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Pilot Testing of the European Association for Palliative Care (EAPC) Basic Dataset

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Abstract:	Background: Inadequate description of patients with cancer receiving palliative care in research studies often leads to results having limited generalizability. The need to standardize the description of the sample led to the development of the European Association for Palliative Care (EAPC) Basic Dataset consisting of 31 core demographic and disease-related variables, divided between a patient form and a health care personnel form. Aim: To pilot-test the dataset to check acceptability, look for possible sources of errors or shortcomings, and identify possible needs for changes. Design: International multi-centre pilot study at 9 study sites in 5 European countries. Mixed methods were used. Setting/Participants: Adult cancer patients and staff in palliative care units and hospices. Results: 191 patients (544 screened) and 190 health care personnel participated. Median time for completion was 5 minutes for patients, 7

	for health care personnel. Ethnicity was the most challenging item for patients. Health care personnel found weight loss, principal diagnosis, additional diagnoses, and stage of non-cancer diseases difficult to respond to. Registration of diagnoses will be changed from ICD-10 codes to a predefined list. Weight loss and stage of non-cancer diseases will be removed. The pilot study has led to minor rewording of some items, improvement in response options, and shortening of the dataset to 29 items. Conclusion: Pilot testing of the first version of the EAPC Basic Dataset confirmed its acceptability. The testing has led to improvements with regard to clarity and more suitable response options. The new version is now subject to further testing.

Pilot Testing of the European Association for Palliative Care (EAPC) Basic Dataset

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What is already known about the topic?

There is a need to standardize the description of a palliative care cancer patient population.

The EAPC Basic Dataset has been developed to standardize research reporting.

The dataset is a combination of patient reported outcome measures (PROMs) and disease related variables recorded by health care personnel.

What this paper adds?

The first version of the EAPC Basic Dataset has been quality assured through thorough and systematic pre-testing in the two target groups, patients and health care personnel, across five European countries.

Pilot-testing has led to a shortened dataset with better comprehensibility.

Implication for practice, theory or policy

The resulting EAPC Basic Dataset is an international, consensus-based, quality assured tool that may increase external validity of research results.

Introduction

Are these findings relevant for my own patients? This is a question all clinicians should ask after having read a report on a clinical study within their field. Palliative care is no exception, and palliative care populations are even more heterogeneous than in many other areas of medicine. Within the palliative care cancer population, differences in patient characteristics such as cancer diagnosis, disease status, symptoms, physical functioning, cancer-directed treatment, and estimated survival, as well as inequality in service models used, are a major concern when considering both applicability and generalizability of research findings [1-5].

Four literature reviews have examined how palliative care populations were described in research reports [6-9]. All four concluded that the populations were inconsistently and insufficiently described. The authors highlighted the need for a set of common descriptors to be used when reporting sample characteristics, a need also acknowledged in several other publications [10-14].

As a response to this, the European Palliative Care Research Centre (PRC) [15] in collaboration with the European Association for Palliative Care Research Network (EAPC-RN) [16] and the EU-funded PRISMA project [17] launched a project to develop and reach consensus on a basic set of variables to describe a palliative care cancer population. Through an international Delphi process of five rounds, consensus was reached on a set of 31 core variables (the EAPC Basic Dataset) to be used to describe a palliative care cancer population in research, and on how the variables should be measured and recorded (Figure 1) [18].

The aim of the present study was to pilot test the EAPC Basic Dataset in palliative care cancer patients and health care personnel to assess its acceptability, comprehensibility, and feasibility, and to use this information to adapt the dataset if needed.

Methods

Study design

This was an international multi-centre study conducted at nine study sites in five European countries; Norway (5), France (1), Italy (1), Ireland (1), and the UK (1), using pre-testing survey procedures combining quantitative and qualitative methods [19].

The centres were recruited through an open invitation presented at palliative care conferences, and from established collaborative research networks. Each centre contributed a minimum of 15 patients to the study.

Data were collected in the period September 2015-December 2016.

Translation

The first version of the EAPC Basic Dataset was developed in English. Translation into the native language was performed in France, Norway, and Italy. The translation process involved one forward translation from English into the target language by a translator with medical background, good command of English, and the target language as his/her native language. The translated version of the dataset was then checked by two independent persons fluent in the target language and with good knowledge of English, and consensus was reached in case of incongruence. Following the translation, the dataset was completed by a small sample of the target population to check comprehensibility.
Two other documents were translated in the same way; 'Pilot testing the EAPC Basic Dataset: structured interview guide' and 'Guidelines for using the EAPC Basic Dataset'.

Participants

Participants for the pilot testing were

1. Patients admitted to palliative care units and hospices. All patients admitted to the unit were screened. Patients were eligible for the study if they had incurable cancer, age ≥18

years, and the ability to give informed consent. Patients who fulfilled the inclusion criteria, but did not speak the language in question, were excluded.

2. The patient's responsible health care provider (physician and/or nurse).

Study measures

With the aim to assess acceptability, comprehensibility, and feasibility of the EAPC Basic Dataset, the following information was collected:

1. Non-participating patients

Age group, gender, diagnostic group, and the Australia-modified Karnofsky Performance Scale (AKPS) [20] score were recorded for all non-participating patients. The reason for not participating was noted, using predefined categories.

2. Included patients

After the included participants had read and signed the consent form, they were asked to complete the EAPC basic dataset (patient form), in paper form, followed by a standard structured interview. To explore how participants perceived each item, they were asked whether the question was difficult to respond to, if it was annoying, confusing or upsetting, if the response options were suitable, or if they had any other comments.

By the end of the interview, the participants were asked about layout of the form, if any items were irrelevant, and if the sequence of items was appropriate. The time for completion and need for assistance were recorded. Only one study entry per patient was allowed.

3. Health care providers

The responsible health care provider (physician and/or nurse) was asked to complete the EAPC basic dataset health care personnel form, on paper, followed by a structured interview asking if the items were difficult to respond to, if the response options were suitable, or if they had other comments. Further questions were related to layout, perceived relevance of items, and if the sequence of items was appropriate. Information about the health care provider's age, gender, profession, and years working in palliative care was recorded, and if assistance had been needed to complete the form.

Data analysis

Data were entered into an online database by local study coordinators, and qualitative data translated into English. Analysis was by mixed methods; quantitative data were analyzed using descriptive statistics, and qualitative data using content analysis. Decisions to change, add, delete, or reword items were made by two of the authors (KRS and DFH).

