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Title: Comparing palliative care in care homes across Europe (PACE): protocol of a cross-sectional study of deceased residents in six EU countries

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Keywords: palliative care; care home; nursing home; European; quality of end-of-life care

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Abstract: Objectives
While a growing number of older people are dying in care homes, palliative care has developed in these settings only recently. Cross-country representative comparative research hardly exists in this area. As part of a large EU-funded project, we aim to undertake representative comparative research in care homes in Europe, to describe and compare six countries in terms of 1) resident outcomes, quality and costs of palliative and end-of-life care; 2) palliative care structures and staff knowledge and attitudes towards palliative care. We also aim to explore country, facility, staff, patient and care characteristics related to better outcomes at resident level.

Design and Methods
To obtain a representative nationwide sample, we will conduct a large-scale cross-sectional study of deceased residents in care homes in Belgium, Finland, Italy, the Netherlands, Poland and the United Kingdom, using proportional stratified random sampling (taking into account region, facility type and bed capacity). In each country, all participating care homes retrospectively report all deaths of residents in and outside the facilities over the previous three-month period. For each case, structured questionnaires including validated instruments are sent to (1) the administrator/manager, (2) staff member most involved in care, (3) treating physician (GP or elderly care physician), and (4) a closely involved relative. It is estimated that, per country, 50 care homes are needed on average to obtain a minimum of 200 deceased residents. Collected data include clinical and socio-demographic characteristics, quality of dying, quality and costs of palliative care and end-of-life care, and palliative care structures at facility level and country level. To obtain a representative view of staff knowledge and

attitudes regarding palliative care, PACE will conduct a cross-sectional study of staff working in the participating care homes.

Conclusion

Considering the growing challenges associated with aging in all European countries, there is an urgent need to build a robust international comparative evidence-base that can inform the development of policies to target improved palliative care in care homes. By describing this research protocol, we hope to inform international research in care homes on how to perform representative end-of-life care research in these settings and better understand which systems are associated with better outcomes.

March 7, 2016

Concerning: submission of EU study protocol “**Comparing palliative care in care homes across Europe (PACE): protocol of a cross-sectional study of deceased residents in six EU countries”**

Dear Prof Morley,

The submitted manuscript describes the research protocol of a large EU-funded FP7 project, PACE (Palliative care for Older People) in six EU countries (Belgium, Finland, Italy, the Netherlands, Poland and the United Kingdom). PACE aims to describe and compare how residents in care or nursing homes are dying in different countries and what the quality and costs of the provided care are, as well as relate palliative care systems and structures to these outcomes. The submitted manuscript describes the design and methodology of the PACE study and aims to inform the international research community on how to undertake analogous representative research, in particular to understand better which systems are associated with better outcomes. Data collection is ongoing and first results are expected by the summer of 2016.

Ethical approval was obtained for the study in all countries in 2015. The research leading to these results has received funding from the European Union’s Seventh Framework Programme (FP7/ 2007-2013) under grant agreement n° **603111** (PACE project Palliative Care for Older People) after extensive international peer review. The funders had no role in study design, collection, analysis or interpretation of the data, in writing or in the decision to submit this article for publication. Proof of both ethics and funding can be sent to the editorial office.

We submit the paper as an original report. It has not been submitted elsewhere. The manuscript has been read and approved by all the authors. The corresponding author for the article is mentioned in the manuscript and below in this letter. For all authors, there are no conflicts of interest.

Author’s contributions**:** the first author conceived the study and all authors have made substantial contributions to conception and design, or acquisition of data. The first author drafted the manuscript and all authors have been involved in revising it critically for important intellectual content. All authors read and approved the final version of the manuscript to be published and agree to be accountable for all aspects of the work.

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Yours sincerely,

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Comparing palliative care in care homes across Europe (PACE): protocol of a cross-sectional study of deceased residents in six EU countries

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ABSTRACT

Objectives While a growing number of older people are dying in care homes, palliative care has developed in these settings only recently. Cross-country representative comparative research hardly exists in this area. As part of a large EU-funded project, we aim to undertake representative comparative research in care homes in Europe, to describe and compare six countries in terms of 1) resident outcomes, quality and costs of palliative and end-of-life care; 2) palliative care structures and staff knowledge and attitudes towards palliative care. We also aim to explore country, facility, staff, patient and care characteristics related to better outcomes at resident level.

