PACE
Comparing the effectiveness of Palliative Care for Older people in long-term care facilities in Europe

1ˢᵗ User Forum
Brussels, 25 September 2015

MINUTES

Participants

- **Users and experts**
  - Alvy Dercks Tai, NL
  - Sture Eriksson, SE
  - Liz Lloyd, UK
  - Elizabeth Sclater, UK
  - Sabine Henry, BE
  - Hilary Doxford, UK
  - Peter Paniccia, UK
  - Bozidar Voljc, SL (chair)

- **PACE project partners**
  - Lieve Van den Block, VUB, BE (project coordinator)
  - Katherine Froggatt, Lancaster University, UK
  - Dianne Gove, Alzheimer Europe
  - Ana Díaz Ponce, Alzheimer Europe
  - Borja Arrue Astrain, AGE Platform Europe (organiser of the User Forum)

Discussions

(See full agenda in annex)

9.30 – 9.35	**Introduction to palliative care**	Lieve Van den Block, PACE coordinator

After the welcoming remarks by the chair Bozidar Voljc and a tour de table to introduce all participants, **Lieve Van den Block** introduced the topic. She explained that 40 million people worldwide need palliative care (PC), but that only 50% actually receive it. Traditionally PC has been delivered only at the very end of the life, and has not been treated as something that could take place already earlier. The lack of timely implementation of palliative care results in older people suffering from severe symptoms throughout their illness, experiencing fragmented care and not living according to their preferences.

She explained that PC is for all people with serious or life threatening issues, for instance frail old people – target of the PACE project – and that it needs to focus on helping people with such conditions live well. It should prevent the use of inappropriate healthcare and ensure old people live and die according to their own preferences.

PC is divided between specialist and general PC, the latter being the one that any regular caregiver should be able to provide. Unlimited access to specialist PC would not be sustainable, a mix with general PC is therefore needed.
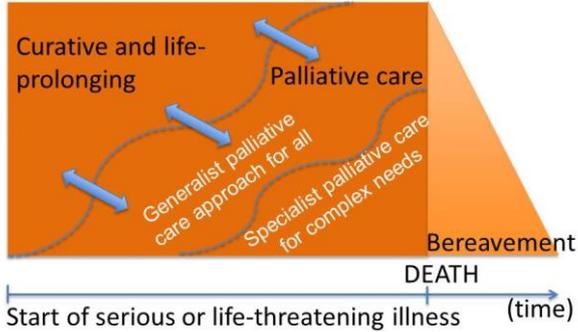
Lieve also explained that PC needs to be provided together with curative care. In the management of chronic diseases care is often linked to the *illness*, and the *needs* are forgotten; PC needs to be available in order to satisfy those needs. It should be available in any setting, and PC is not linked to any particular disease but rather any life-threatening disease.

9.35-10.15	**Group work: quality palliative and end of life care**	Moderated by AGE

Participants had the chance to react to Lieve's presentation. **Sture Eriksson** stressed the importance of differentiating care and cure, and of not stopping the curative side, as this can serve as an encouragement. He agreed that PC is still very often linked to end-of-life care, and he wondered how the term or its traditional meaning can be changed so that the automatic association disappears. **Dianne Gove** highlighted the importance of not assuming that merely changing the term palliative care or minimising references which associate it with the end of life will resolve the issue, as well as the problem of inconsistency in the use of the term amongst healthcare professionals. She suggested the need to explore further the meanings that lay people attach to these terms (as well as to terms linked to dementia) as the way they make sense of whatever terms are used may determine their readiness to engage with the prospect of palliative care. Lieve said that changes in terminology have been considered in order to eliminate the negative connotations or very narrow understanding of PC – such as using the expression "supportive care" instead. She reminded the difficult challenge of talking of issues surrounding death, something about which people don't like talking. **Bozidar Voljc**, chair of the forum, also highlighted the difficulty of challenging the traditional conception of PC.