Ethics and consent

Application for ethical approval was sent to the Regional Committee for Medical and Health Research Ethics (REC), North Norway. Due to the nature of the study approval was not needed, except for the screening process and for recording information about patients who were not included. For the latter purpose, dispensation from confidentiality was granted (11th June 2015, 2015/1056/REC North). The master protocol was also approved by the institutional review board at St. Olavs Hospital, Trondheim University Hospital. Each country or site ensured local research governance approval. Patients gave written informed consent.

Results

Screening

A total of 544 patients were screened; 353 did not participate or were excluded. Table 1 presents recruitment, characteristics of the non-participating patients, and the reasons for not participating. The most common reasons given were ‘too unwell’ (26%), ‘not advanced cancer’ (18%), and ‘unable to give informed consent’ (13%).

Seven of the nine participating study centres screened potential participants. The remaining two centres recruited per convenience. One of the centres did not have access to interviewer on a daily basis; the other was a home care service. There were great differences in the ratio included/screened, ranging from 0.2 to 1 between centres.

Pilot-testing:

Included patients

All together, 191 patients participated, from Norway (n = 90), France (n = 45), Ireland (n = 21), Italy (n = 20) and the UK (n = 15).

Patient characteristics

The patients' mean age was 67.6 years, median 69 (range 25-90). Sixty-five percent were ≥65 years old. The most common cancer group for included patients (n=172) was cancer in; digestive organs (ICD-10 codes C15-26) 24 %, followed by breast (C50) 15%, respiratory and intrathoracic (C30-39) 14%, male genital organs (C60-63) 13 %, and lymphoid and haematopoietic malignancies (C81-96) 9%; 79 % had metastatic /disseminated disease, and 36 % were not receiving anticancer therapy. Seventy-five percent had performance status ≥60. Further details are given in Tables 2 and 3.

Patient responses

Median time to fill in the patient form was 5 minutes (range 1-60 minutes). One hundred and twenty-eight patients completed the form without assistance. Fifty-five patients required assistance; of these 46 received assistance from health care providers, seven from a family caregiver or friend, and two from a family caregiver /friend and health care provider. In five cases, the form was filled in by health care providers alone, and in two by a family caregiver or friend.

Table 2 shows the number of responses for each variable in the patient part of the dataset and missing data for each item. The most challenging variable for patients was ethnicity. The question 'What is your ethnicity?' was answered by 127 patients (66%), out of whom 108 stated their nationalities. Thirty-two patients found the question difficult to respond to, 11 found the question annoying, confusing, or upsetting, and 37 gave other comments (Figure 2), the most common being 'don't understand the word ethnicity'. Figure 2 shows the participants' responses to the standardized questions asked by the interviewers, and Table 2

participants' comments and suggestions for improvement. Based on these findings, ethnicity will be replaced with an open question about nationality in some countries, others will find a predefined list appropriate, while yet others will have to exclude this variable.

Many patients had the same comments for more than one symptom (Table 2). One of the remarks was the order of symptoms on the form. Both patients and health care providers recommended grouping together related symptoms.

Age and gender were the only variables without any form of modifications. Living situation and highest completed level of education have been modified as shown in Table 2.

Health care professionals

Health care professional characteristics

One hundred and ninety health care professionals gave information about themselves: Mean age was 42.7 years; 165 were females; 103 were physicians, and 84 nurses. The median working time within palliative care was six years (range 0-40). Some of the health care professionals probably filled in more than one form.

Health care professional responses

Median time to fill in the health care personnel form was 7 minutes (range 2 -195).

Sixteen health care professionals needed assistance to complete the health care personnel form, most commonly nurses needing information from physicians about ICD-10 codes, medications, performance status, or cognitive functioning.

Five variables were perceived as challenging in the health care personnel part, as based on completion, missing data, and comments: principal diagnosis, date of the principal diagnosis, additional diagnoses, stage of the non-cancer disease, and weight loss. Figure 2 shows the participants' responses to the standardized questions asked by the interviewers, and Table 3 sums up the comments.

- The principal and additional diagnoses

The health care personnel were supposed to fill in the principal diagnosis using an ICD-10 code. ICD-10 codes were used in 59% of the cases, and the type of cancer using free text in 24%. The cancer diagnosis was missing in 11%, while 6% used various other codes. Eighty-seven participants found the item difficult to respond to; the most common reason was, 'don't know the ICD-10 code' (Table 3). Among the recommendations for improvement was to make a standardized list of cancer diagnoses. As a result, ICD-10 codes will be replaced by a standardized list based on ICD chapters and blocks (Table 3).

Some of the same challenges applied to the additional diagnoses. ICD-10 codes were used in 83 cases (46 were non-cancer diagnoses, 29 were cancer or metastases, and eight ICD-10 Z or R codes). The disease was written as text in 25 cases. The result will be to replace the ICD-10 code by a standardized list (Table 3).

- Stage of the non-cancer disease

Fifty-five patients were distributed between the following categories: New York Heart Association (NYHA) Functional Classification class I (19), II (2), III (3), IV (1); Global Initiative for Chronic Obstructive Lung Disease (GOLD) stages 1 (10), 2 (4), 3 (1), 4 (4), and Functional Assessment Staging (FAST) scale, 1 (10), 2 (19). The response distributions with dominance of the first stages arose suspicion about incorrect answers. Sixty-four health care professionals reported difficulties completing this item, and the most common comment was; 'don't know the classification systems' (Table 3). Several participants proposed to exclude this variable, or make it optional. This has resulted in removal of the variable.

- Date of the principal diagnosis

Date of the principal diagnosis was reported as intended in 138 cases (72%) with month and year; 46 with only year, and seven missing. Thirty-nine found the item difficult to respond to, and the most common reason was 'hard to find'. No proposals for change were received. The variable will remain unchanged.

- Weight loss

Only 38 participants (20%) filled in weight loss in percentage and duration of weight loss in months. This item was clearly the most difficult one to respond to (Figure 2). Comments are given in Table 3. As a consequence, the variable has been removed.

Date of the principal diagnosis, and performance status were the only variables without any form of modification. The rest of the variables have been modified as shown in Table 3.

The layout of the forms was suitable for the majority; however, there were a few comments that it was hard to read the black numbers and text on the dark green background. The green colour will consequently be changed to a brighter one.

Discussion

The EAPC Basic Dataset has been pilot-tested by all together 381 individuals from the target groups, in five different European countries. Our results show that palliative care cancer patients and health care professionals are willing and able to use the dataset. The majority of study participants reported to understand the instructions and questions. The following five variables were perceived as challenging: ethnicity, principal diagnosis, additional diagnoses, stage of the non-cancer disease, and weight loss. Consequently, the pilot-testing has led to changes in the first official version of the dataset.