Design and Methods To obtain a representative nationwide sample, we will conduct a large-scale cross-sectional study of deceased residents in care homes in Belgium, Finland, Italy, the Netherlands, Poland and the United Kingdom, using proportional stratified random sampling (taking into account region, facility type and bed capacity). In each country, all participating care homes retrospectively report all deaths of residents in and outside the facilities over the previous three-month period. For each case, structured questionnaires including validated instruments are sent to (1) the administrator/manager, (2) staff member most involved in care, (3) treating physician (GP or elderly care physician), and (4) a closely involved relative. It is estimated that, per country, 50 care homes are needed on average to obtain a minimum of 200 deceased residents. Collected data include clinical and socio-demographic characteristics, quality of dying, quality and costs of palliative care and end-of-life care, and palliative care structures at facility level and country level. To obtain a representative view of staff knowledge and attitudes regarding palliative care, PACE will conduct a cross-sectional study of staff working in the participating care homes.

Conclusion Considering the growing challenges associated with aging in all European countries, there is an urgent need to build a robust international comparative evidence-base that can inform the development of policies to target improved palliative care in care homes. By describing this research protocol, we hope to inform international research in care homes on how to perform representative end-of-life care research in these settings and better understand which systems are associated with better outcomes.

Key words: palliative care, care home, nursing home, European, quality of end-of-life care

MANUSCRIPT

Introduction

Societies in the EU are aging, leading to the need not only to improve health by prevention but also to improve people's quality of life and enabling them to live and die well[1, 2]. The proportion of the world's population over 60 years is expected to double from about 11% to 22% between 2000 and 2050. More people will die in late old age following a slow dying course with multiple chronic diseases, years of disability and complex palliative care needs[2, 3]. The number of people living with dementia worldwide is estimated to double to 65.7 million by 2030 and triple to 115.4 million by 2050[1, 4]. These developments have great clinical, societal and socio-economic implications common to all EU countries.

Whilst health policies in many countries aim to enable people to live in their own homes, many older people will require long-term institutional care at the end of life. A significant proportion of older people also die in care homes (nursing homes or homes for older people or other long-term care facilities): from one sixth in Italy to one third in the Netherlands[5, 6]. However, a number of descriptive studies suggest that end-of-life care and quality of dying in these settings can be less than optimal for older people and their families. Symptoms appear under-estimated and there is a risk of over-treatment that is continuing life-prolonging, burdensome treatments without knowing individual preferences, or of being transferred to a hospital in the last days of life[1, 3, 7-11]. Recent reviews also show there is lack of knowledge about which palliative care systems exist in care homes in Europe and how effective they are in producing high quality end-of-life care[12, 13]. Although examples of good practice have been documented, palliative care in care homes has not been systematically developed across Europe[1, 6]. While in some countries palliative care is highly developed in care homes, other countries lack this and rely on the standard care available for these settings. There is no solid evidence about which care system best fulfills the complex needs of older people at the end of life[12, 13]. Most studies are descriptive, small-scale or focused on specific diseases. Also, most existing research identifying the need for improving palliative care in care homes is limited to only one country or region within a country[13-17]. Thus, we lack large-scale representative and cross-country studies in this area. Additionally, economic evaluations of palliative care are relatively rare. Evidence-based evaluations and comparative EU studies of quality and cost of palliative care are needed to help guide decisions in health care[1, 3, 13, 18].

PACE "Palliative Care for Older People" is an EU-funded project (2014-2019) that aims to undertake comparative representative research on dying in care homes in Europe. This protocol focuses on one major study within PACE which aims to describe and compare six countries (Belgium, Finland, Italy, the Netherlands, Poland, UK) in terms of resident outcomes, quality and costs of palliative/end-of-life care, palliative care structures/systems, and staff knowledge and attitudes towards palliative care, and aims to unpack the relationship between these structures, processes and outcomes.

