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## **Availability of palliative parenteral nutrition to patients with advanced cancer: a national survey of service provision**

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### **Statement of Authorship**

AG, JB, PJS and SJW assisted in the conceptualisation and development of the study. JB and SJW jointly developed the survey. JB and PJS assisted in the distribution of the survey. JB performed the analysis and drafting of the manuscript. PJS and SJW reviewed and provided editorial assistance of the manuscript.

### **Ethical Approval**

Keele University School of Pharmacy Research Ethics and Governance Committee.

Ethical Approval dated 19<sup>th</sup> March 2020. No approval number provided.

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## Biographies

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## **Availability of palliative parenteral nutrition to patients with advanced cancer: a national survey of service provision**

### **Abstract**

#### **Background & Aims:**

Patients with advanced malignancy who are unable to meet their nutritional requirements orally or enterally as a result of intestinal failure may be considered for parenteral nutrition support. Current United Kingdom (UK) guidance recommends that patients with 3-months prognosis and good performance status (i.e. Karnofsky performance status >50) should be considered for this intervention at home (termed Home Parenteral Nutrition; HPN). However, HPN is a nationally commissioned service by NHS England and Improvement which can only be initiated at specific National Health Service (NHS) centres so may not be easily accessed by patients outside of these centres. This survey aimed to identify current clinical practice across UK hospitals about how palliative parenteral nutrition is initiated.

#### **Methods:**

Clinical staff associated with Nutrition Support Teams at NHS Organisations within the UK were invited to complete an electronically administered survey of national clinical practice through advertisements posted on relevant professional interest groups.

#### **Results:**

60 clinicians responded to the survey administered between September and November 2020. The majority of respondents responded positively that decisions made to initiate palliative parenteral nutrition were done in alignment with current national guidance in relation to decision making and formulation of parenteral nutrition. Variation was observed in relation to the provision of advance care planning in relation to nutrition support prior to discharge, and the consideration of venting gastrostomy placement in patients with malignant bowel obstruction unsuitable for surgical intervention.

## Conclusions:

Adherence to current national guidance in relation to the provision of palliative parenteral nutrition is variable for some aspects of care. Further work is required particularly in relation to maximising the opportunity for the provision of advance care planning prior to discharge in this patient cohort.

## Key Points

- The provision of home parenteral nutrition to patients diagnosed with intestinal failure secondary to advanced cancer is recommended for patients with  $\geq 3$  months prognosis and good performance status.
- Home parenteral nutrition in the UK requires the patient to be registered for a home parenteral nutrition service which can only be performed by specialist centres.
- This survey of UK clinical practice identified that the provision of home parenteral nutrition to this cohort of patients is variable for some aspects of care.

## Introduction

Intestinal failure (IF) is defined as “the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth”.<sup>1</sup> In patients with advanced malignancy, defined as a cancer that is unlikely to be cured or controlled with treatment<sup>2</sup>, this often manifests as bowel obstruction, enterocutaneous fistulae, short bowel syndrome following surgical resection, dysmotility or severe mucosal disease.<sup>3</sup> All patients with IF require nutrition and/or hydration to some extent via a route that does not involve the gastro-intestinal tract<sup>4</sup>. This is typically given parenterally and termed “Parenteral Support”. However, some patients with intestinal failure of advanced malignancy may elect to not receive parenteral support and receive palliative care alone whilst patients with sub-acute obstruction may (or may not) receive parenteral support alongside oral intake to supplement their nutritional status.

The provision of palliative parenteral support (PPS) is currently considered controversial due to it being associated with both prolonged survival<sup>5</sup> and complications resulting in prolonged hospital admissions.<sup>6</sup> Ethical considerations surrounding whether the provision of parenteral nutrition is considered a core component of compassionate care, or a medical intervention add to the current controversy<sup>7,8</sup>. This is further confounded by systematic reviews into parenteral nutrition in palliative care currently being unable to determine evidence of clear benefit.<sup>9,10</sup>

Globally, there is an increasing trend in the provision of PPS,<sup>11-13</sup> with advocates arguing that the prolonged survival and facilitation of palliative chemotherapy outweighs the associated risk of complications. In the UK, the provision of PPS has historically been low compared to other comparable countries, primarily due to concerns surrounding the logistics of establishing a community PS service and its perceived risks.<sup>14</sup> More recently in the UK, the NHS has experienced considerable challenges regarding the supply of aseptically prepared injectable medicines and nutritional products (such as parenteral nutrition)<sup>15</sup>. These challenges have impacted the ability for clinicians to discharge patients with home parenteral support that has been tailored exactly to the patient’s needs. Instead, some patients where possible are being discharged with a combination of ready-made multichambered parenteral nutrition products and additional commercially available intravenous fluid products.