Feasibility

Median time to fill in the form was 7 minutes for health care personnel and 5 minutes for patients, and 67% of the patients filled in the form alone. The acceptable time expenditure and the fact that two-thirds of the patients completed the form without assistance, support the feasibility of the dataset. However, many palliative care cancer patients were unable to participate, as only 191 out of 544 were included. The most common reason for not participating was being too unwell, confirming that many palliative care cancer patients are frail. The non-participants were slightly older and had a lower mean AKPS score than the participants. However, we believe it is also possible to use the EAPC Basic Dataset for some of these patients. The patient part can be completed by a caregiver, and rating of symptoms based either on input from the patient or by observer assessment as recommended in Guidelines for using the ESAS-r [21].

Changes in the EAPC Basic Dataset

The fact that this pilot study had almost 400 participants gives reason to believe that the resulting changes are well founded and will give a better version of the dataset. Five variables were found to be challenging. Two of these, ethnicity and weight loss, were variables on which consensus on method of assessment was not achieved in the Delphi process. For the purpose of the pilot testing, the research group based their choice of assessment method on comments from the Delphi panel [18]. However, the pilot testing showed that ethnicity is a tricky variable, requiring decisions at a national level about whether or how to include this item. For instance, France has a law prohibiting individuals being enumerated by ethnicity without their consent or a state committee waiver.

The use of ICD-10 for principal and additional diagnoses was also problematic. To improve the next version, individual coding will be exchanged with a standardized list based on the ICD structure. This may be more sensible, as researchers are accustomed to reporting diseases in wider categories. Hopefully also clinicians will find this solution more agreeable and less time consuming.

The pilot testing also resulted in some adjustments in response options, both by adding new categories and by giving the option to specify in free text when answering 'other'. Relevant symptoms in the patient form have been grouped together, based on feedback from both patients and health care providers.

Strength and limitations

All nine study sites had interviewers without any connection to the development of the EAPC Basic Dataset. By using a standardized interview guide we tried to minimize interviewer bias.

Our study has some limitations. The fact that the translation was not performed according to the EORTC translation guidelines [22] may present a problem. The reason for deviating from these guidelines was that many of the variables within the dataset, and especially the PROMs, originate from internationally established and validated tools and manuals such as the Edmonton Symptom Assessment System revised (ESAS-r) [23], the Australia-modified Karnofsky Performance Status scale (AKPS) [20], and ICD-10 [24], and were taken from authorized translations. The additional items concern objective information only.

Screening was not performed at all participating centres. There were big differences in the ratio included/screened between the study sites. One possible explanation could be differences in the case mix at different centres.

Health care personnel were not supposed to participate in the study more than once. Unfortunately this was insufficiently addressed in the study protocol. The results indicate that some health care professionals participated more than once, but as this deviation only concerned one of nine study sites, we consider it of minor influence.

Despite the above mentioned limitations, the pilot testing has given results leading to rewording, improvements in response options, and removal of items from the dataset. We strongly encourage researchers to use the dataset as part of the case report form for studies in cancer palliative care, realizing, however, that supplementary modules may be needed for specific purposes. Using the dataset in research reporting will lead to a thorough description of the study sample, which is a prerequisite for judging the external validity of the study results [25]. Further work will be needed to test the revised version. The EAPC Basic Dataset is available at https://oslo-universitetssykehus.no/avdelinger/kreftklinikken/avdeling-for-kreftbehandling/prc-research-results#eapc-basic-dataset.

Conclusion

The first version of the EAPC basic dataset has undergone pilot-testing confirming that patients and health care personnel understand the questions in a consistent manner. The pilot testing has led to rewording, changes in response options, and shortening of the dataset, which is now ready for use.

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EAPC ONLUS **BASIC DATASET**

	PATIENT FORM												
	What is your:	**Please fill in or tick the right box as appropriate.**											
1	Date of birth	*(Day.Month.Year)*											
2	Gender	☐ Male ☐ Female											
3	Living situation	☐ Alone ☐ With spouse/partner ☐ With spouse/partner and children ☐ With children ☐ With other adult(s) ☐ In an institution ☐ Other											
4	Highest completed level of education	☐ Primary school ☐ Secondary school / high school ☐ College/university											
5	Ethnicity												
	Symptoms. Please mark the number that best describes how you feel NOW:												
6	No Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Pain
7	No Tiredness *(Tiredness = lack of energy)*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Tiredness
8	No Drowsiness *(Drowsiness = feeling sleepy)*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Drowsiness
9	No Nausea	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Nausea
10	No Lack of Appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Lack of Appetite
11	No Shortness of Breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Shortness of Breath
12	No Depression *(Depression = feeling sad)*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Depression
13	No Anxiety *(Anxiety = feeling nervous)*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Anxiety
14	Best Wellbeing *(Wellbeing = how you feel overall)*	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Wellbeing
15	Best Sleep	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Sleep
16	No Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Constipation
17	No Vomiting	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐	8 ☐	9 ☐	10 ☐	Worst Possible Vomiting