Specific research questions are:

1. To what extent does Belgium, Finland, Italy, the Netherlands, Poland, and the UK differ in terms of resident outcomes (quality of dying), and quality and costs of palliative/end-of-life care?
2. To what extent do countries differ in terms palliative care structures/systems and palliative care knowledge and attitudes of staff?
3. To what extent are country, facility, staff, patient and care characteristics (structures and processes) related to better outcomes i.e. better quality of dying?

In this article, we will outline the research design and methodology developed to answer these research questions. By describing our epidemiological approach, we hope to inform international research methodologies in care homes, in particular on how to perform representative end-of-life care research in these settings, better understand which systems are associated with better outcomes, and use cross-country comparisons to identify areas for improvement in current practice.

Methods

Design: To obtain representative nationwide samples, PACE will conduct a cross-sectional study of deceased residents in care homes in Belgium, Italy, Finland, the Netherlands, Poland, and the United Kingdom, using proportional stratified random sampling. In each country, all participating care homes retrospectively report **all deaths of residents** (ie people who are registered as a resident in the facility records) **in and outside the facilities over the previous three-month period**. While a retrospective design may limit the ability to retrieve certain aspects of the treatment histories of deceased patients[19], it has been identified as the most appropriate design to identify a representative sample of deceased residents[20]. Prognostication on dying in prospective follow-up research is problematic[21, 22] and all patients cannot be followed until death resulting in patients living longer being underrepresented [22, 23]. Using a three-month period limits recall bias and has been successfully tested in previous research [14, 15, 20, 24]. Additionally, to obtain a representative view of **staff knowledge and attitudes** regarding palliative care, we will conduct a cross-sectional study of staff (care assistants, nurses) working in the participating homes.

Setting and participants: Throughout this project, the term "**care homes**" is used for all " collective institutional settings where care – on site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care – is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time"[6]. Three types of care homes can be differentiated within PACE countries, as shown in Table 1, with a variety of labels used throughout the countries[6]. Across the different countries, there is also quite some variation in organisational funding structures with differential reliance on public, not-for-profit and private sectors (Figure 1). Data provided in Table 1 and Figure 1 came from a country mapping survey filled in by consortium members, identical to the one used in a previous European survey concerning palliative care development in care homes[6]. For each **deceased resident** identified in the participating care homes, structured questionnaires including validated instruments will be sent to the (1) administrator/manager, (2) staff member most involved in care (preferably a nurse), (3) treating physician (GP or elderly care physician), and (4) a most closely involved relative (family or friend). For each care home participating in the study, a facility questionnaire will be filled in by the administrator/manager. Additionally, all **care home staff** (care assistants, nurses, head nurses) employed in the care home and on duty at the time the researcher visits the facility will be asked to fill in a separate questionnaire on knowledge and attitudes (not linked to a particular resident).

Sampling and data collection procedures:

Sampling procedures will be specified per country. In each country that can use national lists of certified care homes, facilities will be stratified by region (provinces or other large regions depending on the country) and subsequently by facility type (see Table 1) and bed capacity (above and below the median number of beds in LTCFs in the country) and then sampled randomly to cover the entire country. In addition, in the UK, the specialist research network for care homes (ENRICH) will be involved in highlighting the study to its members. In Italy, where no public lists of the more than 8000 care homes are available, a previously constructed cluster of care homes interested in participating in research will be used. This convenience sample of care homes includes facilities from 15 out of 21 regions, covers the three macro regional areas (North, Centre and South) of Italy and takes into consideration the regional differences in terms of facility size (number of beds) and their characteristics (type, organisational status). A similar strategy was used in previous Italian care home studies including the EU SHELTER project[26].

Data collection procedures are described in detail in a quality assurance manual to ensure high quality processes are adhered to. All researchers involved in PACE will be trained extensively by the coordinator to ensure data collection procedures are followed as instructed.

Step 1: A letter introducing the project will be send to the board of directors/owner/manager asking for voluntary participation (without reimbursement) and telephone or e-mail contact is made.

Step 2: In each participating care home, one contact person for the study (an administrator, head nurse or manager) will be appointed.

Step 3: The researcher will visit each participating care home and assist the contact person – using structured checklists – in identifying:

- all deceased residents (in or outside the care home) over the previous three months
- key respondents for each deceased resident (staff member, treating physician, and relative)
- all employed nursing and care staff present or on duty at the day of the visit
- a key person from the care home management (administrator or manager).