A further barrier in the context of the UK’s free at the point of access healthcare service is the high associated cost of palliative home parenteral nutrition therapy, with an incremental cost-effectiveness ratio of £176,587 per quality-adjusted life year.<sup>16</sup> This high cost is not solely related to the cost of the intervention, as the prescribing of PS necessitates patient review by a

highly specialised multidisciplinary team. Due to this, prescribing is only undertaken at a number of specialist IF centres<sup>17</sup> in the United Kingdom under the auspices of a National HPN Framework agreement between the Department of Health and commercial providers<sup>18</sup>. Despite this, the number of UK palliative HPS discharges has increased, evidenced by a 15% increase in patients registered for parenteral nutrition on the British Artificial Nutrition Survey with “malignancy” as the underlying diagnosis between 2005 and 2015.<sup>19</sup>

Collectively, this may have resulted in somewhat of a “postcode lottery” with respect to whether a patient has access to a specialist IF centre which is commissioned to provide home parenteral support.<sup>20</sup> If care is provided solely by the local hospital this may result in a varied approach to PS provision for patients with advanced malignancy. To date there are no published data exploring the extent to which such variation exists. Therefore, this survey aimed to identify current clinical practice across UK NHS hospitals providing or facilitating palliative home parenteral support.

## Materials and Methods

### Survey Design

The survey initially asked respondent’s information about their profession and level of experience, employing organisation and number of HPS/ palliative HPS for advanced cancer referrals in the preceding five years. No other data regarding participants were collected rendering the responses anonymous. Following this, the survey covered a range of topics relating to different aspects of a palliative HPS discharge from hospital. The four main areas covered were: Criteria used to identify suitable patients; clinical assessment scores (such as performance status assessments) used to inform patient selection; the palliative HPS discharge process at the centre; and the development of follow-up/monitoring plans. Questions were derived from the 2017 British Intestinal Failure Alliance Position Statement on the provision of Palliative Home Parenteral Nutrition<sup>14</sup>, with respondents asked to mark their level of agreement in relation to their organisation’s practice using a 4-point Likert scale. Questions relating to the logistics by which a patient may be discharged from the respondent’s organisation with palliative HPS were asked as binary yes/no questions. For statements relating to elements of practice, a 4-point scale was chosen for this as due to there being no neutral option, respondents are forced to form an opinion.<sup>21</sup> The BIFA position statement was selected to form the basis of the survey as it provided consensus recommendations for palliative HPS provision from expert UK clinicians. As the survey aims focused predominantly on identifying organisations discharge pathways questions focused on patient identification and PN formulation. The survey was administered electronically using Google Forms and conducted between September and November 2020.

Prior to survey release, the wording of questions were reviewed for grammar, clarity of phrasing and ambiguity by the authors, and piloted amongst members of the nutrition support team at the lead author’s hospital, no changes to the proposed survey were felt to be required.

### Recruitment

Target participants were healthcare professionals and members of multidisciplinary Nutrition Support Teams at NHS Hospitals across the United Kingdom, recruited via open invitations to participate in an anonymous survey of clinical practice that were posted on the website of relevant professional groups (British Society of Gastroenterology [BSG]; British Association of Parenteral and Enteral Nutrition [BAPEN] and the British Pharmaceutical Nutrition Group [BPNG]). Where possible, this was supplemented with an “all-user” email to the society’s member base by organisation’s communications team. The decision to capture experiences of all NHS organisations rather than specialist IF centres only was taken to identify if there were

variations in approach dependent on the organisation type and to identify whether there were existing established referral routes between non-specialist and specialist IF centres.

A favourable ethical opinion was received from the Keele University School of Pharmacy Research Ethics and Governance Committee.