EAPC ONLUS BASIC DATASET

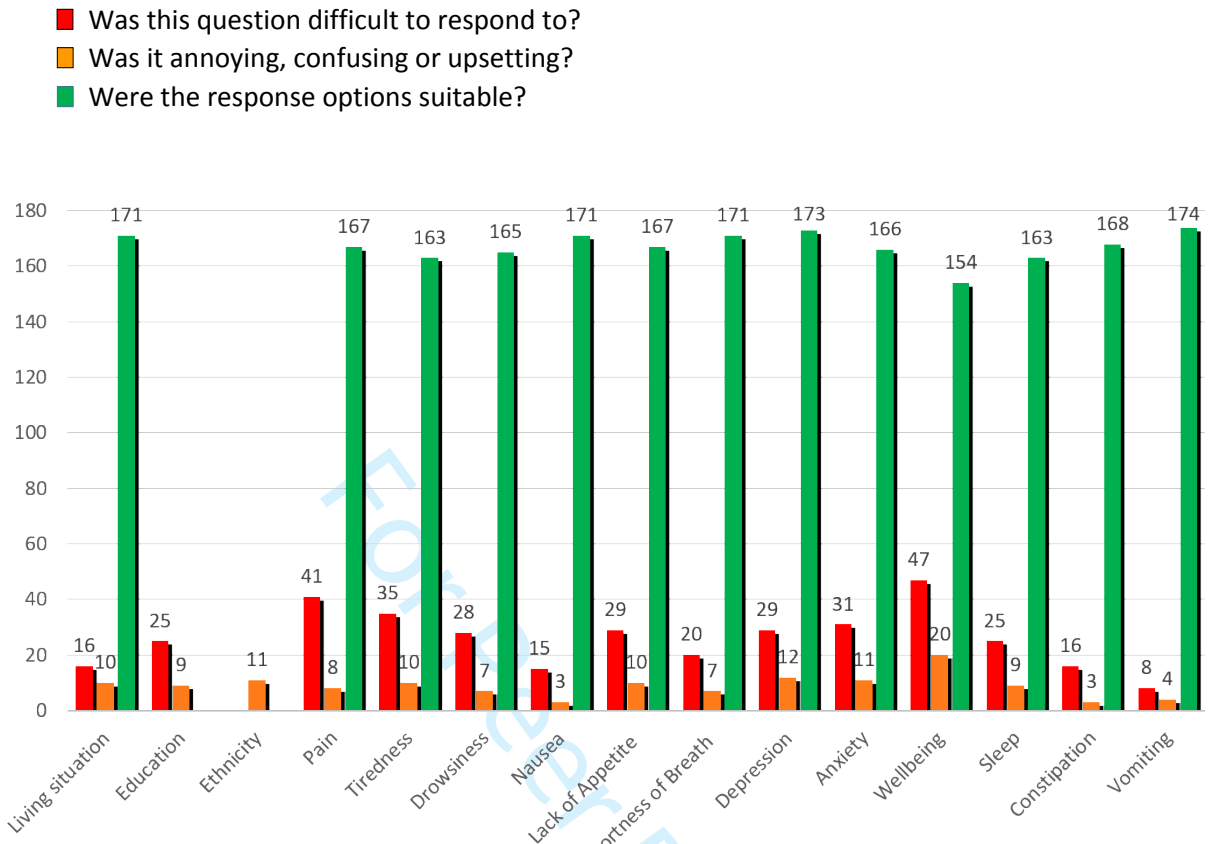
	HEALTH CARE PERSONNEL FORM	
	Patient's:	**Please fill in or tick the right box as appropriate**
18	Date of birth	(Day.Month.Year)
19	Principal diagnosis	ICD-10 code
20	Date of the principal diagnosis	(Month.Year)
21	Stage of the cancer disease	☐ Local ☐ Locally advanced ☐ Metastatic/disseminated
22	Site of metastases	☐ Bone ☐ Liver ☐ Lung ☐ CNS ☐ Other
23	Present anticancer treatment	☐ Radiotherapy ☐ Chemotherapy ☐ Hormone therapy ☐ Other anticancer therapy ☐ No anticancer therapy
24	Additional diagnoses	ICD-10 code(s):
25	Stage of the non-cancer disease	Chronic heart failure (CHF): The New York Heart Association (NYHA) Functional Classification; NYHA class: I ☐, II ☐, III ☐ , IV ☐
		Chronic obstructive pulmonary disease (COPD): GOLD classification; stage: I ☐, II ☐, III ☐, IV ☐
		Dementia: FAST scale; stage: 1 ☐, 2 ☐, 3 ☐, 4 ☐, 5 ☐, 6 ☐, 7 ☐
26	Medication	☐ Non-opioid analgesics ☐ Opioids ☐ Co-analgetics ☐ Corticosteroids ☐ Antidepressants ☐ Antiemetics ☐ Neuroleptics ☐ Sedatives/anxiolytics ☐ Drug(s) for acid related disorders ☐ Laxatives

EAPC ONLUS BASIC DATASET

		☐ Antibiotics ☐ Diuretics ☐ Heart medication / antihypertensives ☐ Other
27	Weight loss	Involuntary weight loss ____% and duration of weight loss ____months
28	Performance status	☐ 100 Normal; no complaints; no evidence of disease. ☐ 90 Able to carry on normal activity; minor signs or symptoms. ☐ 80 Normal activity with effort; some signs or symptoms of disease ☐ 70 Cares for self; unable to carry on normal activity or to do active work. ☐ 60 Requires occasional assistance but is able to care for most of his needs. ☐ 50 Requires considerable assistance and frequent medical care. ☐ 40 In bed more than 50% of the time. ☐ 30 Almost completely bedfast. ☐ 20 Totally bedfast and requiring extensive nursing care by professionals and/or family. ☐ 10 Comatose or barely rousable. ☐ 0 Dead
29	Cognitive function	The patient has cognitive impairment; ☐ No ☐ Mild ☐ Moderate ☐ Severe
30	Place of care	☐ Home ☐ Long-term care facilities ☐ Hospice / Palliative care unit ☐ Hospital ☐ Other
31	Provision of care	☐ Inpatient ☐ Outpatient ☐ Day care

Figure 1. EAPC Basic Dataset first version.

A.



B.

