongside the site (GP/Member of the PC team). The following acronyms are used for ease DoN (Director of Nursing), WN (Ward Nurse), GP (General Practitioner) and PCT member (Palliative Care Team member). It is noted that the unique site is only referred to explicitly when this information is pertinent to the findings.

Table 3. Participants interviewed by site

| Site | Number of interviews | Key individuals interviewed |
|--------|----------------------|----------------------------------|
| Site 1 | Four | DoN, Ward Nurse, GP, SPC member* |
| Site 2 | Four | DoN, Ward Nurse, GP, SPC member |
| Site 3 | Four | DoN, Ward Nurse, GP, SPC member |
| Site 4 | Three | DoN, Ward Nurse, SPC member |
| Site 5 | Two | DoN, SPC Nurse |
| Site 6 | Two | DoN, Ward Nurse |

* In order to prevent identifying participants the report does not distinguish between different members of teams, the term SPC member will be used to refer to both.

In addition to the case studies, individual interviews were planned with participants from other sectors involved in palliative care in Ireland. Due to availability and time limitations two interviews were conducted with senior staff in two large acute settings. The aim of these interviews was to provide some external context for the case studies. A brief note on the key themes from these interviews is included in Appendix C.

Materials

A semi-structured interview schedule was prepared in collaboration with the Working Group and is included in Appendix D. The schedule included six sections, the content of which are detailed below:

- **Opening/General views:** This section gathered information on the participant's familiarity with the PCSBs in the target setting and initial questions on the number of PCSBs in the setting.
- **PCSB Governance:** This section included questions on admission/allocation, funding and management. Specific questions explored the admissions policy, inclusion/exclusion criteria and other aspects of decision-making.
- **PCSBs Resource Utilisation:** This section examined a range of aspects relating to the utilisation of PCSBs including the participants' views on demand, patterns relating to patient characteristics such as diagnosis and age profiles, and plans for service development in relation to the beds.
- **PCSBs Staffing and Training:** This section examined issues relating to the staffing of units containing PCSBs and the expertise and training needs of staff involved in the care of patients. A key aspect of this section was the experience of interactions with the specialist palliative care teams in the regions.
- **Perception of PCSBs:** This penultimate section examined participants' views of the perception of PCSBs within the organisation and the wider community. The interview also considered participants' views of PCSBs within the wider health system.
- **Impact of PCSB:** The final section focused on the participants' views of the impact of PCSBs, examining the impact for patients and families, and whether the beds offer distinct value to the healthcare system. At the end of the interview participants were asked to reflection on the general strengths and limitations of PCSB provision.

Procedure

Initial letters of invitation were issued to key contacts (typically the Director of Nursing) by staff providing administrative support to the Working Group. Once key contacts in the sites responded with an initial expression of interest contact details were passed to the research team. A member of the research team then followed up to confirm the key individuals participating in each setting and to schedule and conduct the interviews. All interviews were

conducted by telephone or VOIP (Voice Over Internet Protocol, e.g., Skype™) to facilitate participants' schedules. A member of the research team transcribed all interviews verbatim.

The data analysis involved two phases. Phase 1 used content analysis (Mayring, 2000; Guerin & Hennessy, 2001) to identify common responses within each site. This analysis facilitated the preparation of a detailed case report for each site, which considered patterns across respondents in individual sites. Each case report identified key themes and representative quotes under each of the six sections of the interview schedule. Phase 2 involved a cross case analysis (Khan & VanWynsberghe, 2008), whereby further analysis identified similarities and differences across the six sites. This analysis focused on patterns within the six interview sections but considered variations across sites. In reporting the findings participants are identified by site and position.

In addition it was agreed that the qualitative component would include two dedicated focus groups that would gather a view from the management level and the patient advocacy perspective. The management group aimed to represent perspectives such as regional leads for palliative care/ regional specialists in palliative care, local hospice CEOs, HSE managers with responsibility for palliative care, local hospital bed managers) and 14 individuals were identified as possible participants.

7. Case Study Findings

The findings report the key patterns identified during the cross case analysis under the main topics considered in the interview schedule.

Opening information

At the outset of the interviews participants were asked about the number of PCSBs available in the setting. Given that the settings had been selected on the basis of the number of beds available and whether these beds had been ring-fenced in 2012 there was expected variation evident in the information provided across the six sites. **In four of the six settings, beds were described as ring-fenced or designated for Level 2 care, and (excluding the unique site) the average number of beds was three (range = 2 – 5 beds).** Of note, while the unique case did have a high number of beds only two thirds of the beds were in operation at the time of interview. Echoing the survey findings, there was some variation in relation to the facilities available. **All settings had designated beds in single rooms with en-suite facilities, though the larger unique site (which had been selected as a unique case due to the number of PCSBs) did have some based in multi-bedded wards.** However **there was variation in the additional facilities available, particularly for family members.**

An interesting theme that had not emerged from the survey data but that was evident across a number of sites was **the manner in which the utilisation of beds varied according to clinical demand.** When palliative care demand for beds was low, beds were used for other needs such as infection control (due to the fact that they were single rooms with en-

suite facilities). Conversely, there was a notable openness to taking on additional patients with palliative care needs in other non-designated beds when the PCSBs were occupied. This theme is reflected in the following two quotes:

“While we have four dedicated beds and neither will I leave a, a bed remain empty while, if there was no palliative patient in it. And neither if I had say four palliative patients in four beds, and if there was another patient required a bed, the other patient will get the bed” [DON, Site 3]

“There are two, supposed to be two to three designated beds but at the moment I only have two patients in the hospital...but I mean I could have anything up to six, providing there was a bed available now” [PCT member, Site 2]

This flexibility appeared to reflect a commitment to meeting the needs of patients if at all possible.

PCSB governance

A key aim of the case studies was to examine the way in which PCSBs were operated across the country. This involved looking at issues such as admission/allocation policy and other aspects of decision-making, management and funding.

In reviewing the admissions process, there were a number of similarities across the sites, though practice was quite different in the larger unique case site. Of note, **although the admissions process could be quite organised, there was little reference to the presence of formal policies governing the process.** In one of the sites the policy was described as “very strict” and the participant went on to associate this with the role of external groups in the funding of the PCSBs. In another site, the policy was seen as being less rigid but the values underpinning the policy were an important lever to meeting patient need, with a DoN stating *“The admission policy is like my flexible friend, I suppose the admission policy is that the requests for palliative beds are prioritised above all others...the overarching policy would be easy access, instant access if possible”* [Site 3].

Who makes a referral to the PCSB?

In the five similar sites participants reported that a range of settings/individuals made referrals to the beds. The most common sources of referrals were members of the local PCT (including palliative care nurses and consultants) and acute hospitals in the relevant regions. This supports the findings from the survey that referrals originate from both community and hospital settings, however **it additionally points to the influence that the PCT have on initiating the process in the community setting.** The role of these referrers can be seen in the following quote from the DoN in Site 2:

“It works really well from the point of view that once there’s a palliative care case identified in the area, in my catchment area, em the clinical nurse specialist will be coming to me saying ‘we have this person, they’re ok at home at the minute, em we’re

monitoring them, the potential is that in a week, a fortnight, a month, this person can run into trouble'. And from very early on I'm aware of them...and I would be watching them to make sure that the minute you know, I would have a bed available"

Four of the six sites reported that they took referrals from local GPs, though another site mentioned that GP referrals might come via the emergency department. However **the remaining two sites did involve GPs in other ways, for example seeking information from them regarding a referral.**

How is a referral assessed?