## Data Analysis

The survey was administered electronically using Google Forms software with the results obtained analysed using descriptive statistics in Statistical Package for the Social Sciences (SPSS) Statistics 26. Statements relating to elements of clinical practice were analysed in the manner that. To assess correlation between whether the respondent's profession or organisation type and statements of practice, data were cross-tabulated and interrogated using Spearman rank correlation with a pre-defined significance level of  $<0.05$ . This statistical test was chosen as it as an accepted test to investigate the correlation of ordinal data<sup>22</sup>.

## Results

### Demographics

A total of 60 respondents answered the survey. The greatest number of responses received were from those who had undergone medical training (table 1), but with a variety of responses from other professions who comprise a nutrition support team. The median level of specialist nutrition experience amongst respondents was between 10 and 14 years (table 2). Geographically, there were widespread responses from throughout England, with a smaller number of responses from clinicians within Scotland and Wales. There were no responses received from clinicians based in Northern Ireland.

Table 1 Frequency of survey respondents by profession

Profession	Frequency	Percent
Consultant Gastroenterologist	29	48.3
Consultant Surgeon	1	1.7
Gastroenterology StR/Clinical Fellow/ Specialty Doctor	4	6.7
Nutrition Nurse	6	10.0
Nutrition Pharmacist	10	16.7
Dietitian	10	16.7

Table 2 Frequency of survey respondents experience in clinical nutrition

Years clinical experience	Frequency	Percent
0-3	9	15.3
4-9	19	32.2
10-14	12	20.3
>15	19	32.2
No response recorded	1	1.7

Respondents reported being from a broadly even range of NHS organisations, with 58.6% (34) being associated with one contracted to provide specialist adult severe IF services (Table 3).

Table 3 Frequency of organisation types represented by respondents

Organisation Type	Frequency	Percent
National referral centre for Intestinal Failure and/or Intestinal Transplantation	14	23.3
Regional referral centre for Intestinal Failure	20	33.9
Teaching Hospital, Non-referral centre for Intestinal Failure or Intestinal Transplantation	10	16.9

General Hospital, Non-referral centre for Intestinal Failure or Intestinal Transplantation	15	25.4
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Regarding geographical spread, responses were received from a variety of organisations throughout England, Wales and Scotland (Table 4).

*Table 4 Location of respondents*

<b>Location (National Institute for Health Research Clinical Research Network locality)</b>	<b>Frequency</b>	<b>Percent</b>
Yorkshire and Humber	10	16.7
North West Coast	9	15
Eastern	7	11.7
North West London	7	11.7
Greater Manchester	4	6.7
South London	4	6.7
West Midlands	3	5
Wessex	3	5
North East and North Cumbria	2	3.3
East Midlands	2	2
North Thames	2	2
East Scotland	2	2
West of England	1	1.7
Thames Valley and South Midlands	1	1.7
South West Peninsula	1	1.7
West Scotland	1	1.7
South Wales	1	1.7

### HPS Referrals

Respondents were asked report the number of HPS referrals sent or received by their organisation for all indications and where the intention was for palliative HPS due to advanced cancer in the previous five years (Tables 5 and 6).

*Table 5: Number of HPS referrals for all indications sent or received by respondent's organisation in the previous 5 years*

<b>No. HPS referrals for all indications in previous 5 years</b>	<b>Frequency</b>	<b>Percent</b>
1 – 20	15	25.0
20 – 50	10	16.7
50 – 100	6	10.0
150 – 200	7	11.7
200 – 250	3	5.0
250 – 300	6	10.0
>300	12	20.0
No response recorded	1	1.7

*Table 6: Number of HPS referrals for palliative HPS due to advanced cancer sent or received by respondent's organisation in the previous 5 years*

<b>No. HPS referrals for palliative HPS in previous 5 years</b>	<b>Frequency</b>	<b>Percent</b>
1 – 10	20	33.3
11 – 20	9	15.0
21 – 40	12	20.0
41 – 60	7	11.7
61 – 80	3	5.0
81 – 100	2	3.3
>100	4	6.7



No response recorded	3	5.0
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### Patient eligibility

Most respondents (51, 86.4%) reported that the decision to initiate palliative PS at their organisation was made by a multidisciplinary team comprised of the organisation's nutrition support team, palliative care team and the patient's oncologist. Reassuringly, 98.3% (58) respondents reported that for palliative parenteral support to be considered, the patient must have an established diagnosis of IF. For patients with a diagnosis of malignant bowel obstruction, 85% (51) respondents reported that it was usual clinical practice for the patient to be referred for general/colorectal surgical review to assess if an operative resolution would be feasible prior to initiation of PS. Conversely, the consideration of venting gastrostomy alongside HPS was less common, with only 19.4% (12) respondents reporting that this was considered usual clinical practice within their organisation.