The organisational aspects were also taken into consideration. Lieve explained that the health systems and the organisation of tasks need to change in order to integrate a new,

wider understanding of PC in an adequate way. She linked the organisational challenges to those facing the integration of care, and highlighted that the sharing of values that already exists between most professionals should serve as a good basis for the organisational changes needed. With this regard, Sture, whom agreed with the need to rethink the organisation of care, highlighted the difficulty of expecting general practitioners (GP) to cover all areas. He wondered how PC can be integrated in the service provision, as not all institutions and professionals have the capacity to cover everything.

Bozidar highlighted the important role that GPs need to play: they need to be aware of their limits, but their role is strongly needed. In this sense, Lieve highlighted that GPs need to receive further training on communication skills and that they also need to get closer to the reality of death: many GPs start their professional careers without having ever seen a person die; they are "too far" from death, and also from PC.

The necessity for an active involvement of PC recipients was also discussed by the Forum. **Ana Díaz Ponce**, from Alzheimer Europe, explained that it is essential that recipients of PC play an active role. In the same sense, **Hilary Doxford** highlighted the importance of the social context, especially families. She expressed her concerns about the impact of the weakening family ties in the quality of life of people in need of PC. Currently more cure than before is provided, but death takes place less often in a good way. She highlighted the importance of patients' spiritual side, and how that shapes their attitudes regarding a serious chronic or live threatening issue.

Regarding pain, **Liz Lloyd** mentioned the concept of "biographical pain", which represents pain as a disruption in a person's biography and highlights the need the person feels for an empathetic and accommodative social context. She explained how people in poor health in old age become unhappy, and how pain impacts negatively their state of mind. In reaction to this, Hilary highlighted how some pain can actually play a role in keeping a person with a serious or life threatening health condition alive; she explained that pain can play the function of reminding someone in that situation the need to seek cure and fight to move out from it. She called to take into account the psycho-social conditions of the person. Both Hilary and **Peter Paniccia** stressed the importance of family and home as essential elements, given the challenges facing the sustainability of PC.

10.15-10.20	**Wrap up on group work**	Lieve Van den Block, PACE coordinator and Katherine Froggatt, Lancaster University

As a wrap-up, Lieve summed up the issues that were raised during the first part of the meeting. She highlighted the importance given to satisfying individuals' needs, which requires important changes in the organisation of care; and also the general agreement of the User Forum with the need to move out of the narrow perspective of PC as purely end-of-life care. As a final remark, Sture highlighted the need to think about the topic in a truly comprehensive way.

10.40 – 11.00	**Overview of the PACE project**	Lieve Van Den Block, PACE coordinator

The second part of the Forum started with a presentation of PACE by Lieve. As a response to the questions of the participants of the User Forum, she explained that the project focuses on long-term care facilities (LTCFs), but that the policy recommendations to be developed at the end of the project with the key input from the User Forum should go beyond facilities. She presented a graph that shows how in Belgium, taken as a representative example, more and more people are dying in care / nursing homes.
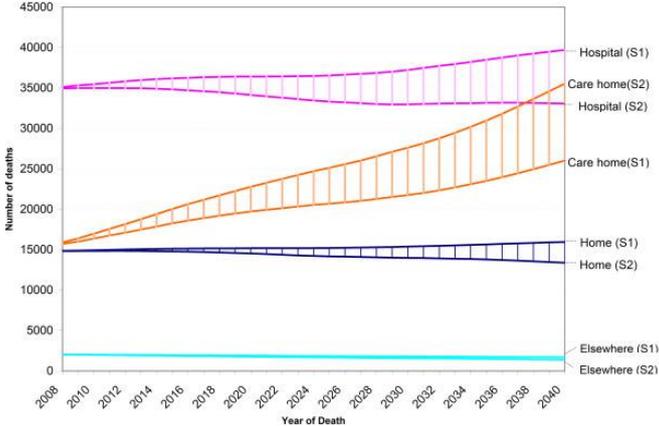
She explained that there is a number of risks, including the risk of overtreatments and the lack of access to PC in such settings. She explained also how care homes risk becoming stigmatised as places where people die. This tendency raises critical issues such as when to transfer a person who is approaching death to a hospital.