In terms of the decision making process once a referral was received, **two of the sites described a formal committee/team process that considered referrals**, (one of these was the unique case). **In other settings the DoN** (or a nominee, particularly during nights and weekends) **was centrally involved in the decision making process**. Other key individuals noted as involved in this process, though less frequently, included a senior ward nurse with responsibility for the PCSBs, a regional placement coordinator, and the local palliative care nurse (where specialist needs had been identified during the referral process). The involvement of multiple individuals in this process is highlighted in the following quote from the SPC team member in Site 2:

"First of all the patient would be ... on my caseload. Anybody in the community, once they're in the community, the Director of Nursing would know that they are out there. If they're, you know, maybe become more ill towards the weekend she will also know that there's a possibility that they might be admitted. The GP, usually the GP would admit, if I need a bed I can ring up, but obviously the GP needs to be in on the situation as well. We work very well together"

The importance of clinical information in supporting the referral process

Central to the referral and decision-making processes is the information provided or sought at the point of referral. Participants in a number of sites referred to the information gathered upon receipt of a referral or during the decision making process. In the unique site information was gathered by members of the admissions committee in the form of a formal assessment, while two other sites (Site 4 and Site 6) reported using other structured systems for determining admission. The SPC team member in Site 4 stressed the equity that this created saying:

"To make it as objective and as fair as possible, and also in order to try and make sure that any patient who might potentially benefit from the bed...instead of thinking oh, you know people saying oh you know Mary Bloggs lives up the road, she might need the bed, that they actually fill a form in and we get more of an idea of the demand"

"Staff depend on very clear communication from, from the hospital in relation to referrals, and since the unit opened, we actually we're using em the specialist palliative

care referral form, and when the national [form] was introduced there recently and circulated, [palliative care consultant] had huge input into that, and it's the form we were using anyway, with I think there was just three items that weren't on the form we were using. And I know em, so they've always been very em acutely aware of the reason for referral and you know is it urgent, can it wait a day or two, or is it kind of just initial contact with families to develop a relationship for later in the care" [DoN, Site 6]

It was noted that communication with the other professionals involved in referral and admission was important and **having a member of the SPC team physically based in the same setting was seen as a factor in successful communication.**

Inclusion/ exclusion criteria and reason for admissions

Participants were asked about the types of conditions/needs that would warrant allocation to PCSBs. This discussion did not relate to patterns of use (which are discussed later) but to the situations in which an individual might be allocated a PCSB. All sites discussed the extent to which patients would be allocated to PCSBs for three reasons – end of life care, respite care and pain/symptom management. **All of the sites allocated beds for end of life care, and this was described in some settings as the priority:**

"The highest request need would be for end of life [care], and palliative care in terms of respite, not as much, but we could certainly do it, people would come in for symptom management and we would send them home again" [Site 3].

In one setting end of life care was prioritised due to the limited number of beds:

"In a way it's kind of to try and protect the beds from being you know, kind of occupied by somebody ... that's actually even more limiting if you know... It means you know that if there's for example a lady in the bed for kind of six months plus, that no one else can access the bed during that time" [PCT member, Site 4]

Four of the sites reported that they also allocated beds for respite and symptom management. Despite some sites seeing respite care as less of a priority, other sites commented on its importance, as evidenced by the following quotes:

"Sometimes just people can't cope at home and you give them a little break and then you can manage the care from here, you know they can go out with a package of care out home that people can eventually return home because that's where they want to be at the end of the day, and that's where we want them, but I suppose this is the next best thing to home, here. You know in this area" [PCT member, Site 2]

"You know something happens at home and people just can't cope and we would often get them from say you know the local hospital...where they've been on an open ward

and you know it's very difficult for the family, you know it's a private time for them, so we would take them kind of you know as a priority as well" [DoN, Site 1]

Formal exclusion criteria for admission to PCSBs were not common. It was clear that individuals would not be excluded on the basis of a non-malignant diagnosis, with the WN in Site 6 commenting, *"Initially when the beds were opened it would have been mainly for malignancy, but increasingly strokes and em respiratory, as in em pulmonary fibrosis. So yes malignancy, stroke is huge and em respiratory end stage"*. The distinction between the nature and purpose of a palliative care support bed and long-term care bed was evident.

In practice, there was evidence of appropriate exclusion on the basis of the complexity of care needs. In Sites 2 and 3 the DoN reported that they were able to cater for quite a high level of care, though in contrast Site 4 reported a reluctance to take on complex cases, saying *"There was a reluctance because of our capability, because of our Level 2 structure, for us to take the Level 3, em because you know, were we going to meet the needs is basically where our reluctance was"* [WN]

Funding

The final aspect of governance considered in the interviews related to the funding for PCSBs. This was generally a topic that was addressed in greatest detail by the DoN in each site. **In contrast to the survey findings, there was significant variation in the funding models described,** and this is linked to the nature of the settings. **In three of the settings the beds were described as being funded from the organisation's own funds, while in the other three settings funding was described as coming from the HSE.** In two of these three settings it was noted that external groups provided additional funding for PCSBs (through fundraising and charitable funds). In Site 2, which received support through fundraising, the DoN commented on the challenges this brings during times when overall charitable given declined. In Site 3 the DoN suggested that there should be a specific cost associated with the provision of care to these beds (as was the case for residential beds in the setting), and that the current funding mechanism heightened the risk of discontinuity in the funding for these beds:

"At the moment you know we don't get anything other than what is the budget and they are quite expensive beds and because they're very expensive beds there's a danger they're going to disappear because there's no money available for those beds and you know the funding, particularly when all the new directorates have been formed and the money has been you know funnelled into each directorate, it's going to put those beds at high risk, quite honestly" [DON]

PCSBs utilisation

Having discussed the governance of PCSBs, the interview moved to explore utilisation of these beds. **All of the sites reported that patients with a range of conditions, including cancer, MS, motor neuron disease, COPD and heart failure, were admitted to the beds.**

However, in common with survey findings, **participants in four sites (1, 2, 3 and 4) reported that the patients with cancer were the predominant users.** As one DoN reported, *“It’s mainly cancers, in the last couple of months, it’s a lot of throat and oesophageal cancers”* [Site 4], while the PCT member in Site 2 commented, *“When I came here initially, palliative care was palliative care for cancer patients...now it’s I mean I suppose 20% of my caseload are non-malignant, you know people with pulmonary fibrosis”*.

However, even in sites where there was a dominance of cancer diagnoses, this was not a criterion for access and there was a clear sense that the beds were available to individuals with palliative care needs independent of diagnosis. As one PCT member reported;

“It’s whoever is in, has a need in the community, em in fact that policy it’s kind of, in many ways it’s kind of wide open, and if they have a bed and somebody is palliative, they’ll accept the person, regardless of non-malignant or malignant diagnoses” [Site 1]

The age profile of patients using the PCSBs was also examined, with **all of the sites reporting that patients with a range of ages were admitted to PCSB.** However it was not unusual that participants reported patients were **typically older**, with the key patterns evident in the following quotes:

“When I would have started initially you know I suppose before it became level two we would have been seeing you know more of an elderly population, but it’s certainly becoming more widespread now, we’ll have younger people, people with both cancer diagnoses and other life limiting illnesses” [WN, Site 2]

“Obviously with strokes the age profile would be higher and with the malignancies, generally, I mean we’ve had, no more so than any other area, we’ve had some very very young...with the malignancies kind of 40s to 60s, but there has been some youngers and there has been obviously older” [WN, Site 6]

The WN in Site 3 provided some insight into age profiles, suggesting:

“Younger people do tend to stay more at home or their disease may be of such an aggressive nature that they’re in the acute sector do you know for longer, or have more complications or just you know their diseases are so advanced. We’ve definitely had you know young people but it is like the older person usually has less people to care for them at home, you know less structure or less supports” [WN]

Demand for PCSBs

In addition to examining use of the PCSBs participants were asked about their perceptions of demand for the beds in the area. **The discussion on this topic was notable for the level of variation evident in the responses, both across settings and, somewhat confusingly, also within them.**

In two of the sites the demand was considered to be high, particularly in the unique site. In fact, it was noted in the unique site that the presence of a waiting list was resulting in some referrals not even being made as the process was felt to be futile.

In two of the sites the internal staff described demand as variable, with one WN commenting:

It's a bit like peaks and troughs, that you can be really, really busy and I suppose it depends on what's happening out in the community with diagnoses and with hospitals and everything, we can get you know a lot of referrals at you know one time and then you go for a month or so where it's very, very quiet and you liaise at the palliative care home team and they would be maybe quiet at that stage as well" [Site 1]

However, the view of the PCT members in both of those settings was that there was more pressure for the beds. One PCT member commented that demand was high and increasing, and the other reported;

"I think there's constant pressure because a lot of the older clients are waiting for beds in nursing homes ... There's no money at the minute to move so we have people here who are in hospital who probably could be better served in a nursing home ... that would mean there'd be less pressure" [Site 2].

This mismatch between perceived community demand and PCSB recognition of need is concerning and merits further exploration.

In the final two sites there was a sense that the number of beds was meeting demand and to some extent the beds were under-utilised. However, the difficulties in accurately gauging need and demand were again reported:

"The thing I find it's particularly hard to capture is the demand because you know, if people know, you know including ourselves, if we know that the [beds are in use] until we manage to work out an alternative plan ... then it really isn't an option for anyone else. So it's kind of hard to capture that kind of potential demand in the meantime" [CON]

Ring-fenced beds

It was noted that one of the advantages associated with allowing flexible use of the beds (rather than ring-fencing them) was the beds could be operated at maximal efficiency. One DoN noted:

"If they're not for palliative, they're always used in here because there is, there is a demand on the beds from the acute hospitals" [Site 3].