With regard to the assessment of performance status, the Karnofsky Performance Status scoring tool<sup>23</sup> was reported to be the most commonly used scoring tool, with 88.3% (53) respondents reporting its use within their organisation to assist in identifying patients most likely to benefit from palliative HPS. Conversely, the Eastern Cooperative Oncology Group (ECOG) performance status score<sup>24</sup> was reported to be used in 53.3% (32) of respondent's organisations.

### Palliative PN Discharge Arrangements

Logistically, 65% (39) respondents reported that patients do not need to be transferred to their local adult severe IF centre to enable discharge on palliative PS. 31.7% (19) organisations reported that HPS discharges at their organisation are facilitated remotely by their local adult severe IF specialist centre whilst 40% (24) respondents reported that their organisation provided remote HPS discharge pathways to other local organisations.

Regarding certain aspects of the palliative discharge process, the responses to each statement are described in Table 5.

Table 7: Responses obtained with regard to palliative discharge processes

Statement	Frequency (Percent)				
	Strongly Disagree	Disagree	Agree	Strongly Agree	Non-Response
Patients are provided with clear Advance Care Plan	2 (3.4)	26 (44.1)	25 (42.4)	2 (3.4)	5 (8.3)
Patients/Family are encouraged to learn connection/disconnection of intravenous therapy	1 (1.7)	9 (15.3)	28 (47.5)	18 (30.5)	4 (6.7)
Organisation utilises Multichambered Parenteral Nutrition products where possible to speed up discharge	1 (1.7)	7 (11.9)	22 (37.3)	25 (42.4)	5 (8.3)
Clear communication with all stakeholders prior to discharge		8 (13.6)	32 (54.2)	14 (23.7)	6 (10.0)
Organisation takes all reasonable efforts to reduce burden of HPS	1 (1.7)	8 (13.6)	24 (40.7)	22 (37.3)	5 (8.3)
Clear, patient-specific action plan created prior to discharge	4 (6.8)	27 (45.8)	19 (32.2)	4 (6.8)	6 (10.0)
Patients are provided with a copy of the action plan on discharge	4 (6.8)	26 (44.1)	19 (32.2)	3 (5.1)	8 (13.3)
Patients who survive >3 months receive standard HPS monitoring		11 (18.6)	26 (44.1)	19 (32.2)	4 (6.7)

With respect to the differing opinions of professions relating to the discharge process questions, the correlation matrix presented in table 8 shows variation with respect to advance care planning and action planning surrounding HPS withdrawal non-medical professionals reported this occurring less frequently. However, there were no significant correlation between medical/non-medical professional groups and their response to the survey.

Table 8: Correlation matrix showing median response for medical and non-medical respondents

Statement	Modal Response by Profession		Spearman Rank Correlation	Significance (p)
	Medical Professional (n=33)	Non-Medical Professional (n=26)		
Patients are provided with clear Advance Care Plan	Agree	Disagree	-0.084	0.544
Patients/Family are encouraged to learn connection/disconnection of intravenous therapy	Agree	Agree	-0.058	0.673
Organisation utilises Multichambered Parenteral Nutrition products where possible to speed up discharge	Strongly Agree	Agree	-0.108	0.431
Clear communication with all stakeholders prior to discharge	Strongly Agree	Agree	-0.213	0.18
Organisation takes all reasonable efforts to reduce burden of HPS	Agree	Agree	-0.322	0.119
Clear, patient-specific action plan created prior to discharge	Agree	Disagree	-0.240	0.08
Patients are provided with a copy of the action plan on discharge	Agree	Disagree	-0.263	0.06
Patients who survive >3 months receive standard HPS monitoring	Strongly Agree	Agree	-0.175	0.197

When looking at responses to questions surrounding discharge processes by organisation type there are less clearly defined variations in practice between specialist and non-specialist organisations (Table 9). When considering the correlation between the respondents' organisation type and level of agreement with the statements, there were no significant correlations.