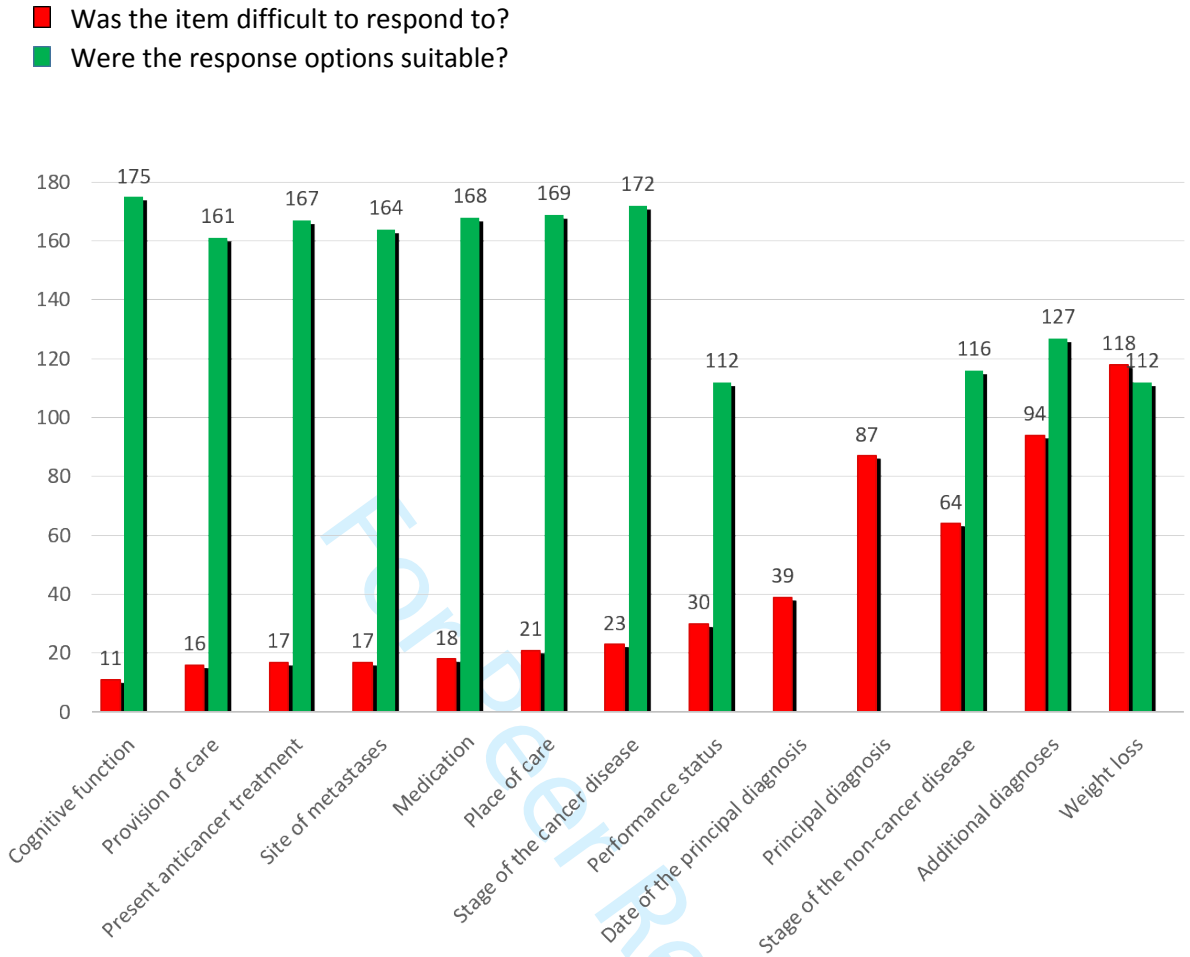
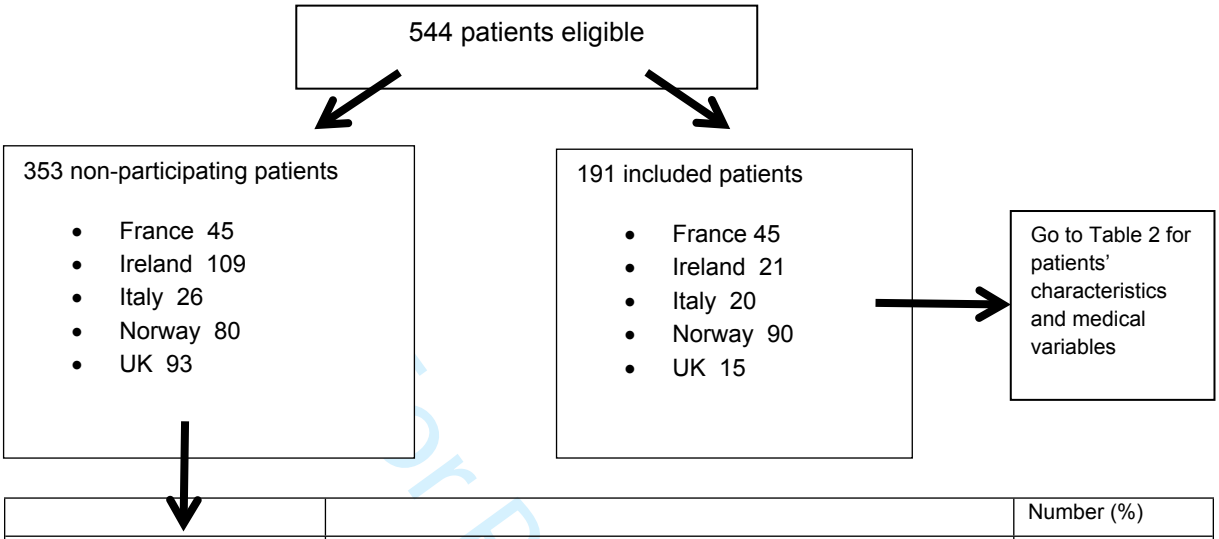


Figure 2. Pilot-testing the EAPC Basic Dataset: The number of patient participants (n=191; A) and health care professionals (n=190; B) who answered Yes to the standardized questions asked by the interviewers.

Table 1. Recruitment to pilot-testing of the EAPC Basic Dataset, characteristics of non-participating patients, and reasons for not participating.



		Number (%)
Age groups	25 - 34 years	3 (1)
	35 - 44 years	11 (3)
	45 - 54 years	36 (10)
	55 - 64 years	72 (20)
	65 - 74 years	102 (29)
	75 - 84 years	93 (26)
	85 years and over	34 (11)
Gender	Male	183 (52)
	Female	166 (48)
Cancer diagnoses by site (ICD 10 codes)	Lip, oral cavity & pharynx (C00-14#)	4 (1)
	Digestive organs (C15-26#)	85 (27)
	Respiratory & intrathoracic (C30-39#)	44 (14)
	Breast (C50#)	52 (16)
	Female genital organs (C51-58#)	14 (4)
	Male genital organs (C60-63#)	23 (7)
	Urinary tract (C64-68#)	13 (4)
	Eye, brain & CNS (C69-72#)	16 (5)
	Lymphoid, haematopoietic (C81-96#)	34 (11)
	Other specified sites (C40-49, and 73-75#)	15 (5)
	Independent multiple sites (C97#)	1 (0)
	Ill-defined, secondary, unspecified including carcinomatosis (C76-80#)	11 (3)
	Not recorded	5 (2)
Non-cancer diagnoses (ICD-10 codes)	Motor neurone disease (G12#)	6 (3)
	Neurological conditions (G00-99#), excluding G12# and G30#	11 (5)
	Dementia including Alzheimer's disease (G30 and other, F00-03#)	5 (2)
	Heart failure (I50#)	17 (7)
	Other heart and circulatory conditions	40 (17)