Another DoN commented:

“It makes the available beds you know, full all the time ... it would make no sense to have those beds sitting empty now for the past two months, whereas those beds have been in use all the time” [Site 2].

Review of utilisation

The final topic discussed in relation to utilisation of PCSBs explored the procedures used within the settings to review the use of beds. The procedures for review were discussed in three settings, with all three referring to meetings between the staff in the setting and members of the SPC team and one referring specifically to the Hospice Friendly Hospitals audit.

PCSBs Staffing, Training and Support

Staffing

Moving on to discuss aspects of staffing and support relating to the provision of PCSBs, the first issue considered was staffing levels for PCSBs. **All of the sites employed both nursing staff and healthcare assistants (HCAs)**, with one DoN recognising the important contribution made by HCAs:

“The healthcare assistants are fantastic...a lot of them are here for a number of years. They are working in the [palliative] area all the time, that’s their choice to do that and they’ve been training to do it, em so you know they get on very well, they know the patients well, they deal with them very, very well. The nurses and themselves get on, they, I mean they’re a great help to the nurses” [Site 1]

Perhaps unsurprisingly, there was **significant variation in staffing in the different sites**, based on the size and nature of the unit the PCSBs were in or attached to. Looking at the type of staff in the settings, there was also **differences in the ratios of nursing staff to health care assistants, which ranged from 25:75 to 60:40**, again depending on the nature of the unit (i.e., high dependency etc.). Nevertheless a common theme was that staffing of PCSBs was governed by the allocation of the entire ward/unit, as can be seen in the following quotes.

“We actually didn’t change our staffing levels at all, when we brought in the [PCSBs] I do have less nurses than say [a specialist PC setting], I have more care assistants but we’d have quite skilled care assistants ... we actually do have a good staffing ratio here” [DoN, Site 5]

“We would look at the dependency overall. We do a Barthel Assessment every month, now obviously that doesn’t measure everything, it doesn’t measure drug rounds, it doesn’t measure the time that you might spend talking to patients or the time that you might spend talking to relatives to support and re-assure them and all that, but we do, we do use that tool to look at dependency levels and if we feel and we’ve kind of got our dependency levels quite right [WD, Site 4]

There was a perception among some external participants that staffing was low in some settings. The SPC member in Site 1 felt that the staffing levels in relation to the PCSBs were low in comparison to a specialist PC setting.

“They’re [staffing levels] not adequate anyway...having worked within an inpatient unit that in times when it’s extremely busy they do require, I mean one person dying, a nurse may need to be allocated, I mean actively dying, may need to be allocated to the patients and the family for the day like...but they wouldn’t be given that” [Site 1]

A SPC member in another site (where the GP had commented on low nursing staff levels) additionally stated, *“The care here is excellent and the staff are still giving the same care despite the fact that numbers are way, way down” [Site 2]*. Internal participants, also noted the changing availability of nursing staff with the DoN in Site 3 describing it as,

“A huge problem, I don’t know what the reason [is], there is some sense that nurses can be replaced quite easily by health care assistants and I’ve no, there’s huge need for health care assistants, I haven’t a problem with that, but I do think in terms of technical skills, em you know, medication management, that’s a nursing function”

There was clear evidence that staff in settings containing PCSBs worked hard to ensure that the care needs of patients receiving palliative care were met despite the constraints of low staffing levels. The WN in Site 2 described how *“In the morning you just prioritise your workload for the day, and you know it depends, if we have palliative care patients they are prioritised”*, while in Site 3 the WN referred to management of the staff team to meet the needs of patients in PCSBs, and this flexibility and responsiveness was echoed by the PCT member in that setting saying, *“if someone was dying, they wouldn’t be left alone, you’d be looking into a one to one and you’d be re-grouping ... if the patient was needing one to one, they’d be re-allocating themselves within the team” [Site 3]*.

Staff in one site reported that when the PCSBs had been opened there was no possibility of securing/being assigned additional staff. However the staff team were committed to supporting the PCSBs:

“... Staffing levels had been agreed for [number of beds removed] ... but they wouldn’t give us any more staff for two extra beds which were [PCSBs]. And we sat down and we talked to the staff, now, I know this sounds absolutely unbelievable, but the staff said they would take it on, because it was end of life. So we didn’t get any extra staffing” [DoN, Site 6]

Following the discussion of staffing and staffing levels, participants were asked about training needs and opportunities within teams. **There was evidence of a clear interest in and commitment to palliative care training**, as seen in the following quotes:

“An awful lot of our nurses have been training and we’ve had training just recently for our health care assistants as well” [DoN, Site 1]

“All staff really nursing and non-nursing would have really embraced that because a lot of the staff have undertaken em courses and of different levels to you know in order to be ready for that change” [WN, Site 2]

“We’re trying to train up staff em to do palliative care courses and that. And to get education provided to them” [DoN, Site 4]

Training

Several participants discussed how training needs were identified within the organisation, and these varied from formal processes such as surveying staff (*“We did a survey [and staff] wanted a little bit more on different symptom control and em also on the psychological stuff, the breaking bad news and things like that” [DoN, Site 5]*) to informally reviewing cases to identify needs, and encouraging staff to highlight their own training needs.

In all of the sites staff had accessed a range of training courses including Final Journeys, Princess Alice Certificate, Certificate in Essential Palliative Care, Higher Diploma in Palliative Care and formal courses offered by specialist organisations such as individual hospices, the Irish Hospice Foundation and the Irish Cancer Society. In addition participants referred to specialist equipment training (e.g. for syringe drivers). However a clear theme reflected the extent to which informal training was also important, as can be seen in the following quote:

“Particularly care assistants, they kind of wanted a lot of training so we thought shadowing would be good for them, because they, our care assistants as well a lot of them have FETAC and some of them are here a long time and they become quite skilled so they are able to teach each other as well” [DoN, Site 5]

An interesting point is that, in a number of settings, the participants noted that the effects of training were not limited to staff involved directly with PCSB patients. One WN felt that the ethos of palliative care had extended throughout the site and that this had increased interest in training opportunities. However the WN in a second site did not think that this could be problematic if staff did not then have the opportunity to practise the skills learnt saying, *“You’ve to be sensible as well about it because you could get off and get training and then if you don’t utilise those skills you’ve kind of forgotten it again by the time the next person comes” [need site]*. Linked to this, other challenges regarding training related, perhaps unsurprisingly, to costs and time limitations, with the demands of releasing staff to travel to Dublin noted in one site.

A final key theme regarding training related to the role of the local SPC in both formal and informal training opportunities. The important support provided by community SPC and specialist settings was noted in a number of sites. For example, the DoN in Site 2 explained that *“local nurses, specialists, come in and they do workshops on constipation, syringe driver*

use, anything that would be out of the ordinary or that [staff] wouldn't have done in a while...they provide workshops". This was echoed by the SPC member in Site 3 saying:

"There would be huge educational needs, even to update them on all the different em patches that are out there, analgesic patching, em switching from one opiate to another, like they wouldn't have the confidence to do that, and they would never put up a syringe driver, generally without, or change any of the medication without consulting us, because they just wouldn't have the expertise".

External supports

The final topic examined in this section explored the support that sites containing PCSBs received, both from PC specialist teams and services (including home care teams and consultants), and other relevant professionals. Across all sites it was noted that there was **ongoing support for staff in the sites from local SPC teams**, as is highlighted by the following quotes:

"We also link in a lot with [specialist setting] ... it's great for advice like, I mean the GPs would contact you know the registrars or the consultants in [specialist setting], if they have a problem you know em with any of the hospital patients, you know that facility is there. So it's a great back up." [DoN, Site 1]

"We do have huge communication and liaison with our community service ... [They] are always at the end of a phone with regards em clinical [issues], as I say, I use them as a sounding board" [WN, Site 6].

Participants also highlighted a wide range of other professionals and individuals/groups that supported the operation of the PCSBs. These professionals and services include GPs, registrars, physiotherapy and occupational therapy, counselling, patient advocates and in some cases volunteers. There was a high level of variation across the sites, and in some settings a perception that other supports were limited was evident, however the following quote illustrates the situation in one setting:

"The GP support here is excellent. The GPs care for their own patients here and if they have a palliative care patient, they make themselves available 24/7" [DoN, Site 2]

"We've Headway, we've MS specialist nurses who are dealing with the MS people, we've Motor Neuron people that come in for their patients, obviously all the [occupational therapies, speech and language, dietetics, they all come...the public health nurses we talk to all the time]" [WN, Site 3]

The importance of the quality of working relationships:

The importance of good working relationships between and within the staff in the setting and the external supports was highlighted. The DoN in Site 6 noted, *"It's [the relationship is] historic. Yes but you know we never take it for granted and we work hard at it"*, while a

GP commented on their relationship with the PCT saying, *"I work very closely with the [PCT member] in this area... we would spend a lot of time working together"* [GP, Site 2]. This participant went on to comment on the importance of trust to the operation of PCSBs saying:

"It's all to do with trust ... it's that they trust that I won't leave them high and dry if they're in bother and vice versa, ... it boils down to that ... you work together as a team, it's not us and them, it's not the doctors versus the nurses. You know we really do kind of depend on one another and work together" [GP, Site 2].