This set the scene to explain the approach adopted by PACE and the studies that the project aims to deliver:

1. A report describing PC in LTCFs in Europe
2. A cross-sectional descriptive study (so called "study I")
3. A cluster randomised controlled trial to integrate PC in LTCFs, through the "PACE Steps to success" intervention (so called "study II").

The expected impact of the project is to assist policy and decision-makers in adopting and implementing the best possible PC practices in LTCFs.

Lieve explained the ambition of the study I, which is "to compare the effectiveness of healthcare systems with and without formal PC structures in LTCFs in six EU countries" by looking at:

• Quality of dying
• Quality of palliative and end-of-life care
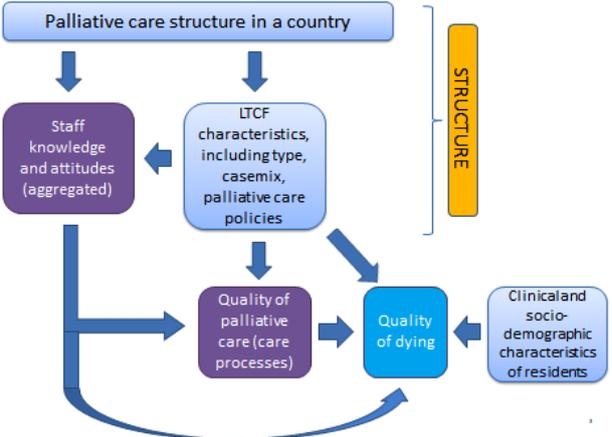
- Staff knowledge and attitudes
- Cost-effectiveness

She presented a comparison between practices in Belgium and the Netherlands. In the former, the GP is the patient's main treating physician even after the person has been admitted to the nursing home, while in the latter nursing homes have a physician specialist on care for older people who becomes the treating physician upon admission. The comparison between the two countries shows that relatives have similar levels of satisfaction regarding the PC provided, but their views are very different regarding the comfort while dying, with relatives in the Netherlands showing a higher level of satisfaction. One reason for this might be that Dutch professionals interpret better when or how a person dies.

The project will elaborate on these analyses for the 6 countries included in the project – Belgium, Netherlands, United Kingdom, Finland, Poland and Italy.

11.00 – 12.00	**Palliative care policies, long-term care policies: experiences from European countries**	Overview by Katherine Froggatt, Lancaster University and contributions of the participants

Katherine Froggatt presented the report describing PC in LTCFs in Europe. She explained that the report starts with a study of the current availability of LTCFs in order to describe trends in use (proportion of older people in LTCFs). The report also maps the existing legislation and policies on LTC, LTCFs and PC. She explained how policies tend to support living at home but not necessarily dying at home – which won't be actually possible for many. She presented a graph showing the % of deaths in LTCFs:
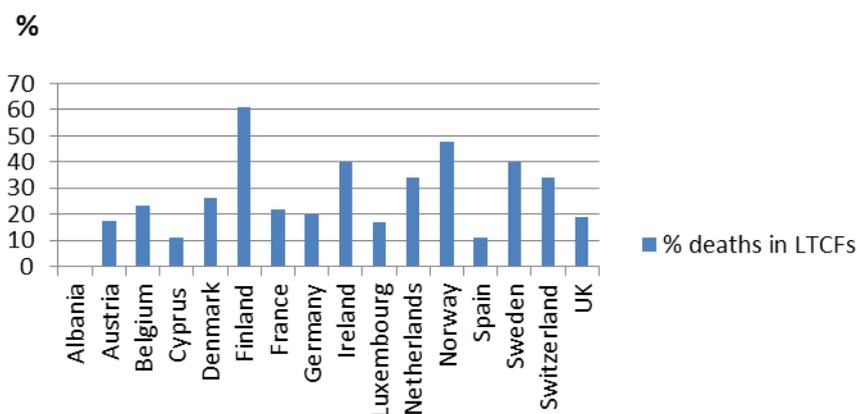
The high proportions in many countries raise the question on how to know when the moment of death comes and the difficulties surrounding death in general.