	(I00-99, excluding I50#)	
	Chronic respiratory disease (J40-70#)	28 (12)
	Chronic renal failure (N18#)	13 (5)
	All other non-cancer diagnoses	45 (19)
	Diagnosis not recorded	72 (30)
Patient's performance status	100 Normal; no complaints; no evidence of disease	8 (2)
	90 Able to carry on normal activity; minor signs or symptoms	28 (8)
	80 Normal activity with effort; some signs or symptoms of disease	26 (8)
	70 Cares for self; unable to carry on normal activity or to do active work	31 (9)
	60 Requires occasional assistance but is able to care for most of his needs	66 (19)
	50 Requires considerable assistance and frequent medical care.	72 (21)
	40 In bed more than 50% of the time	35 (10)
	30 Almost completely bedfast	25 (7)
	20 Totally bedfast and requiring extensive nursing care by professionals and/or family	41 (12)
	10 Comatose or barely rousable	8 (2)
Reason for not participating	Not advanced cancer	67 (18)
	Unable to give informed consent	46 (13)
	Has already participated in the pilot-testing	6 (2)
	Too unwell	92 (26)
	Patient 'didn't want to'/ 'Not interested'	33 (9)
	Weekend/evening admission (researcher unavailable)	25 (7)
	Declined consent, reason unknown	21 (6)
	Other, please specify*	64 (18)

*Other; attends daycare on a day researcher is not available (24), time issues (lack of time, patient had left before researcher had time) (12), mental health issues (5), speaking difficulties (4), does not speak the language (3), hearing impairment (2), patient too tired/fatigued (4), and diverse (10). #ICD-10 codes.

Table 2. Results of pilot-testing the EAPC Basic Dataset patient form: Characteristics of the included patients (n=191); number of responses and missing data for each item; qualitative responses grouped as comments on difficulties and proposals for improvement; resulting changes made to the dataset.

Patient form		**Number of responses (%)**	**Mean (range)**	**Missing data, Number (%)**	**Comments on difficulties**	**Proposals on how to improve the dataset**	**Resulting changes in the EAPC Basic Dataset**
Age		191 (100)	67.6 (25-90)				
Gender	Male	97 (51)					
	Female	94 (49)					
Living situation	Alone	59 (31)		2 (1)	Living with adult child A temporary stay in an institution	Define a child (< 18 years old) Specify living situation as NOW	Current living situation With spouse / partner and children (< 18 years old) With children (< 18 years old)
	With spouse/partner	70 (37)					
	With spouse / partner and children	33 (17)					
	With children	4 (2)					
	With other adult(s)	9 (5)					
	In an institution	4 (2)					
	Other	13 (7)					
Highest completed level of education	Primary school	43 (22)		2 (1)	Education was completed long ago, and schools and systems have changed 4 patients had vocational training and missed an option for that 2 patients had not completed primary education	To add one more category; other; please describe	Other; please describe_____
	Secondary school / high school	87 (45)					
	College/university	65 (34)					
Ethnicity		127 (66)		64 (33)	Don't understand the word ethnicity, what it means	Ask for nationality instead of ethnicity To use tick boxes with predefined categories	Nationality Predefined categories at the national level

					Didn't understand the question Unsure about what to answer		
Symptoms	Pain	191 (100)	3.1 (0-10)		Many patients had the same comments for more than one symptom. The comments could be categorized into the following: - Difficult to quantify symptom and to use numerical rating scale - Using the time frame now when symptoms fluctuate - Difficult to differentiate between symptoms - Understanding and meaning of words - The order of symptoms	To change the order of symptoms	Pain Shortness of Breath Tiredness Drowsiness Lack of Appetite Nausea Vomiting Constipation Depression Anxiety Sleep Wellbeing
	Tiredness	183 (96)	4.8 (0-10)	8 (4)			
	Drowsiness	187 (98)	3.7 (0-10)	4 (2)			
	Nausea	188 (98)	1.2 (0-8)	3 (2)			
	Lack of Appetite	190 (99)	3.2 (0-10)	1 (1)			
	Shortness of Breath	189 (99)	2.9 (0-10)	2 (1)			
	Depression	188 (98)	2.5 (0-10)	3 (2)			
	Anxiety	187 (98)	2.4 (0-10)	4 (2)			
	Wellbeing	184 (96)	3.9 (0-10)	7 (4)			
	Sleep	186 (97)	3.3 (0-10)	5 (3)			
	Constipation	188 (98)	2.9 (0-10)	3 (2)			
	Vomiting	187 (98)	0.7 (0-9)	4 (2)			

Health care personnel form		Number of responses (%)	Missing data, Number (%)	Comments on difficulties	Proposals on how to improve the dataset	Resulting changes in the EAPC Basic Dataset
Principal diagnosis	ICD-10 code	113 (59)	21 (11)	Don't know the ICD-10 code Hard to find Don't use it Only used in hospitals Only used in death certificates Time-consuming to find the code	Write the diagnosis Use a standardized list with cancer diagnoses	□ Malignant neoplasms of lip, oral cavity and pharynx (C00-14#) □ Malignant neoplasms of digestive organs (C15-26#) □ Malignant neoplasms of respiratory and intrathoracic organs (C30-39#) □ Malignant neoplasms of bone and articular cartilage (C40-41#) □ Melanoma and other malignant neoplasms of skin (C43-44#) □ Malignant neoplasms of mesothelial and soft tissue (C45-49#) □ Malignant neoplasm of breast (C50#) □ Malignant neoplasms of female genital organs (C51-58#) □ Malignant neoplasms of male genital organs (C60-63#) □ Malignant neoplasms of urinary tract (C64-68#) □ Malignant neoplasms of eye, brain and other parts of central nervous system (C69-72#) □ Malignant neoplasms of thyroid and other endocrine glands (C73-75#) □ Malignant neoplasms of ill-defined, secondary and unspecified sites (C76-80#)

						□ Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue (C81-96#) □ Malignant neoplasms of independent (primary) multiple sites (C97#) □ Benign neoplasms (D10-36#) □ Neoplasms of uncertain or unknown behaviour (D37-48#)
Date of the principal diagnosis	Month. Year	138 (72)	7 (4)	Hard to find, especially the month Need to look for it Time-consuming to find		
Stage of the cancer disease	Local	12 (6)	4 (2)	Hard to find Hematologic cancer Now or at the time of diagnosis Don't know the difference between local and locally advanced	Specify now Specify solid cancer disease Add no/missing information	Current stage of the cancer disease
	Locally advanced	27 (14)				
	Metastatic/disseminated	152 (79)				
Site of metastases	Bone	76 (40)		Hard to find Now or at the time of diagnosis	Add lymph nodes The possibility to specify other with free text	Other, please specify _____
	Liver	62 (32)				
	Lung	61 (32)				
	CNS	18 (9)				
	Other	80 (42)				
Present anticancer treatment	Radiotherapy	38 (20)	2 (1)	Difficult to find out what is meant by present, some of the patients had a pause from treatment	Add surgery Add targeted therapy Add immunotherapy	Surgery Immunotherapy Other anticancer therapy, please specify _____
	Chemotherapy	75 (39)				
	Hormone therapy	24 (12)				
	Other anticancer therapy	11 (6)				
	No anticancer therapy	69 (36)				
Additional diagnoses	ICD-10	83 (43)		Don't know ICD-10 Don't use ICD-10 Hard to find Time consuming	Use standardized list of relevant diagnoses To be able to write out the name of the diseases Opportunity to tick Yes or No	Additional diagnoses (other diagnoses than the cancer diagnose, having substantial impact on the patient's health)