The challenges of out of hours support

A number of sites did highlight the challenge of out-of-hours access, with one DoN commenting *"Obviously outside hours ... there'd only be one person on call you know so it can be difficult for them"* [DoN, Site 6]. Another DoN reported:

"When you don't have someone there in the evening or at night when a problem arises. Em it's very difficult sometimes to manage things, and usually you have to pre-empt it but it's not always possible" [Site 4]

Despite limitations in structured out of hours supports, professional commitment in terms of ensuring access to support was evident. A number of sites stated that both PCT members and GPs were willing to be contacted out of hours, or by phone for specific queries (*If I rang, I could ring at any time you know, day or night for advice*" [GP, Site 2]).

Geographical proximity of specialist palliative care teams

In three sites, the SPC member was physically based in the same location as the PCSBs. This was discussed explicitly by participants in these settings as a key factor in the successful operation of the PCSBs, with one WN stating that *"Our [PCT member] is based in the hospital...so access to her would be quite eh easy really ... [and] if she's not there, she'll always be available by phone and would be very supportive"* [site 2]. In one site participants attributed a strong working relationship to the close location, as can be seen in the following excerpt:

WN: I suppose the fact that we communicate well, em, you know em, there's ownership I think felt with the beds as well, do you know they're felt that there's access here and they're welcomed and do you know I suppose we do, we work really well together as a team and we acknowledge everyone's expertise you know.

I: And in terms of you know you mentioned that the [PCT member is] on site, does that have a role in terms of that relationship?

WN: I think so, yeah it's part of it, they feel part of us, and I think they feel, we feel that they're part of us, and they feel part of us, so it must do, yeah it must do.

In contrast, in one setting where the PCT was based at a remove from the setting the PCT member appeared less confident of their relationship with the PCSB staff, who said *"You'd have to be, you know very careful in how you would make suggestions or recommendations"* [Site 1]. However this reserve did not appear to have impacted on the quality of the PCSB relationship with the PCT with the WN commenting:

"I mean the [PCT] are brilliant, we've got to know them very well, they come in, if some of their residents, if some of their patients are in for say respite or even to come in for symptom management, they'll often come in to see them, and you know we would meet up with them and we would ring them up if there was any query about drugs or anything like that, so we work very well and very closely. We mightn't ring each other every day or anything, but we know that they're there should we need them" [Site 1].

PCS Community awareness and pride

The final area of investigation considered the perception and impact of PCSBs, both in the immediate local setting and in the wider context of health care delivery. **The general perception and awareness of the PCSBs in the local community was considered to be positive**, and this was expressed by a significant majority of the participants.

At the organisational level PCSBs were considered to be valuable and indeed were associated with positive changes in awareness and perception of the organisation in the community. Indeed in one site the PCSBs were seen as increasing the desire for admission to the organisation, which is highlighted in the following quote:

A lot of people seen that the care could be given here and now a lot of families are asking for the care given here...because it's closer to home, because people want to be looked after in their own area" [PCT member, Site 2]

The quotes below represent participants' sense of good awareness and a positive perception of the service among the community:

"You know there's a lot of respect for them and people are very grateful that they're available and em it's very close to home for a lot of people" [WN, Site 1]

"There's always [donations] towards the [setting charitable fund] and towards the hospital and towards the palliative care you know in the area, it's phenomenal. I suppose people recognise the need for it and everybody has been touched by it at some stage like you know... So the [setting] is a main hub really and people know what goes on, you know they're all very aware" [GP, Site 2]

The only comments that reflected more negative perceptions were in relation to perceptions of accessibility of the PCSBs, both in terms of waiting lists or the lack of availability of respite care.

Value and impact of PCSBs

In addition to considering the perceptions of PCSBs within the organisation and community, participants were also asked for their views of the value and impact of this type of care. The general evaluation of PCSBs was predominantly positive, with **participants reporting benefits for patients, families, communities, staff members and the wider healthcare system**. Before discussing these benefits it is important to note that, when asked whether formal assessment of impact was conducted, this was typically not the case. However participants did state that feedback from families had provided an important insight into the impact of the service, with one PCT member reporting, *“There’s been a very positive sort of informal feedback from patients or residents themselves who have come in to us and their families”* [Site 5]. Nevertheless, there was evidence of openness to more formal evaluation, with one DoN saying, *“Maybe we should do more auditing”* [Site 6]. Interestingly the WN in the same site noted the challenges of objectively assessing the impact of PCSB:

“[If we were to] reflect back to senior management the benefits of what happens when somebody is dying ... you can’t have, you know facts and figures and checklists for things ... how do you measure quality of life at dying, it is subjective. Because what is happening for everybody is not just facts and figures, it’s emotional and it’s life changing and the effects and affects of death and dying in how somebody dies can be with somebody for a long time. And can effect how they interact and deal with people for a long time” [Site 6]

Benefits for patients and families

Moving to the benefits reported by participants, there was a clear theme of positive benefits for patients and their families, with specific reference to the **quality of care** received by patients, as seen in the following quote, *“We can give a far more dignified level of care, individual person-centred here, because we just don’t have the demands the acute sector have”* [WN, Site 3]. The positive benefit for patients and families was strongly linked to the ability of PCSBs to provide appropriate **care to people in their own areas/communities**. This was stated by many participants and is illustrated by the following quotes:

“I think [the benefit is] huge because the, what people often want when they’re dying is to be in their own homes, now if they can’t be in their own homes, they want to be close to their own homes because then their family can, you know spend time with them and ... I think it’s not such a burden on the relatives” [GP, Site 1]

“We’ll have a patient in the [site] and they can be in for one or two days and maybe longer and I think that’s, it gives people security. It gives people peace of mind. It

means families can be there, I mean most of these little units in the different hospitals throughout the country I'm sure the suites are private so people will enter by another door, they don't have to go through the main door of the hospital...it's sort of home from home really" [PCT member, Site 2]

"From a community perspective, I would see it as home from home, where they would receive a high level of skilled em personal care, eh, very much person centred and family centred ... That can only, that's only possible when we have the services and the facilities and the support of the palliative care consultant and the home care team, based in the hospital. [DoN, Site 3]

"For families you know they the physical location is you know, altogether ... it's at the end of the corridor, they have access to the area, they can come and go" [WN, Site 6]

The provision of **respite care** was also highlighted as a benefit for families, with the PCT member in Site 1 commenting, *"The respite situation as part of it and that is actually very, very important ... you know people going in for maybe a week or two weeks respite"*.

Benefits for staff

Within the context of the setting itself, a number of participants identified **positive impacts on staff**, as highlighted by the following quotes;

From the staff side, I suppose they learn an awful lot, sometimes the care is complex, sometimes it's very technical care in terms of medication and dosages and management and having to be creative, so they learn an awful lot from that" [DoN, Site 3]

"We've carried out a questionnaire to staff, lots of the extended care staff have enjoyed the learning and the em the I suppose the increased awareness and learning in palliative care" [PCT member, Site 5]

"It's very beneficial to the staff, it keeps them interesting, it keeps them motivated, it keeps their skills very highly up to date, because a lot of their other work would be older people services" [DON, Site 2].

These gains were not just limited to staff members involved in direct care provision. One participant noted that managers had had to develop skills in supporting staff to deliver palliative care saying:

"The managers would have to develop, helping staff to come to terms with that, or even helping staff to realise, because some people were like 'oh this is a palliative patient, this is an older person', to help them realise, they're our patients and we're able to look after them all. So that would have been a skill managers would have had to develop as well" [DON, Site 5]

Benefits for hospitals

From the perspective of the health care system more broadly, **the availability of the PCSBs in local settings was seen as a significant positive influence in freeing up beds within acute settings.** The WN in Site 3 commented that admission to a Level 2 bed *“keeps people out of acute sector, frees up those acute beds”*. This view is echoed in the following quote from a PCT member:

“There are so many instances of patients em, being in acute hospitals who no longer need acute hospital care but who can’t go home because they can’t look after themselves and em whose prognosis is, is kind of reasonably short ... to go down the kind of referral for nursing home path seems somewhat futile because their prognosis might be two, three months, and it might take two, three months to get the kind of funding approval for a nursing home so [PCSBs] are, you know really valuable in those situations em, in terms of not having people dying in acute hospitals ... it’s kind of an inappropriate use of hospital beds really” [Site 4].