Table 9: Correlation matrix showing median response by respondent's organisation type

Statement	Modal Response by organisation type				Spearman Rank Correlation	Significance
	National SIF Centre (n=14)	Regional SIF Centre (n=20)	Teaching Hospital (n=10)	General Hospital (n=16)		
Patients are provided with clear Advance Care Plan	Agree	Agree	Agree	Agree	-0.008	0.953
Patients/Family are encouraged to learn connection/disconnection of intravenous therapy	Agree	Agree	Agree	Agree	-0.154	0.261
Organisation utilises Multichambered Parenteral Nutrition products where possible to speed up discharge	Agree	Strongly Agree	Agree	Agree	-0.29	0.33
Clear communication with all stakeholders prior to discharge	Strongly Agree	Strongly Agree	Agree	Agree	-0.020	0.559
Organisation takes all reasonable efforts to reduce burden of HPS	Agree	Agree	Agree	Strongly Agree	0.082	0.883
Clear, patient-specific action plan created prior to discharge	Agree	Disagree	Disagree	Disagree	0.090	0.522
Patients are provided with a copy of the action plan on discharge	Disagree	Disagree	Disagree	Agree	0.317	0.23
Patients who survive >3 months receive standard HPS monitoring	Agree	Strongly Agree	Agree	Strongly Agree	-0.013	0.925

## Discussion

A key theme highlighted by the survey responses was the wide variation in reported approach to communication of advance care planning in relation to palliative PS to both the patient and their wider clinical support teams. This is underpinned by the responses suggesting that in many cases, patients are discharged without a written advance care plan / action plan. This may be a result of there being no standardised, palliative PS specific advance care plan template. Historically, a similar theme in general palliative care provision was identified in the early 2000s which resulted in the development and introduction of the Gold Standards Framework<sup>25</sup>. Analysis of this intervention to date has shown significant improvements in the processes associated with and quality of palliative care service provision.<sup>26-28</sup>

Due to the highly technical and multidisciplinary nature of PS provision, it is associated with high treatment costs<sup>16</sup> and in some instances can be burdensome to the patient and/or their family<sup>29</sup>. For these reasons, it is extremely important that patients who are offered such an intervention are carefully selected and allowed the opportunity to make an informed decision about whether the intervention is suitable for them. This survey found that multidisciplinary working was common throughout the UK, with patients suffering from malignant bowel obstruction often being reviewed for an operative resolution prior to discharge with palliative PS.

Many respondents reported that their organisation favoured the use of multichambered parenteral nutrition products and encouraged the patient or their family to administer HPS where possible. These findings may be as a result of the issues faced by UK HPS providers relating to the lack of aseptic production capacity and shortage of suitably trained nursing staff<sup>15</sup>. Being able to use multichambered parenteral nutrition products and self-administration negates these potential delays and could result in a timelier discharge for the patient.

A large proportion of respondents reported that in patients discharged with PS for malignant bowel obstruction, a venting gastrostomy is not routinely considered. Although not without its own risks, placement of a venting gastrostomy can provide symptomatic relief of nausea and vomiting for a patient whilst also negating the need for repeated nasogastric drainage tube insertions.<sup>30</sup> A recent qualitative study of patient's experiences of this intervention in the UK identified that patients do not regret having such an intervention, and experience psychosocial and symptomatic benefit.<sup>31</sup> However, placement of a venting gastrostomy may not be appropriate in all patients due to co-morbidities such as peritoneal tumour burden or ascites<sup>32</sup>, or patients themselves may decline placement of a venting gastrostomy tube in favour of nasogastric drainage.