The checklists will be filled in by the contact person using the administrative files and consists of a part A containing identifiable names of residents and respondents (to be kept in the facility and never accessible to the researchers), and a part B with unique pseudonomised codes.

Step 4: The structured checklists will be used to prepare the questionnaires and pre-stamped envelopes, and distributed or mailed by the contact person. The questionnaires only contain anonymous codes and will be sent back directly to the researchers (not to the facility or contact person).The relatives will receive the questionnaire at least two weeks to three months after the resident’s death, depending on what is allowed in each country (as advised by the approving ethics committees). All questionnaires will be accompanied by a letter containing information about the study.

Step 5: The facility questionnaire will be filled in by a key person of the management during the visit, who may need to consult other staff members to gather all requested information about the facility.

Step 6: The researchers will continuously monitor incoming questionnaires using excel files. Up to two reminders (after 3 weeks) will be sent to physicians, staff and relatives via the contact person in the facilities, except in Poland and the UK where relatives will receive one reminder (following ethics committees’ requirements).

Measurements: Table 2 provides on overview of all measures and instruments used in the study.

Translations: The consortium will use strict procedures for forward-backward translations of questions or questionnaires that are not officially translated in earlier studies, following guidelines from the EORTC[27]: English will be the source language; forward translation will be performed in each country with two translators/native speakers with a high level of proficiency in English; the Principal Investigator (PI) of each country will merge them into one single forward translation in consultation with the translators; two other translators/native English speakers with high level of knowledge of the target language will perform the backward translations independently; the PI will compare these translations with the original questionnaires and discuss any identified problems with the translators. All results and problems are discussed in the PACE consortium to reach a consensus.

Feasibility Testing: After all translations will be finalized, each country will test all questionnaires, materials and data collection procedures in three care homes per country (excluded from main data collection). The questionnaires for physicians and relatives are to be tested separately by contacting three GPs/elderly care physicians and three relatives recruited by the researchers. All questionnaires are tested in a face-to-face manner for comprehensiveness, length and lay-out. In the UK, feasibility was judged in consultation with stakeholders in the field, without contacting relatives. The reports of the feasibility testing are discussed in the consortium to make decisions about the final questionnaires and procedures.

Estimated sample sizes: Power calculation was aimed at comparing two countries with each other. Assuming coefficient of variation of true means between care homes within each country of 0.09, group sample sizes of 12 LTCFs times 4 deaths (=48) achieve 90% power to detect a difference of -5.2 in quality of dying (CAD-EOLD scale) with estimated group SDs of 6.13 and 4.67 and α=.0540 CAD-EOLD scores are based on comparative BE-NL study[28]. Based on average length of stay and size of facilities in the six countries, we estimated average number of deaths over a three-month period across the care homes is at least 4 (BE n=5, FI=4, IT=10, NL=4, PL=5, UK=4 to 12 depending on type of care home). Estimating the number of people with at least moderate dementia at time of death at 50% and taking into account a nonresponse of 20% for staff but 50% for relatives, PACE aims to include a minimum of 48 care homes (=12*2*2) per country to identify at least 192 deceased residents per country or 1,152 deceased residents across countries, 576 with relative responses.

Data analyses: Each country will enter survey data in LimeSurvey, a secure open source survey application. Double data entry is required for 5% of questionnaires (random selection) so as to assess accuracy and to avoid typing errors. If a double entry does not match the original on less than 3% of the total number of data entries, the respective partner will be asked to correct the errors. If the number of errors on any given questionnaire exceeds 3% of entries, all questionnaires must be re-entered. Analyses will focus on describing and comparing countries in terms of resident outcomes and care processes (quality of palliative/end-of-life care) (research question 1), and in terms of palliative care structures/systems at country/facility level, and staff knowledge and attitudes (research question 2). We also aim to identify the characteristics most strongly related to better outcomes for residents ie country (eg palliative care systems), facility (eg facility type, palliative care policies and structures), staff (eg attitudes), patient (eg functional status, having dementia or not) or care characteristics (perceived quality) (research question 3). As data collected in PACE are nested data (with multiple levels: resident, staff member, facility type, facility and country), hierarchical analysis techniques will be used such as cluster-robust standard errors or multilevel models as appropriate in various stages of the analyses. An in depth non-response analysis will be performed, as well as missing data analyses.