She explained that even in cases with advanced integration, PC is not properly integrated in nursing homes. Available data on PC policies and practices from the European Association for Palliative Care (EAPC) is reduced in scope as it focuses on cancer.

The report classifies countries in four groups according to the level of integration of PC and the LTCF policy engagement:

- Active policy engagement: Austria, Belgium, France, Switzerland and the United Kingdom

- Broader policy only (ageing, dementia): Denmark, Hungary, Italy, Portugal, Norway and Spain
- No engagement: Albania, Croatia, Cyprus, Czech Republic, Greece, Iceland, Latvia, Lithuania, Luxemburg, Netherlands, Poland, Romania, Sweden and Turkey
- NGO engagement (hospice/LTCF-led): Germany

The participants of the User Forum had the chance to verify the information available for their countries of origin (United Kingdom, Netherlands, Belgium, Slovenia and Sweden) and provide clarifications and updates, which were used to update the report accordingly.

13.15 – 14.30	**Introduction to the PACE 'Steps to Success' programme in palliative care** (15 min)	Katherine Froggatt, Lancaster University
	Discussion with experts on **implementing interventions for quality palliative care in long-term care facilities**: building recommendations for policy and decision makers	Discussion moderated by Bozidar Voljc

Katherine continued the session with a presentation of the PACE Study II 'Steps to success', which is a key component of the project. She explained that these steps are based on a UK intervention, to be adapted and tested in the countries represented. The steps to implement high-quality PC in LTCFs are the following:

Katherine explained how the implementation process takes place, including the training of the trainers and the resources developed in order to train and inform LTCF staff, PACE coordinators and the country trainers. **Sabine Henry** highlighted that quality communication between all actors is key in such an implementation process, and that it should take place through personal communication rather than in writing. Regarding the training package, participants asked to what extent it will be adapted to the different countries where the

intervention will be implemented. The protocol states that trainers will contact the LTCFs and arrange a first meeting to discuss PC delivered at the current time in the LTCF. In doing so, they acknowledge any documents that are already using related to PC and ensure there is no 'double work' being done e.g. if a LTCF already uses a certain ACP document, then it could be that they may continue to use that instead of the PACE document. Lieve added that the intervention will be implemented in 8 (i.e. in CH and PL) or 12 (i.e. in UK, IT, BE, NL, FI) facilities per country where key staff members will devote 0.5 days a week to PACE. A set of indicators have been designed in order to observe how each step is implemented (e.g. an attendance list will be completed at each training session to state the reach of the training programme).

Regarding the engagement with the staff, Lieve highlighted the importance of communication, and described the two possibilities to be used: either an 'opportunistic' communication strategy – letting people talk – or a planned conversation. With this regard, **Elisabeth Sclater** reminded that staff in nursing homes / LTCFs is extremely busy and would maybe tend to forget the steps/procedures involved in the implementation of the practice. She explained that making this happen is a challenge that requires good communication and that it is very important to engage with the board of directors of the given LTCF to ensure the successful implementation of the steps. Other participants highlighted that families are also involved in advanced care planning, and that a systematic approach to the implementation needs to be combined with some adaptability and dynamism.

Upscaling the 'Steps to success' and making them feed into public policy is a concern for which the coordinator Lieve Van den Block requested User Forum's input. Elisabeth pointed to the important role played by the inspection and oversight regimes of each country on nursing homes. She suggested the project to identify and contact the board or institutions in charge of such inspection as a way to influence policymaking.