The use of a scoring tool to assess a patient's performance status prior to initiating therapy appears to be in widespread clinical use, with parenteral support only being offered to those with good performance status. Both the Karnofsky and ECOG performance status scoring tools were designed to assess fitness of patients for systemic anticancer therapy and to predict prognosis in advanced malignancy.<sup>33</sup> Both scores estimate the patient's ability to perform certain activities of daily living (ADLs) without the help of others, The Karnofsky score ranges from 10 (moribund) to 100 (no limitations on ADLs) while the ECOG ranges from 0 (normal activity) to 4 (bedridden). Current guidance surrounding the provision of palliative HPS recommend that these tools be used to assist clinicians in identifying patients who are likely to benefit from the intervention.<sup>3</sup> Although use of performance status assessment is useful, it does not provide the full picture as to how a patient will respond to palliative PS. One centre in the UK has published a retrospective analysis of their palliative PS dataset which identified the biochemical marker of inflammation CRP as being a significant predictor of survival, with serum albumin also being of borderline significance.<sup>34</sup> Other predictors of survival reported within the same analysis were white cell count and serum sodium. High HPS volume and potassium requirements were associated with a worsening prognosis.<sup>34</sup> In a similar vein to this, an Italian centre developed a tool which utilises a composite of performance status and tumour activity to predict a patient's prognosis.<sup>35</sup> The use of tools like this do not appear to be currently in widespread practice within the UK, and no prognostic tool like this appears to have been validated for use in a UK patient cohort.

### **Strengths and Limitations**

This appears to be the first survey of how palliative parenteral nutrition is approached across NHS organisations in the UK and obtained response from a range of NHS organisations throughout the UK.

As the survey did not include the opportunity for respondents to provide "free-text" responses to the survey, there was no opportunity to obtain a qualitative component to the questions asked which would have provided additional context to the responses received. As a result of recruitment being performed using open recruitment methodology through professional networks, it is not possible to determine how representative of the national picture the results obtained are. The professional groups engaged included two single-discipline interest groups

BPNG (Pharmacy) and BSG (Gastroenterology) and one multidisciplinary interest group (BAPEN). It was thought that this would allow for sufficient notification of the survey to all interested parties. Engagement of single-discipline professional interest groups for nutrition nursing and dietetics may have further improved recruitment from members of these professional interest groups. This survey was also distributed in September – November 2020 during the Covid-19 pandemic potentially impacting on the number of clinicians able to set aside time to complete the survey due to competing clinical demands. These factors undoubtedly present a potential limitation of non-response bias in the results presented. Furthermore, this survey recruited small numbers from Wales and Scotland with no representation from Northern Ireland limiting the generalisability of the results to organisations based outside of NHS England. Despite this, the paper presents the first snapshot of how English NHS organisations approach palliative parenteral support and has identified some key areas where there is variation in systems.

A further limitation was the lack of internal consistency testing of responses to questions asked, however, no issues with question phrasing were identified during the piloting process.

### **Implications for Practice**

Identified areas for future work include strengthening guidance for clinicians regarding patient selection, parenteral regime selection/formulation and discharge processes and the potential for the development of communication aids to support both patients and their supporting clinicians. Communication tools to assist decision making consultations have been widely employed in other specialties and enhance shared decision making<sup>36 37</sup>. For example, the development of materials to help clinicians in discussing the risks and benefits of HPS as an intervention may assist patient's decision whether to agree to the intervention. Additionally, the development of a conversation guide may assist clinicians in creating advance care plans for patients discharged with palliative HPS. Introduction of materials such as these as part of routine clinical practice could provide a marked benefit in not only patient care (through providing a written, agreed action plan of how decisions relating to their future nutritional care will be made), but will support the patient, their family and clinicians involved in the patient's treatment to provide safe and effective care.

### **Conclusion**

Adherence to /awareness of guidance published by the British Intestinal Failure Alliance appears to be variable across NHS organisations. Further work is required particularly in relation to maximising the opportunity for the provision of advance care planning prior to discharge in this patient cohort.

### **Conflict of Interest Statement**

The authors have no conflict of interest to disclose.

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**Legends:**

Table 1: Frequency of survey respondents by profession

Table 2: Frequency of survey respondents experience in clinical nutrition

Table 3: Frequency of organisation types represented by respondents

Table 4: Location of respondents

Table 5: Number of HPS referrals for all indications sent or received by respondent's organisation in the previous 5 years

Table 6: Number of HPS referrals for palliative HPS due to advanced cancer sent or received by respondent's organisation in the previous 5 years

Table 7: Responses obtained with regard to palliative discharge processes

Table 8: Correlation matrix showing median response for medical and non-medical respondents

Table 9: Correlation matrix showing median response by respondent's organisation type