Interestingly the DoN in Site 3 cautioned against seeing the reduction in pressure on or demand for beds in acute settings as the only benefit of PCSBs saying, *“it’s perceived in terms of keeping people out of acute care...the value of community hospital beds, but that’s not necessarily the same message as providing a person-centred care, end of life service”*.

Limitations of the PCSB system and areas for development

In addition to considering the benefits of PCSBs, participants were also asked to reflect on the limitations and areas for development evident in this level of palliative care provision and a number of themes were evident. **A number of practical limitations and challenges were noted such as the limited number of PCSBs available, the challenges of general resourcing and funding for PCSBs, as well as ongoing staffing and training demands. Importantly, training needs were discussed not just in relation to staff in the sites but also the GPs who support them.**

A further identified constraint reflected some of the issues noted earlier around **access to specialist supports**, with a number of participants noting the need for **out of hours support** in particular, as is illustrated by the following quote:

“I suppose the big deficit at the moment is not having weekend or out of hours cover...I could be depending on my senior nurse ringing around to the hospice and other places to get advice, to give then to [out of hours doctor service] at the weekend. Now I have to say that palliative care nurses are excellent but we did go through a phase that ... there wasn’t that scope for them to be in as often as you’d like” [DoN, Site 4]

Echoing the earlier discussion of the benefits of having specialist PC input on-site, some participants reported not having this facility as a limitation. It is worth noting that solutions posed by participants to the lack of such support, are associated with the risk of

inappropriate fragmentation or duplication of specialist palliative care services. For example, the DoN in Site 6 articulated a desire to develop a local CNS in Palliative Care role:

"It would be great if we could get funding for someone to do the Higher Diploma and develop CNS on site here. That would be fantastic. It just gives us I suppose em professional competence and em an educated member of the team, not to replace or to substitute what we're currently doing but to enhance it, and perhaps em you know just be a clinical leader within the team...and there's huge potential within the team for people to em aspire to that"

Another respondent favoured the idea of developing a local palliative care unit:

"We'd love to basically build on a wing here that would be designated totally palliative so we'd expedite those beds into a separate little unit... You could offer them to oncology, so you could use like chemo respites and radiotherapy respites so your typical mom whose burnt out from her chemo but doesn't want to be miles away ...wants to be near her kids, she could have her chemo and come down here, and use the free reflexology and the other therapies that are available here and just have a couple of nights sleep and whatever so, you could utilise the beds in that way, in the same kind of family ... You know we'd bring in, motor neuron, not just palliative cancer, motor neuron end of life or we've a couple of palliative who are COPDs and end stage coronary syndromes, Which wouldn't be your normal thinking of palliative" [WN, Site 3].

Specialist palliative care respondents posed an alternative vision for future developments:

"I feel would be the most appropriate model is a model whereby ... the kind of primary care is developed, is kind of provided by the Level 2 care facility and their employees you know and that they do have some extra training in palliative care and that they are just supported in doing that by the specialist palliative care team rather than it being the specialist palliative care team take the primary role in managing these patients ... I think there's potentially more, more value in em, in consulting and advising and providing educating to generalists to provide that care. In terms of kind of improving their skills in palliative care but also em, it's more feasible from a ... work force perspective ... I don't really think that specialist palliative care has the man power to do all that" [PCT member, Site 4]

A overarching theme reflected in the discussions of PCSB provision appeared to be that, despite the limitations and challenges, the provision of care was effective in these settings. However the tenor of the conversations reflected the sense that the effectiveness was ensured and the system was made to work, by the staff involved.

8. Case Study Discussion

To a large degree, the findings of the case study interviews supported the findings of the national survey. Although some similarities were present, there was marked variability in certain areas of the organisation and operation of the PCSBs.

Variability in the proportion of patients cared for with non-malignant disease was noted, but this did not appear to be related to the willingness of the organisations to provide such care. All sites reported that they would be open to providing care to patients with non-malignant disease. As discussed previously, this suggests that the variability may be due to other external factors such as referral practices and merits further exploration.

While the relative lack of formal processes governing admissions is associated with some advantage in that it allows for flexibility, it is also associated with a number of potential disadvantages. The process is so organic, it is difficult to obtain an objective view of demand and supply of beds. It is difficult to determine whether variability in allocation and function of beds is an appropriate response to local context, or whether it is a reflection of sub-optimal utilisation of the PCSB resource. These issues merit further consideration, including the possibility of developing a Palliative Care Admission and Management Model of Care to guide processes for referral, admission, integration with specialist palliative care services, management and discharge.

The stakeholders' opinion on the distinct value of the PCSBs was clear. Benefits were observed for patients, families, staff and local community. While patient and family benefits had been clearly noted in the national survey, additional detail was provided on the wider benefits for staff and community. Interestingly, the perspective 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, was voiced. 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 notable.

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. Patient experience can be difficult to capture for this type of healthcare as many patients cannot communicate easily, are experiencing distress or approaching the end of their lives. However, consideration should be given to how such obstacles might be overcome, as without some form of outcome measurement, organisations may not understand where they are falling short of patient or family expectations.

Additional information provided in the case study interviews relates to the relationship between SPC services and PCSBs. The value of, and indeed apparent need for, a close

working relationship between SPC and PCSB staff was clear and in many cases this relationship was one of the key factors in ensuring the effective provision of care. It appeared that geographical proximity enhanced the quality of that relationship. This raises the issue of integration of SPC and PCSB services and merits further consideration as to the optimal manner to achieve this. Linking services together into networks may result in an improved experience for patients, as well as a more efficient system overall. Networks are also more likely to have linked reporting and patient information systems. This not only allows clinicians working in different locations to access detailed patient information, but also allows the collation of data for research purposes, driving improvement in treatment for the future.

Ensuring adequate staffing is critical to the safe delivery of care; indeed, having sufficient staff to meet demand avoids the unnecessary costs associated with lower quality of care. Both the survey and case study data highlighted the need to consider workforce planning in a thorough and considered manner. However, particular challenges need to be considered before engaging in such a process with PCSB organisations:

- To make judgments about numbers of staff needed requires insight into the roles and competences of different staff groups (and these appear to vary considerably between localities). Basically, we need to know who does what, before we can judge how many of each are needed.
- Staffing requirements will also depend on the efficiency and effectiveness of processes used (and these also appear to vary between localities).

Therefore, there is a need to ensure that good quality data (human resources, quality and outcomes) acts as the cornerstone of effective staff planning and review. Staffing decisions cannot be made effectively without having good quality data on: patient mix (acuity/dependency), current staffing (establishment, staff in post), factors that impinge on daily staffing levels (absence, vacancies, turnover), and evidence of the effectiveness of staffing - quality/ patient outcomes/staff sensitive indicators. Consideration should be given to collecting such data.

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. It is perhaps not surprising, therefore, that some stakeholders consider that the best way forward for PCSBs is to behave more like SPC in-patient unit beds (e.g. to develop CNS in palliative care roles, to care for patients with greater complexity of need). However, such development would lead to duplication and over-use of the more resource-intensive services, as the provision of SPC in-patient unit beds has already been planned on a national basis. It is important that capacity is appropriately managed within the healthcare system to ensure that resources are targeted so that patients get the right care, in the right place in a timely manner. PCSBs should function at an intermediate level, providing care to patients with intermediate levels of palliative care need.

Finally, additional information on funding of PCSBs was provided that was at odds with the survey responses. The reasons for such a mismatch are not clear and may relate to the time interval between survey and interview. Only half of the organisations reported that funding was provided by the HSE. In the other three cases, supplementary funding was raised, fundraising and charitable donations. To support the case for further investment, accurate information on service funding and costs will be required going forward.

9. 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 team³, 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.