Training was highlighted by participants as a key element for the success of the practice. Liz suggested that it would be important that, in case countries have training bodies for staff working in LTCFs, these are identified and contacted in order to influence curricula and hopefully favour the adoption of the 'Steps to success'. In the same line, Elisabeth talked about the need to influence the training programmes of private companies and service providers, which have an important weight in the LTC sector. Sture encouraged the project to get inspiration from other research projects, such as RICHARD, which developed a toolkit with detailed steps on how to create supportive environments for the implementation of complex innovative interventions so that these can flourish.

Also regarding training, Bozidar highlighted that the UK organisation for family practitioners does offer trainings that the project could target. Regarding university education for health professionals, he explained that in Slovenia it is the Medical Chamber who decides the curricula of doctors. However, he warned of the risk that the implementation of the practice could face difficulties in case finance ministers consider it to be too costly. This highlighted the importance of taking into account the financial aspect when trying to push for the up-scaling of the steps and their integration in public policy.

Elisabeth mentioned the importance of engaging with inspectors and also with the volunteers at the local level. Katherine explained that the policy messages of the project should aim at targeting the different policy levels, the European Union, the European countries and also the local level, which requires tailoring them to the roles/competences of each level. Liz added that it is better for the intervention to be led by practice, with which Lieve agreed while stressing also the need to respect, at least minimally, the steps implemented by the project.

Liz highlighted the important role that families need to play in the process. All participants to the User Forum agreed with this point. According to Katherine and Elisabeth, this is even more important given the uncertainty that characterises the process of provision of PC.

Referring to the case of the UK, Hilary explained that the National Dementia Strategy should become policy, and that dementia is a point of entry in the issue of PC. Bozidar elaborated on this by saying that, in the case of Slovenia, there was strong stigma around dementia and Alzheimer in the past, and that this has improved considerably in the last years; in his opinion, this is a positive example proving that there is probably room for destigmatising also PC. He added that PC for people with dementia is also about preparing the family; he called for a comprehensive approach as an essential element to PC, similarly to the comprehensiveness that characterises general practice.

Lieve commented that PC for older people with dementia is less well taken into consideration than for people suffering cancer, given the strong consciousness about this illness. Peter reacted saying that building on the work already done on PC for people with cancer and learning from it can actually be helpful to make the case for PC also for older people with dementia.

It was suggested that most people, especially with dementia, in care homes have incontinence. Dianne pointed out that whilst this is one of the common reasons often influencing the decision for a person with dementia to enter into a care home, incontinence in care homes is often due to poor management (putting people in continence pads due to insufficient staffing and failing to take appropriate measures to maximise continence for people with dementia).

The issue of comprehensiveness, which was highlighted by several participants in different moments, gave way to a discussion on the community approach and wider policy approaches such as dementia-friendly and age-friendly cities. Participants highlighted that PC is largely absent from such strategies. Lieve stressed the importance to embed the issue in wider policy discussions or in policy discussions not obviously but actually linked to the provision of quality PC.

14.30-15.00	Main outcomes of the User Forum (to be circulated after the meeting to all participants for comment/feedback) to send eventually to the PACE consortium	Evaluation tour de table moderated by AGE

The meeting ended with a tour de table that allowed all participants to highlight their views, reflections or any reactions on the basis of the discussions.

Elisabeth expressed that the meeting was useful to better understand PC.

Alvy Dercks Tai highlighted the importance of cultural differences on this issue, and called to take them further into account by integrating migrants in the analyses – which was positively received by Lieve, who explained, however, that the sample used by the project is too small to include them in a meaningful way.

Sabine explained that talking about PC for people with dementia should bring to talk about PC for all people who need it.

On her side, Liz, highlighted the importance of the implementation issues, and how essential it is to take into account the preferences, which vary not only across countries but also within them.