				What is meant by additional diagnose	To specify in the text what is meant by additional diagnoses	□ Certain infectious or parasitic diseases (A00-B99#) □ Neoplasms (C00-D48#) □ Diseases of the blood or blood-forming organs and certain disorders involving the immune mechanism (D50-89#) □ Endocrine, nutritional or metabolic diseases (E00-90#) □ Mental and behavioural disorders (F00-99#) □ Diseases of the nervous system (G00-99#) □ Diseases of the eye and adnexa (H00-59#) □ Diseases of the ear or mastoid process (H60-95#) □ Diseases of the circulatory system (I00-99#) □ Diseases of the respiratory system (J00-99#) □ Diseases of the digestive system (K00-93#) □ Diseases of the skin and subcutaneous tissue (L00-99) □ Diseases of the musculoskeletal system or connective tissue (M00-99#) □ Diseases of the genitourinary system (N00-99#)
Stage of the non-cancer disease	Chronic heart failure (CHF): The New York Heart Association (NYHA) Functional Classification; NYHA class I - IV	25 (13)		Don't know the classification systems Hard to find Too complicated	Exclude it from the dataset Add if needed	Removed
	Chronic obstructive pulmonary disease	19 (10)				

	(COPD): GOLD classification; stage I - IV					
	Dementia: FAST scale; stage: 1 - 7	11 (6)				
Medication	Non-opioid analgesics	108 (56)		Information not available Difficult to place drugs in categories Uncertainty about the medication, if it is by the clock or as needed or both	To add new categories; no medication, information not available Add anticoagulation, antiepileptic, antidiabetic Others have the opportunity to write free text	Antidiabetics Anticoagulants Antiepileptics Other, please specify _____
	Opioids	129 (67)				
	Co-analgesics	39 (20)				
	Corticosteroids	84 (44)				
	Antidepressants	43 (22)				
	Antiemetics	75 (39)				
	Neuroleptics	22 (11)				
	Sedatives/anxiolytics	63 (33)				
	Drug(s) for acid related disorders	94 (49)				
	Laxatives	119 (62)				
	Antibiotics	24 (12)				
	Diuretics	34 (18)				
	Heart medication / antihypertensives	50 (26)				
	Other	78 (41)				
Weight loss	Involuntary weight loss ____ % and duration of weight loss ____months	38 (20)	153 (80)	No routine for weighing patients Information not available Difficult to use percentage	To use kilograms instead of percentage Fixed timeframe over 6 months Weight gain should also be an option	Removed
Performance status	100 Normal; no complaints; no evidence of disease.	4 (2)	3 (2)	Challenging to choose the right category, did not fit the case Accustomed to use WHO/ECOG scale	To use combined ECOG/Karnofsky scale	
	90 Able to carry on normal activity; minor signs or symptoms.	22 (11)				
	80 Normal activity with effort; some signs or symptoms of disease.	31 (16)				
	70 Cares for self; unable to carry on normal activity or to do active work.	41 (21)				

	60 Requires occasional assistance but is able to care for most of his needs.	47 (25)				
	50 Requires considerable assistance and frequent medical care.	28 (15)				
	40 In bed more than 50% of the time.	8 (4)				
	30 Almost completely bedfast.	8 (4)				
	20 Totally bedfast and requiring extensive nursing care by professionals and/or family.	2 (1)				
	10 Comatose or barely arousable.					
	0 Dead					
Cognitive function The patient has cognitive impairment;	No	160 (84)	2 (1)	Lack of definitions No formal assessment, only based on clinical judgment Fluctuates	Add “fluctuating cognitive impairment = delirium”	Fluctuating cognitive impairment added
	Mild	27 (14)				
	Moderate	2 (1)				
	Severe					
Place of care	Home	60 (31)	3 (2)	Usual or now	Specify current Specify only one option	Place of current care Other, please specify _____
	Long-term care facilities	2 (1)				
	Hospice / Palliative care unit	75 (39)				
	Hospital	65 (34)				
	Other	2 (1)				
Provision of care	Inpatient	93 (49)	2 (1)	What is the difference between outpatient and day care?	Specify current	Provision of current care
	Outpatient	63 (33)				
	Day care	33 (17)				

#ICD-10 code

PALLIATIVE MEDICINE AUTHOR SUBMISSION CHECKLIST

Please complete this checklist for all papers submitted. Please indicate, very briefly, how this has been addressed. This checklist is a mandatory upload on submission.

Item	Explanation	How this has been addressed (briefly, a sentence will suffice)
Article title	***WHY: Because we want readers to find your work.*** Have you followed our guidelines on writing a good title that will be found by search engines? (E.g. with methods in the title, use of common words for the issue addressed, no country names, and possibly indicating findings). If your study has an acronym is it included in the title?	Guidelines have been followed. The title is short and clear and includes the method used.
Abstract	***WHY: Because structured abstracts have more detail for readers and search engines.*** Have you followed our guidelines on writing your structured abstract? Please remember we have separate abstract structures for original research, reviews and case reports. There should be **no** abbreviations in the abstract, EXCEPT a study acronym which should be included if you have one. If a trial (or other design formally registered with a database) have you included your registration details?	Abstract is written according to the guidelines.
Key statements	***WHY: Because readers want to understand your paper quickly.*** Have you included our key statements within the body of your paper (after abstract and before the main text is a good place!) and followed our guidelines for how these are to be written? There are three main headings required, and each may have 1-3 separate **bullet** points. Please use clear, succinct, single sentence separate bullet points rather than complex or multiple sentences.	Key statements are included
Keywords	***WHY: Because MeSH headings mean it is properly indexed.*** Have you given keywords for your study? We ask that these are current **MeSH** headings unless there is no suitable heading for use (please give explanation in cover letter). https://meshb.nlm.nih.gov/search	MeSH headings have been used
International relevance	***WHY: We have readers from around the world who are interested in your work.*** Have you contextualised your work for an international audience and explained how your work contributes to an international knowledge base? Avoid drawing from policy from one context only, think how your work could be relevant more widely. Do define terms clearly e.g. hospice has a different	This has been addressed