³ Consultant may be a Palliative Medicine physician or from another specialty, typically Medicine for the Elderly

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

10. References

- Ahmedzai, S. H., Costa, A., Blengini, C., Bosch, A., Sanz-Ortiz, J., Ventafridda, V., et al. (2004). A new international framework for palliative care. *European Journal of Cancer*, 40, 2192-2200.
- Bainbridge, D., Brazil, K., Krueger, P., Ploeg, J., & Taniguchi, A. (2010). A proposed systems approach to the evaluation of integrated palliative care. *BMC Palliative Care*, 9 (8).
- Canadian Hospice Palliative Care Association. (2006). *The pan-Canadian gold standard of home care: Toward equitable access to high quality hospice palliative and end-of-life care at home*. Ottawa, ON: Canadian Hospice Palliative Care Association.
- Cassel, B. J., Webb-Wright, J., Holmes, J., Lyckholm, L., & Smith, T. J. (2010). Clinical and financial impact of a palliative care programme at a small rural hospital. *Journal of Palliative Medicine*, 13 (11), 1339-1343.
- Centeno, C., Clark, D., Lynch, T., Centeno, J., Praill, D., De Lima, L., et al. (2007). Facts and indicators on palliative care development in 52 countries of the WHO European region: Results of an EAPC task force. *Palliative Medicine*, 21, 463-471.
- Dale, J., Petrova, M., Munday, D., Koistinen-Harris, J., Lall, R., & Thomas, K. (2009). A national facilitation project to improve primary palliative care: Impact of the gold standards framework on process and self-ratings of quality. *Quality and Safety in Healthcare*, 18, 174-180.
- Department of Health and Children. (2001). *Report of the National Advisory Committee on Palliative Care*. Dublin.
- Gold Standards Framework. (2011, September). *GSF*. Retrieved July 7, 2012, from Prognostic Indicator Guidance, 4th Ed.: <http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf>
- Guerin, S, & Hennessy, E. (2002). Pupils' definitions of bullying. *European Journal of Psychology of Education*, 17, 249-261.
- Hansford, P., & Meehan, H. (2007). Gold standards framework: Improving community care. *End of Life Care*, 1 (3), 56-61.
- Higginson, I. (2005). End of life care: Lessons from other nations. *Journal of Palliative Medicine*, 8(1), 161-173.
- Irish Hospice Foundation. (2011). *Primary palliative care in Ireland: Identifying improvements in primary care to support the care of those in their last year of life*. Dublin: IHF, ICGP, HSE.
- Khan, S. & VanWynsberghe, R. (2008). Cultivating the under-mined: Cross-case analysis as knowledge mobilization. *Forum: Qualitative Social Research*, 9 (1), Article 34.
- National Clinical Programme for Palliative Care (2014). *Glossary of Terms*. Dublin: HSE Clinical Strategy and Programmes Directorate.

- Schuurman, N., Crooks, V. A., & Amram, O. (2010). A protocol for determining differences in consistency and depth of palliative care service provision across community sites. *Health and Social Care in the Community*, 18 (5), 537-548.
- South Australia Department of Health. (2009). *Palliative Care Services Plan 2009-2016*. Government of South Australia.
- Sub-Group Area Consultative Committee. (2008). *Mapping the level of intermediate care in the HSE south*. Cork, Ireland: Health Service Executive.
- Vogt, W.P. & Johnson, R.B. (2011). *Dictionary of statistics and methodology: A nontechnical guide for the social sciences*. Thousand Oaks, CA: Sage.
- World Health Organization. (2002). *National cancer control programmes: Policies and managerial guidelines* (2nd ed.). Geneva: World Health Organization.

11. Appendices

Appendix A: Palliative Care Consultants Survey Methods and Findings

Methods

Participants and Sampling

An exhaustive purposive sampling method was used to whereby all palliative care consultants working in Ireland (n = 29) were invited to take part in an online survey. Overall 20 responses were received to the consultants' survey, representing a 69% response rate. Just under half of the participants (45%, n = 9) were based in the Dublin/Greater Dublin area, and the remaining participants were drawn from across the country. In addition 50% of the respondents (n = 10) were female.

Materials

A semi-structured survey was developed to gather information on the use of PCSBs in target organisations. As with the main survey the consultants survey was designed by the PCPWG subgroup. Questions including closed questions (e.g., Likert scale and Yes/No questions), and open-ended questions that offered an opportunity for brief comments. The survey gathered information on the number and provision of PCSBs, practice regarding the access to the beds, consultants' involvement in the governance and support of these beds, and finally the strengths, weaknesses, opportunities and threats evident in the provision of PCSBs. (The survey is available in Appendix E).

Data Analysis

The data collected were exported from Survey Builder into a Microsoft Excel file and from there into SPSS. The data were reviewed to identify and remove duplicates. Once the final dataset was established descriptive analysis was conducted to identify frequency of response to categorical data (e.g., yes/no questions, multiple choice questions, etc.) and free text questions were analysed using content analysis based on Guerin and Hennessy (2002).

Results

All participants reported that there were PCSBs in geographical region in which they provide services, however only 40% (n = 8) reported that they were involved in the formal governance of these beds. In comparison 80% of participants indicated that their organisation provided clinical services to PCSBs. Participants were asked to indicate their role in governance and responses were varied. The two most common levels of involvement noted were the development of policy related to the use of PCSBs and the provision of support/consultation to the team/staff responsible for PCSBs.

Just under one third of participants (n = 7) reported that there were formal arrangements in place to ensure that every individual referred to a PCSB was reviewed by a member of the palliative care team. An additional 45% (n = 9) reported that this only happened at the

request of the staff in the facility where the PCSBs were provided. The members of the palliative care team described as being involved in this care commonly noted included the community (home care) team and 'all members of the team'. Overall 45% of participants reported that members of the palliative care team are involved in decision making regarding admission to PCSBs.

As with the main survey, consultants completed a series of open-ended questions, examining strengths, weaknesses, threats and opportunities in the provision of PCSBs. In reporting the strengths of the system the most common themes were that PCSBs **free up specialist beds**, provided **an option for localised community care** (*'[they] allow patients to be discharged back to their local communities if home is not an option'*) and **provide a place for patients who are not suited for other placements**, as can be seen in the following quote:

They provide a cohort of beds for a group of patients who are unable to be placed at home or an alternative community environment and otherwise end up staying in acute hospital, which is inappropriate.

A number of themes emerged from comments on the weaknesses of the PCSB system. Common responses included the **lack of beds**, the **length of time to access** beds, the **lack of integration with the wider healthcare system** (*'Lack of local agreements to copper-fasten the working relationships between "specialist" and "Level II" providers. Organisations can operate in complete isolation*), a **lack of referral criteria** (*'No structure currently in place as to who should be admitted to these beds'*) and **inappropriate bed use** (*'Sometimes, GPs admit patients who are not palliative care patients to these beds'*).

Looking to the threats perceived to PCSBs, perhaps unsurprisingly **resourcing** was a major issue, with reference to both funding and staffing challenges. However participants also included comments relating to a **misunderstanding of PCSB purpose**, with comments including *'Families seeing it as a way to bypass the nursing home support scheme'* and *'That they are seen as a cheaper option for patients requiring level 3'*. Other practical threats reflected the weaknesses noted above and included a **lack of referral criteria** and **inappropriate bed usage**. Finally, respondents were asked to identify opportunities within the PCSB system. While the comments made were varied the most common responses stressed the potential for **more PCSBs** and **more flexibility** in the existing system.

Appendix B. Palliative Care Support Bed Provider Survey Questions

1. What is the name of your organisation?
2. What is your role within the organisation?
3. How many beds were there in your facility in 2011?
 - a. How many designated palliative care support beds were there in your facility in 2011?
4. How are the palliative care support beds in your facility funded?
 - a. Completely funded by the HSE
 - b. Partially funded by the HSE
 - c. Completely funded by the voluntary sector
 - d. Other (please provide details)
5. Are the designated palliative care support beds ring-fenced for use by palliative care patients only?
 - a. If the beds are not ring-fenced, what other use may the beds be put to?
6. Patients are admitted to palliative care support beds for different reasons. Please indicate how frequently patients are admitted to your facility for the following reasons:
 - a. Symptom control (rarely, sometimes, often, frequently, very frequently)
 - b. End of life care (rarely, sometimes, often, frequently, very frequently)
 - c. Respite (rarely, sometimes, often, frequently, very frequently)
 - d. Rehabilitation (rarely, sometimes, often, frequently, very frequently)
7. Are there any other important reasons why patients are admitted to your facility that are not included in the above
8. If yes, please describe
9. Approximately what proportion of patients admitted to palliative care support beds in your facility are admitted from the:
 - a. Community (0-24%; 25-49%; 50-74%; 75-100%)
 - b. Acute hospital setting (0-24%; 25-49%; 50-74%; 75-100%)
 - c. Palliative care units (0-24%; 25-49%; 50-74%; 75-100%)
10. What is the average length of stay of patients admitted to palliative care support beds in your organisation?
 - a. Less than one week
 - b. One-two weeks
 - c. Two-four weeks
 - d. One-three months
 - e. Three-six months
 - f. Six months-one year
 - g. More than one year
11. What proportion of patients admitted to palliative care support beds in your facility are discharged home? (0-24%; 25-49%; 50-74%; 75-100%)
 - a. What proportion of patients admitted to palliative care support beds in your facility die during the course of their admission? (0-24%; 25-49%; 50-74%; 75-100%)
12. What members of the multidisciplinary team (other than doctors, nurses and healthcare assistants) are available to provide care to patients admitted to palliative care support beds in your facility>