Sture said that it is essential to make correct diagnoses and establish a correct treatment. He added that staff education is crucial, and that sustainable implementation is a challenge – he explained that this it requires avoiding excessive staff turnover.

Hilary said that he was satisfied with the views shared by the participants. She stressed the importance of bearing in mind that one size doesn't fit all, and showed her satisfaction that PACE adopts this approach. She also spoke about the challenges facing PC, such as the fact that some people don't want to know about it. She said that, when they happen, wrong diagnoses have a very strong impact and called to take fully into account the spiritual and community sides of PC, which in her opinion are essential.

Ana said that the meeting showed the potential of PC and the need to reflect the diversity in Europe regarding the issue. Dianne added that the meeting had highlighted the complexity of the topic, and also stressed the importance of taking into account the diversity of perspectives.

Bozidar said that PC cannot be treated as a separate entity, and that it needs to be integrated in other programmes. He suggested integrating PC in initiatives such as AFE-Innovnet, which pushes for the design of age-friendly environments with a multidisciplinary and comprehensive policy approach. He asked for further reflection on how to connect PC with other EU projects. He said that PC needs to become more 'domestic' or familiar to everyone.

The tour de table ended with Lieve's remarks, who agreed that PC has been marginalized and that it shouldn't be seen as a separate intervention. She said that supporters are needed to help integrate PC into public policies.

At the end of the session, Borja informed all participants that the minutes would be circulated for comments before consolidation. He also explained that the User Forum will keep meeting in the near future in order to further exchange views and share knowledge to feed the Policy Recommendations that will be produced by the end of the project.

PACE project User Forum

Draft agenda - 25 September 2015

Venue: Brussels – Kartuizer center - Rue des Chartreux 70, 1000 Bruxelles, Belgium

Main objectives of the User Forum: introduce PACE project to the experts (older people and persons with dementia representatives), collect their experiences and views from different countries on palliative care, get their feedback on the methodology and provide a basis for the elaboration of policy recommendations on palliative and end-of-life care in long-term care facilities in Europe.

Participants:

- Alvy Dercks Tai, NL
- Sture Eriksson, SE
- Claudia Kaiser, DE
- Liz Lloyd, UK
- Elisabeth Scatler, UK
- Bozidar Voljc, SL
- Hilary Doxford, UK
- Peter Paniccia, UK
- Sabine Henry, BE

- Borja Arrue Astrain, AGE Platform Europe
- Dianne Gove, Alzheimer Europe
- Ana Diaz, Alzheimer Europe
- Lieve Van den Block, VUB, BE
- Katherine Froggatt, Lancaster University

9.00-9.10   Welcome by Chair and Introduction to the User forum by Borja Arrue, AGE Platform Europe

9.10-9.30   Tour de table

9.30 – 9.35   **Introduction to palliative care** by Lieve Van den Block, PACE coordinator

9.35-10.15   Group work: quality palliative and end of life care moderated by AGE

10.15-10.20   Wrap up on group work by Lieve Van den Block, PACE coordinator and Katherine Froggatt, Lancaster University

10.20 – 10.40 Coffee/Tea break

10.40 – 11.00 **Overview of the PACE project** by Lieve Van Den Block, PACE coordinator

11.00 – 12.00 **Palliative care policies, long-term care policies: experiences from European countries**

- Overview by Katherine Froggatt, Lancaster University (15 min)
- Exchange of experiences with experts on policies (45 min)

12.00 – 13.15 *Lunch break*

13.15 – 13.30 **Introduction to the PACE 'Steps to Success' programme in palliative care**, by Katherine Froggatt, Lancaster University

13.30 – 14.30 Discussion with experts on **implementing interventions for quality palliative care in long-term care facilities** : building recommendations for policy and decision makers

14.30-15.00 Main outcomes of the User Forum (to be circulated after the meeting to all participants for comment/feedback) to send eventually to the PACE consortium