	meaning in many countries.	
Publishing guidelines	***WHY: Because clear and robust reporting helps people interpret your work accurately*** Have you submitted a completed checklist for a relevant publishing guideline as a supplementary file? http://www.equator-network.org/ These include CONSORT, PRISMA, COREQ checklists, but others may be more relevant for your type of manuscript. If no published checklist exists please create one as a table from the list of requirements in your chosen guideline. If your study design does not have a relevant publishing guideline please review closest matches and use the most appropriate with an explanation.	COREQ checklist submitted
Word count	***WHY: Because readers want to find the core information quickly.*** Does your paper adhere to our word count for your article type? Please insert number of words in the box to the right. Remember that tables, figures, qualitative data extracts and references are not included in the word count.	2990 words
Figures and tables and/or quotations	***WHY: Because readers want to find the core information quickly.*** Have you adhered to our guidelines on the number of tables and figures for your article type? Data (e.g. quotations) for qualitative studies are not included in the word count, and we prefer that they are integrated into the text (e.g. not in a separate table).	3 tables and 2 figures included
Study registration	***WHY: Because this means readers understand how you planned your study*** Where appropriate have you included details (including reference number, date of registration and URL) of study registration on a database e.g. trials or review database. If your study has a published protocol, is this referenced within the paper?	Not applicable
Other study publications?	***WHY: So readers can understand the full context of your study*** If there are other publications from this study are these referenced within the body of the paper? Please do not reference papers in preparation or submitted, but in-press publications are acceptable.	This is a follow up study, with reference to "The European Association for Palliative Care basic dataset to describe a palliative care cancer population: Results from an international Delphi process" published in Palliat Med 2014

Scales, measures or questionnaires	***WHY: So readers can understand your paper in the context of this information*** If your study primarily reports the development or testing of scales/measures or questionnaires have you included a copy of the instrument as a supplementary file?	Included as Figure 1
Abbreviations	***WHY: Because abbreviations make a paper hard to read, and are easily misunderstood*** Have you removed **all** abbreviations from the text except for extremely well known, standard abbreviations (e.g. SI units), which should be spelt out in full first? We do not allow abbreviations for core concepts such as palliative or end of life care.	Few well known abbreviations are used and all are spelt out in full first.
Research ethics and governance approvals for research involving human subjects	***WHY: We will only publish ethically conducted research, approved by relevant bodies*** Have you given full details of ethics/governance/data protection approvals with reference numbers, full name of the committee(s) giving approval and the date of approval? If such approvals are not required have you made it explicit within the paper why they were not required. Are details of consent procedures clear in the paper?	Details given in the paper
Date(s) of data collection	***WHY: So readers understand the context within which data were collected*** Have you given the dates of data collection for your study within the body of your text? If your data are over 5 years old you will need to articulate clearly why they are still relevant and important to current practice.	Timeframe is given
Structured discussion	***WHY: So readers can find key information quickly*** Papers should have a structured discussion, with sub headings, summarising the main findings, addressing strengths and limitations, articulating what this study adds with reference to existing international literature, and presenting the implications for practice.	This has been addressed
Case reports	***WHY: So that participants are protected, and its importance made clear*** If your study is a case report have you followed our clear structure for a case report, including highlighting what research is needed to address the issue raised? Have you made clear what consent was required or given for the publication of the case report? Have you provided evidence of such consent as a supplementary file to the editor?	Not applicable
Acknowledgements and declarations	***WHY: So readers understand the context of the research*** Have you included a funding declaration according to the SAGE format? Are there acknowledgements to	This has been addressed

	be made? Have you stated where data from the study are deposited and how they may be available to others? Have you conflicts of interest to declare?	
Supplementary data and materials	***WHY: So the context is clear, but the main paper succinct for the reader*** Is there any content which could be provided as supplementary data which would appear only in the online version of accepted papers? This could include large tables, full search strategies for reviews, additional data etc.	The final version of the EAPC basic dataset could be provided as supplementary data
References	***WHY: So people can easily find work you have referenced*** Are your references provided in SAGE Vancouver style? You can download this style within Endnote and other referencing software.	References provided in SAGE Vancouver style
Ownership of work.	Can you assert that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.	I declare that I am submitting original work for first publication and that it is not considered for publication elsewhere. I have the rights in the work and there is no reproduction of any copyright works in the paper.

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	How this has been addressed
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Nine study sites participated with nine different interviewers. Four of the authors conducted interviews (MH,CT,CA,RM)
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	The researchers had different credentials (RNs, MDs, PhDs)
3.	Occupation	What was their occupation at the time of the study?	Research nurses, physicians and one medical student.
4.	Gender	Was the researcher male or female?	Both
5.	Experience and training	What experience or training did the researcher have?	There was a great variety of research experience within the group
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Not between patients and researchers
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*	The participants were both patients and health care providers. Some of the health care providers knew their respective researcher.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and*	No details are given about characteristics of the nine interviewers. All nine study sites had interviewers without any connection to the development of the EAPC Basic

		interests in the research topic	Dataset. By using a standardized interview guide we tried to minimize interviewer bias.
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Content analysis was used
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participants were consecutively recruited at palliative care units and hospices. All patients admitted to the unit were screened, and reason for not participating recorded using predefined categories.
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Potential participants were approached by the local study coordinator, who gave oral information about the research project. If the patient was willing to participate, he/she was asked to read and fill in the consent form.
12.	Sample size	How many participants were in the study?	381
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	A total of 544 patients were screened; 353 did not participate or were excluded. Reason for not participating were: Not advanced cancer Age < 18 years Unable to give informed consent

			Has already participated in the pilot-testing Too unwell Patient “didn’t want to”/ “Not interested” Family objection Weekend/evening admission (researcher unavailable) Declined consent reason unknown Other, please specify
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	Data was collected in palliative care units, hospices and home care settings.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Yes, in some cases.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	The EAPC Basic Dataset was used to describe the sample. The dataset consists of 31 demographic and medical variables.
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	‘Pilot testing the EAPC Basic Dataset: structured interview guide’ was developed. The interview guide was pilot tested
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeated interviews were conducted
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	No recordings
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made during the interview within the interview guide
21.	Duration	What was the duration of the interviews or focus group?	Duration of interviews was not recorded

22.	Data saturation	Was data saturation discussed?	Not applicable. It was decided that each study sites should include minimum 15 patients.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Not applicable
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	One
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes derived from the data
27.	Software	What software, if applicable, was used to manage the data?	SPSS and Excel
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	No quotations were used.
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Not applicable
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes

32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No