- a. Physiotherapist
 - b. Occupational therapist
 - c. Social worker
 - d. Chaplain
13. Other, please detail
14. Do you have access to bereavement support for families if necessary?
15. Has the number of palliative care support beds in your facility changed in recent years? If so, please detail e.g. increased, decreased, how many, why?
16. Are there plans to change the number of palliative care support beds in your facility? If so, please detail

About access to the palliative care support beds in your facility:

17. How many new patients have been admitted to the palliative care support beds in the 12 months from 1 Jan 2011 to December 2011?
- a. How many of those patients had a malignant diagnosis?
 - b. How many of those patients had a non-malignant diagnosis?
 - c. How many return patients have been admitted to the palliative care support beds in the 12 months from 1 Jan 2011 to December 2011?
18. Can patients who are under 65 years of age access palliative care support beds in your facility?
19. Does your organisation have the ability to care for patients with any of the following needs in the palliative care support beds in your facility?
- a. PEG feeding
 - b. Nasogastric feeding
 - c. Tracheostomy
 - d. NIPPY (non invasive positive pressure breathing/ ventilation)
20. Which of the following are available to patients who are admitted to a palliative care support bed in your facility?
- a. Bed in a multibedded ward
 - b. Single room
 - c. Single room ensuite
 - d. Relative's room
 - e. Relative's room ensuite
 - f. Access to kitchenette
21. Which of the following pieces of equipment are available to patients who are admitted to a palliative care support bed in your facility?
- a. Profiling bed
 - b. Pressure relieving mattress
 - c. Reclining chair
 - d. Oxygen
 - e. Suction machine
 - f. Syringe driver (e.g. Graseby MS-16A or McKinley)

About your facility's interactions with other services:

22. Who has the decision-making authority to admit a patient to a palliative care support bed in your facility. Please tick all that apply
- a. Patient's own GP
 - b. The doctor under whose care the patient will be admitted (e.g. geriatrician, GP)

- c. Director of Nursing (or his/her deputy)
 - d. Bed Manager of your facility (or his/her deputy)
 - e. Public health nurse
 - f. Member of the local specialist palliative care team
 - g. Other, please detail
23. Does the local specialist palliative care team provide care to patients admitted to the palliative care support beds?
24. If yes, please state whether the input of the specialist palliative care team is
- a. Routine (i.e. formal arrangements are in place so that every patient admitted to a palliative care support bed is reviewed by a member of the specialist palliative care team)
 - b. Only when requested by staff of the facility
25. Please indicate which members of the specialist palliative care team are available to visit patients in the palliative care support beds:
- a. Palliative care consultant
 - b. NCHD
 - c. Community specialist palliative care nurse (Home care nurse)
 - d. Specialist palliative care social worker
 - e. Specialist palliative care physiotherapist
 - f. Specialist palliative care occupational therapist
 - g. Specialist palliative care chaplain
 - h. Specialist palliative care advanced nurse practitioner

About governance

26. Who is the doctor responsible for the care of the patients admitted to the palliative care support beds?
- a. Patient's own GP
 - b. GP employed by the facility
 - c. Consultant geriatrician
 - d. Palliative medicine consultant
 - e. Other, please explain
27. Do you have an admissions policy detailing access to the palliative care support beds?
28. Do you have of the following policies in place within your organisation (note, these policies may not be separate documents but may all be contained within one policy relating to palliative care provision, if this is the case, please tick 'yes' to all options)
- a. Do Not Attempt Resuscitation
 - b. Communication with patients with life-limiting conditions/ breaking bad news
 - c. Care of the imminently dying patient
 - d. Feeding/ fluids at the end of life
29. Has your organisation conducted an audit relating to any aspect of the palliative care support beds in 2011?
30. If yes, please detail the subject of the audit(s)
31. Does your organisation formally seek feedback from patients or their families on their experience of the care provided in the palliative care support beds?
32. Have nursing staff providing care to patients in the palliative care support beds received specific education in palliative care in the last 2 years?

33. If yes, please specify which of the following courses were attended by nurses and what proportion of the total nursing staff number who work with patients admitted to the palliative care support beds attended the courses(s)
 - a. Short programme in palliative care (e.g. introduction to palliative care, communication skills training, pain and symptom management course)
 - b. Postgraduate course in palliative care (e.g. graduate certificate, diploma, MSc in palliative care)
 - c. Bereavement support course
34. Have doctors providing care to patients in the palliative care support beds received specific education in palliative care in the last 2 years?
35. If yes, please specify which of the following courses were attended by doctors and what proportion of the total doctor staff number who work with patients admitted to the palliative care support beds attended the courses(s)
 - a. Short programme in palliative care (e.g. introduction to palliative care, communication skills training, pain and symptom management course) [0-24%; 25-49%; 50-74%; 75-100%]
 - b. Postgraduate course in palliative care (e.g. graduate certificate, diploma, MSc in palliative care) [0-24%; 25-49%; 50-74%; 75-100%]
 - c. Bereavement support course [0-24%; 25-49%; 50-74%; 75-100%]
36. Have healthcare assistants providing care to patients in the palliative care support beds received specific education in palliative care in the last 2 years?
37. If yes, please specify which of the following courses were attended by healthcare assistants and what proportion of the total healthcare assistants staff number who work with patients admitted to the palliative care support beds attended the courses(s)
 - a. Short programme in palliative care (e.g. introduction to palliative care, communication skills training, pain and symptom management course) [0-24%; 25-49%; 50-74%; 75-100%]
 - b. Postgraduate course in palliative care (e.g. graduate certificate, diploma, MSc in palliative care) [0-24%; 25-49%; 50-74%; 75-100%]
 - c. Bereavement support course [0-24%; 25-49%; 50-74%; 75-100%]
38. Please comment:
 - a. What are the strengths of the palliative care support bed system?
 - b. What are the weaknesses of the palliative care support bed system?
 - c. What opportunities are there for the further development of the palliative care support bed system in the current healthcare system in Ireland?
 - d. What threats are there to the further development of the palliative care support bed system in the current healthcare system in Ireland?
39. Any additional comments

Appendix C: Note on Individual Interviews

In order to complement the case studies conducted in six sites around the country, it was decided to gather the views of local and regional managers in the health services with regards to the provision of PCSBs (also known as Level 2 Beds). The aim was to contextualise the findings from the case studies

Methodology

Participants & Sampling

A purposive sampling approach was selected whereby individuals who would be in a position to offer a managerial perspective on the PCSBs, and in particular their role and contribution to the general health service, were targeted for recruitment. A sampling frame was generated in collaboration with the Working Group. This list included individuals working in palliative care, geriatric care and general health settings, in both senior management and senior care positions, in acute hospital settings, units within the HSE and the Department of Health. In all 14 possible participants were identified for inclusion in this element of the research. The initial intention in the study was to conduct two focus groups with this sample, however this proved difficult to schedule. The decision was taken to revert to telephone interviews and ultimately only two participants indicated their availability to take part during the phase of data collection. These two participants represented management and direct care roles, as well as specialist palliative and general acute care setting expertise.

Materials & Procedure

An adapted version of the semi-structured interview schedule used in the case studies was used to guide the materials. In particular, the schedule examined participants' general views on PCSB, the nature of funding involved, the perception of PCSBs at higher levels of the health sector in Ireland, and their suggestions for the further development of PCSBs.

An initial invitation was issued to targeted individuals by email. Once the decision was made to revert to interviews the groups were contacted again with an invitation. In total three members of the group responded and two interviews were completed within the timeframe. Interviews were conducted by telephone or VOIP (Voice Over Internet Protocol, e.g., Skype™) to facilitate participants' schedules. Content analysis (Mayring, 2000; Guerin & Hennessy, 2001) was used to identify common responses within the interviews that would provide a context for or a broader perspective on the issue of PCSB provision.

Interview Findings

The findings report the key patterns identified in the interviews in relation to the key topics of discussion as described in the methodology.

Role and Contribution of PCSBs

There were a number of views expressed in relation to the role and contribution of PCSBs in the overall context of the health services. The role mentioned first by both participants was that PCSBs meet the needs of individuals where death is not imminent and there is a balance in the care needs in that the needs were not significant enough to require more advanced care but did exceed the support that would be available to the person in a home care context. As one participant reported, *"I think the key is ... if the person has, you know,*

nobody to go home to [or] where nobody can support them [then] they are in a better environment for care that allows them better um support." The second participant echoed this saying;

"the level two beds are really helpful when you have some patients who are, first of all, they are clearly not able to go home and not well enough to live at home and hire the amount of care that then can be provided at home for one reason or another, and secondly they have palliative care needs that are in excess of standard care needs"

An interesting point made by one of the participants was that these beds (like palliative care in general in their perspective) were more likely to be accessed by individuals with malignant conditions.