With regard to cost calculations, we will make an inventory of volumes of care based on the RUD instrument (Resource Utilisation in Dementia[29]) and costs of specific treatments in the last month of life. Prices will be calculated preferably by using unit cost prices per country. In the absence of unit cost data from all participating countries, a standard price vector based on the prices of one reference country (eg the Netherlands) will be used for all. This price vector will be adjusted for differences in price levels across countries using the technique of purchasing power parity (PPP) see for example Adang[30]. The cost calculation will be the product of prices and country specific volumes of care. To determine whether care homes with higher level of palliative care development are more efficient than care homes with lower levels and which factors influence the (difference in) efficiency, we will perform a two-stage approach by using stochastic (bootstrapped) data envelopment analysis (DEA; stage 1) and Tobit or truncated regression (stage 2) with potential confounders and case mix variables as covariates (fixed effect). In this way, we ascribe any differences found primarily to systemic differences between countries.

Ethical and legal issues: All countries obtained ethical approval from the relevant ethics committee in the country or university, except in the Netherlands and Italy where this is not needed because retrospective data of deceased residents are used (ethical committees were informed in these countries to judge whether or not formal ethical approval is needed and a waiver can be provided). The care home directors provide informed consent in writing. The questionnaires sent to the participants in the surveys are anonymous and do not collect identifiable data of respondents or residents. All participants take part on a voluntary basis hence their written responses will be taken as valid informed consent. To protect residents’ personal data, the lists of those selected for research and the questionnaires are pseudonymosed at LTCF level. The pseudonymisation key is kept by the care home directors. The involved researchers will not be informed of the deceased residents’ identity or other personal data that can reveal their identity. Although sensitive and disturbing questions will be avoided in the questionnaires, some respondents (eg close relatives) may still become distressed by some questions. Insurance cover is provided by each participating partner (usually within the frame of the general university insurance). To handle any signs of distress of the relatives receiving the questionnaires, contact details of the researchers will be clearly mentioned, a written protocol for dealing with queries and distress is made available for all researchers involved in data collection, and all researchers will keep a communication log record about the conversations.

Discussion

This PACE study will result in the first large-scale international database describing and evaluating quality and costs of palliative care in several types of care homes in Europe, based on representative samples of care homes in six EU countries. The PACE methodology described in this protocol can inform other countries on how to initiate analogous representative research in these settings. For as far as we know, such rich data collection integrating structural, system-level data with quality and costs of care, and relating these to resident outcomes, has not been done before. The different countries selected (Belgium, Finland, Italy, the Netherlands, Poland, and the UK) are a good spread of countries on a number of important parameters: they cover Northern, Western, Eastern and Southern Europe, include countries with varying histories of economic growth, with different types of health care systems and long-term care systems in particular, and with different levels of development of palliative care[6]. This can inform a large number of other countries that can use this methodology to perform analogous representative research in these complex settings.

An important strength is the measurement of outcomes (eg quality of dying) as well as care processes (eg quality of care), staff competence and attitudes towards palliative care, and care home structures/ characteristics (eg facility type, educational level of staff) and costs, making it possible to analyze associations between these different levels and make hypotheses about which palliative care practices might effectuate better outcomes in these settings. The challenge to provide high-quality palliative care in care homes is great in all EU countries. Palliative care was originally developed for and still is mainly provided to end-stage cancer patients, who typically have short and well-defined end-of-life trajectories, contrary to many older people in care homes, who have needs that fluctuate over a long period of time and trajectories that are difficult to predict. This has resulted in a lack of focus on palliative care in care homes and the question remains what the optimal systems for palliative care in care homes are.

The main limitation of the study is the cross-sectional study design. This will allow to describe and compare countries on a number of characteristics and outcomes, and to find associations between structures, processes and outcomes of care. However, such data cannot detect cause-and effect relationships; they can only lead to the formulation of hypotheses about what is needed to achieve better outcomes in care home residents. Another limitation concerns the retrospective design and the use of proxy respondents. Research has shown that the congruence between patients and proxies concerning subjective variables such as symptoms or quality of life is not always high[31]. Additionally, respondents need to recall different elements of the care provided up to three months earlier, hence some memory bias cannot be excluded. However, the use of multiple perspectives in this study (physicians, staff, and relatives) is an important advantage adding to the reliability of the data.