One contribution that was noted was the way in which the availability of PCSBs supported the discharge planning in large acute settings, with specification reference to the perception that this allowed families to prepare for the next stage in the journey. As the first participant noted:

"[PCSBs] supported ... discharged planning for us and end [of life] planning ... allows people to go home and people who ... eventually went in to hospice but the family needed time, you know, to get the much bigger picture ... if they weren't quite ready, they got devastating news, things are advancing quickly and then that allows a lot of time as well for them to be supported in another environment and then they may go home with medical management or with hospice support."

Another aspect of the role of PCSBs as related to discharge was noted by Participant 1 was to allow for time to prepare for appropriate care for people with palliative care needs, saying *"[PCSBs] gives you time to do that [prepare for discharge], It gives you time to get the beds and get the equipment, make your contact with you community nurses."*

The impact on the availability of specialist beds was also noted by the second participant who reported:

"In a [specialist palliative care unit] you have patients that are likely to die over the next month and for that reason you have to admit them, but people who are relatively stable but have higher care needs and are probably going to be stabilized would probably, usually, do much better in a level two palliative unit ... [this] would allow me to use that bed for maybe ten other people ... its a huge [knock on] effect for other users who would be trying to access the beds"

However it was also noted that there were limitations to the contribution that PCSBs can make, with specific reference made to ageing patients who may have higher support needs. Related to this the second participant referred to the fact that individuals receiving care in PCSBs may decline saying:

"After a period of time there [the patient] becomes uncontrolled or develops severe pain or develops something out of care need, it requires skills higher than a level two provision, and I think that's the difficulty in seeing into the future, you know you can't predict what's going to happen to [the patient]."

Another limitation, or perhaps challenge, which was noted by Participant 2 was the challenge of ensuring that staff involved in PCSBs had the correct skills for the care provided. However this participant felt that there was a lack of clarity in the skills required for PCSBs, as highlighted in the following quote:

"I think you have to ensure that staff are [skilled], you know, so if it is level two you have to make sure that they have level two skills ... that they have more than level one, you know, general medical nursing, whatever it is, skills. You know, they need to have specific palliative care ... They seem a bit hazy as to what they are required, to what the national council report on palliative care want, they would basically say somebody who has extra skills in the area, but they don't really quantify exactly what you need."

Perception of PCSBs in the health system and possible future developments

The perception of PCSBs was highlighted in a number of areas of the discussion, including direct comments on the views of the wider health service, and consideration of the funding model of these beds (with reference to the overall health budget).

In relation to the funding model for PCSBs both participants highlighted a number of funding models including both statutory and privately funded PCSB provision. Participant 2 noted in relation to funding for palliative care that *"if you could commit some of the money to go elsewhere in that last year of life to [PCSB] it would make an enormous difference to the care of people in their last year, I think, so I would see an enhanced dedicated palliative care budget as in the way forward"*. However this participant also expressed a concern that PCSBs would be seen as a cheaper alternative to level three (specialist) palliative care. Participant 1 referred in their comments to the need for an accurate estimate of cost/benefit associated with the PCSBs.

A theme that overlapped the consideration of the role of PCSBs and the perception of this level of care in the health services was the way in which these beds were seen as part of a continuum of care for people with palliative care needs. Participant 2 discussed the challenge of current care provision, with particular reference to the view that at present 25% of people who are dying engage with palliative care services. This participant saw PCSBs as playing an important role in the continuum of care:

"we can't possibly see 100% [of people who are dying], you know, and so level two is definitely going to have to come in there. Now not everybody actually needs level two, there are some people who can die peacefully in level one ... but it would be preferable if most people had level two experiences. How I would see it happening is specialist palliative care becoming a little more, um, educational and acting as a resource."

Interestingly in the course of their interview Participant 2 talked about the potential to develop level 2 home-based care. This participant felt strongly that home-based care needed to be an option whatever level of palliative care support is needed.

Discussion

A key point from the consideration of these two interviews is the extent to which they reflect points made in the case studies, including the importance of PCSBs in meeting the needs of patients, the extent to which these beds sit within a continuum of care, and the importance of training and skill development for staff involved in PCSBs.

Taking these two participants as representing some of the views evident in the broader health settings (given the fact that they themselves have very varied experiences of the health sector as detailed in the participants' section above), it seems to be fair to say that the views expressed are generally very positive. Nevertheless there are points made regarding the natural limits of PCSBs as the second level of care, the potential for challenges to arise based on patients' needs and the need for dedicated funding within the context of the wider health and palliative care budget.

Appendix D: Case Study Interview Schedule

General views

- Initial questions on the number of PCSBs and whether they are ring-fenced (to confirm the organisation's classification)

PCSB Governance (Allocation, funding and Management)

- Is there an admission policy for PCSBs? If so, what are the key aspects of the policy? If not are criteria for inclusion /exclusion in practice?
- Can you tell me about the governance of these beds? Who is involved in and responsible for the process of decision making regarding use of these beds?
- Are you aware of any particular patterns in the allocation of beds, for example what type or care (end of life, respite) and what type of conditions (malignant/non-malignant). Is equal access given to malignant/non-malignant conditions? AGE
- What way are the beds funded? In your opinion, in what way should they be funded?
- Have you any suggestions for changes to the allocation of PCSBs?

PCSBs Resource Utilisation

This will be examined in the context of settings where PCSBs are and are not ring-fenced.

- Can you describe the demand for PCSBs in your organisation/region/area?
- Are there particular pressure areas or groups in this regard?
- Are there any issues regarding turnover of these beds? NB under/over usage.
- Is there any service planning or development relating to these beds?
- Is there any review of or reporting in relation to usage? Who is involved in these reviews, are patients or their families involved?
 - Query re: Death reviews – do you review 'difficult' deaths or deaths in particular?
- What is the perception of PCSBs within the wider organisation? Or in the wider region (for PCT) - transfers to level 3 where there is a campus
- Does the organization have the capacity to provide a range of palliative care services within the community?

PCSBs Staffing and Training

- Are the staffing levels different/ same to staffing levels for other beds? (Explore RGN vs. Care Assistants).
- Are the staff competencies different/ same to other beds? (Explore RGN vs. Care Assistants)
- Are their training needs among staff involved in PCSBs?
- What is the access to SPC input? For PC team member what is your experience of providing supported

- What is your experience of support from the SPC team?
- Is there any engagement with other sectors relevant to PCSBs?
 - Prompt re geriatricians, primary care staff, volunteers/families/communities.

Impact of PCSB

- Do the beds offer distinct value to the healthcare system? In what way? If not – why is this?
 - In what way are these beds 'different' from other residential care beds?
- How do you assess the impact of these beds? What are the challenges of assessing impact?
- What are the implications of PCSBs for patients and/or families?

General evaluation of PCSB

- What are your views of PCSBs as a general palliative care resource for all the community?
- What are the general strengths and limitations of PCSB provision?
- What works well? Badly? Any suggestions for future development?

Appendix E. Consultant Survey

1. Name
2. Work Location
3. Are there palliative care support beds in the geographical area in which you provide specialist palliative care services?
4. Are you involved in the governance of palliative care support beds? (Please provide details if you answered 'yes')
5. Does your organisation provide clinical services to support the care of patients admitted to the palliative care support beds?
6. If you responded 'yes' above, please state whether the input of the specialist palliative care team is:
 - a. Routine (i.e. formal arrangements are in place so that every patient admitted to a palliative care support bed is reviewed by a member of the specialist palliative care team)
 - b. Only when requested by staff of the facility
7. Please state which members of the specialist palliative care team are available to provide care to those patients
8. Are members of your specialist palliative care team involved in the decision-making process around who is admitted to the palliative care support beds?
9. If you responded 'no' above, do you think that you ought to be involved in their governance? Please explain the reason for your response.
10. Please comment:
 - a. What are the strengths of the palliative care support bed system?
 - b. What are the weaknesses of the palliative care support bed system?
 - c. What opportunities are there for the further development of the palliative care support bed system in the current healthcare system in Ireland?
 - d. What threats are there to the further development of the palliative care support bed system in the current healthcare system in Ireland?
11. Any additional comments?

Report of the First National Palliative Care Support Bed Review, June 2014

Health Service Executive, Dublin

ISBN 978-1-906218-81-2