There are also a number of important challenges related to performing representative research in these settings. One of the main difficulties of the study design is the identification of a representative sampling frame for each country. In some countries (eg Belgium or Poland) public lists are available of all individual care homes in the country, whereas in other countries (eg the Netherlands) a lot of extra effort will be needed to prepare a full list of available facilities in the country, or alternative sampling frames will need to be identified (eg Italy). The long distances between care homes in some countries (eg , Finland, Italy, Poland, , UK) makes data collections very time consuming, and in some countries there is no strong research tradition in care homes making data collection very time-consuming for researchers. The analyses of the results will include an in-depth non-response analysis to optimally understand the representativeness of the obtained samples for each country. A particular additional challenge in this comparative research is the large diversity in sizes, organizational structures, funding mechanisms, and populations in care homes in Europe, making cross-country comparisons difficult with multiple factors and levels needed to take into account.

Conclusion

More and more people will live to a very old age in Europe and many of them will develop severe functional and cognitive deficiencies in the last years of life. The number of people dying in care homes after being admitted for a relatively short period is predicted to increase substantially. Hence, this study is timely and aims to optimally inform policy- and decision-makers at international but also at national and regional levels on the current state of affairs of dying in care homes and the possible benefits of different systems of care provision. Using the results of the six-country study, we hope to provide important recommendations that can also apply to other countries with similar health and long-term care systems as those of the countries involved in PACE. The PACE methodology can also serve as a reference for other countries that wish to initiate large-scale representative end-of-life care research in these settings.

List of abbreviations

PACE = Palliative Care for Older People

Competing interests

The author(s) declare that they have **no competing interests.**

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Table and Figure legend

Table 1 Types of care homes in PACE countries

Table 2 Measurements, unit of analyses, respondents and measurement instruments in the study

Figure 1 Care home providers by organizational status

Table

Table 1 Types of care homes in PACE countries

	Type 1 care homes with on-site care from physicians*, nurses, care assistants		Type 2 care homes with on-site care from nurses, care assistants, but off-site care from physicians		Type 3 care homes with on-site care from care assistants, but off-site care nurses and physicians	
	Available (Y) or not (N)	Label used	Available (Y) or not (N)	Label used	Available (Y) or not (N)	Label used
Belgium	N	Not Applicable	Y	Nursing homes (“woonzorgcentra”)	N	Not Applicable
Finland	Y	Long term care facilities with 24/7 care	Y	Long term care facilities with 24/7 care	N	
Italy	Y	Nursing homes (RSA)	Y	Homes for older people	N	Not Applicable
The Netherlands	Y	Nursing homes (“verpleeghuizen”)	Y	Residential homes (“verzorgingshuizen”)	N	Not Applicable
Poland	Y	Care and treatment centres (ZOL) Care and nursing centres (ZPO)	Y	Residential homes (DPS)	Y	Residential homes (DPS)
United Kingdom	N	Not Applicable	Y	Care homes (nursing)	Y	Care homes (residential)

* GPs or other elderly care physicians

Table

Table 2 Measurements, unit of analyses, respondents and measurement instruments in the study

Measurement		Unit of analysis*	Respondent*	Measurement instruments
Primary and secondary outcomes	Quality of dying of the residents	Deceased resident	Staff Relative	End-of-Life in Dementia Scales – Comfort Assessment while dying (EOLD-CAD[32, 33]) Quality of Dying Long Term Care (QoD LTC)[34]
	Resident's health-related quality of life in last week of life	Deceased resident	Staff Relative	EuroQoL EQ-5D-5L (http://www.euroqol.org/)
	Relative's health-related quality of life	Relative	Relative	EuroQoL EQ-5D-5L (http://www.euroqol.org/)
Palliative and end-of-life care processes and quality	Quality of palliative care	Deceased resident	Relative	End-of-Life in Dementia Scales – Satisfaction with Care (EOLD-SWC) [32, 33]
	Palliative care received Psychosocial interventions and religious/spiritual care	Deceased resident	Staff	Country specific questions depending on the services available eg presence of specialist palliative care in care homes
	Advance care planning and advance directives	Deceased resident	Staff Relative	Based on Belgian survey in care homes [35]
	Communication with family about the resident	Deceased resident	Relative	Family Perception of Physician-Family Communication (FPPFC)[36]
	Possibly life-prolonging treatments (artificial food or fluid, ventilation, CPR, blood transfusion, antibiotics etc), hospitalisations Treatments discontinued or not initiated Palliative sedation	Deceased resident	Staff Physician	Based on Belgian survey in care homes[37] and end-of-life decisions survey in several EU countries[38]
	Medication of the resident (opioids, antipsychotics, hypnotics, sedatives)	Deceased resident	Staff	Proposal made by consortium
Costs, resource use	Health care resource use last month of life	Deceased resident	Staff	Resource Utilisation in Dementia RUD 3.2 (part A2.1 & A2.2)[29]
Staff knowledge & attitudes towards palliative care	▪ palliative care knowledge ▪ attitudes towards palliative care ▪ self-efficacy (staff confidence in providing palliative care) ▪ interdisciplinary communication and ethical work environment ▪ patients and family communication and cultural ethical values	Care home staff	Care home staff	▪ Palliative Care Survey (PCS)[39] ▪ Move2pz[40] ▪ Self-Efficacy in End-of-Life Care Survey (S-EOLC)[41] ▪ Items selected from the IPEQS Interprofessional Practice and Education Quality Scales[42] Ethical Climate Questionnaire [43] ▪ End-of-Life Professional Caregiver Survey (EPCS)[44]
Structural and facility level characteristics	Palliative care systems in a country (the existence of legislations, regulations, and funding mechanisms for palliative care in care homes; whether or not palliative care	Country	PACE consortium member	Proposal made by consortium

	initiatives are systematically implemented in a country in this setting)			
	Facility status (see Figure 1), type (see Table 1), case-mix, size, averaged length of stay, staffing and educational level of personnel	Facility	Key management person	Proposal made by consortium
	Palliative care policies in the facility	Facility	Key management person	Based on Belgian survey[45]
	Palliative care structures in the facility: Infrastructure and access to palliative care	Facility	Key management person	EU FP7 IMPACT Structural Quality Indicators for palliative care[46]
Clinical and background characteristics	Comorbidities and cause of death	Deceased resident	Staff Physician	Based on Belgian survey in care homes[47]
	Expectation of death of resident	Deceased resident	Staff Physician Relative	Based on Dutch survey in nursing homes[20]
	Functional and cognitive status	Deceased resident	Staff	Bedford Alzheimer Nursing Severity-Scale BANS-S[48]
	Clinical judgements on dementia and stage of dementia	Deceased resident	Staff Relative/ Physician	Global Deterioration Scale stage 7 (GDS) [49] Cognitive Performance Scale (CPS)[50] Overall clinical judgement
	Sentinel events in last month of life (eg pneumonia, febrile episode, eating or drinking problem) and treatment	Deceased resident	Staff	as used in the US CASCADE study[51]
	Goal of treatment last week of life (curative, life-prolonging, maintaining function, maximising comfort)	Deceased resident	Physician	Based on care goals literature[52]
	Background characteristics (age, gender etc) and relationship to deceased	Deceased resident	Relative Physician	Proposal made by consortium
	Background characteristics of deceased resident (timing of admission, place of death, socio-demographics, socio-economic status, religion/ethnicity)	Deceased resident	Staff Key management person Relative	Proposal made by consortium
	Background characteristics care home staff (age, gender, experience, level of education, palliative care training)	Deceased resident Staff	Staff	Proposal made by consortium
	Background characteristics physician (age, gender, experience, palliative care training)	Deceased resident	Physician	Proposal made by consortium

Table 2 legend: Staff = staff member most involved in care for that resident (preferably a nurse); Care home staff = care assistants, nurses and head nurses employed in the care home and no duty at the time of researcher's visit; Physician = GP or elderly care physician

Figure

Figure 1 Care home providers by organizational status