

# PRoF Award abstract – Call 2015

## <Project acronym and name>

### 1. Research Outline

Acronym	COMPALL
Project name in English	Comfort in Palliative care
Pitch (1 sentence)	Development of a patient-centred system for monitoring comfort and awareness in palliative patients who want to die at home.
Executive summary (max. 10 lines)	
<p>Please provide an executive summary of the project, maximum 10 lines</p> <p>Once death is imminent, a major concern is to assure patients maximal comfort. Two conditions are pivotal: 1) being free of pain and other symptoms and 2) dying surrounded by the loved ones in a familiar setting (which is usually at home). However, both conditions are now often not fulfilled. With our monitoring system we aim to assess pain and awareness in patients to assure them a comfortable death at the place they prefer. This system is based on interdisciplinary research from the social sciences, neurosciences, anaesthesiology and engineering. In the future this might lead to a regional monitoring system making all essential information available in real-time to palliative home care team, the treating physician and –in a non-technical way – to the family members.</p>	

## 2. Cause and context of the research

Once death is imminent, a major concern is to assure patients maximal comfort. Two conditions are pivotal:

1. being free of pain and other symptoms such as dyspnea, and delirium,
2. dying surrounded by the loved ones in a familiar setting (which is usually at home).

Notwithstanding that 1) most patients prefer to die at home, 2) the fact that this improves the quality of the dying process and 3) dying at home saves costs, many patients still die

- in a hospital and
- are experiencing pain and distress.

A main problem for assuring optimal comfort has to do with the measurement of pain and well-being. The golden standard for assessment of pain is simply to ask it the patient and the most often tool used is a Visual Analogue Scale (VAS). However, many patients in the last phase of life have become unable to communicate. Therefore, caregivers have to assess comfort of the patient. As we showed in a paper, behavioural assessment is not always a reliable method (Deschepper et al, 2013). Many patients are sedated with the aim that they do not experience the (refractory) symptoms leading to unbearable suffering such as intolerable pain, dyspnea, and delirium. However, patients are sometimes mistakenly considered to be unaware and consequently might experience pain and distress. (Monti et al, 2010; Sanders et al, 2012)

Because of the importance attached to a comfortable death, palliative home care teams are now more and more involved. However, due to insufficient staff and budget restrictions, these teams are increasingly overburdened and hence innovative ways are needed to address the growing need for palliative home care.

## 3. Innovation results achieved

The aim of our project is to assure patients a comfortable death in a familiar setting, for instance at home or at a WZC.

To ensure this we have developed a new way to monitor comfort and depth of sedation (in case patients are sedated) that is not merely based on –unreliable- subjective and behavioural assessments. We can do this by using EEG-based technology (NeuroSense-monitor) as used in the operating theatre. We also have found indicators for a more objective assessment of pain and discomfort. Although we have now basic knowledge on assessment of pain, we are still working to improve ways to optimally assess comfort and wellbeing by using some simple neurophysiological indicators. This enables real-time and remote monitoring.

However, assuring a comfortable death does not depend solely on technological innovation and therefore we also need a thorough understanding of what dying patients experience and what they really want. Therefore we have conducted interviews with palliative patients to find out what really important to them (Deschepper et al, 2003, Benoot et al 2014, Pardon, 2011)

Based on the above achievements we are now developing a system to monitor palliative patients who wants to die at home. By using some small wireless sensors, real-time detection of awareness and comfort is possible. This information is combined with information about preferences of the patients about how and where patients want to die. In the future this might lead to a regional monitoring system where all essential information will be available to a central palliative care centre (where patients can be monitored 7/7 days, day and night) and the treating physician(s). In principle, also the family can be informed in a non-technical format, for instance, to assure them that their family member is not suffering, or in case on an imminent death, to warn them.

#### 4. Link to the PRoF values

Our project focuses on assuring comfort and well-being of the vulnerable group of dying patients, especially those who are unable to communicate. We have used new technologies from the neurosciences and anesthesiology to ensure a safety of the dying patients. By ensuring good conditions to die at home and optimal monitoring by palliative home care teams, we believe many deaths in the hospital can be avoided. Dying in a hospital increases the risk of dying without being surrounded by their loved ones which is a main concern of patients and their families.

To our knowledge, this is the first endeavour to develop a patient-centred holistic monitoring system to enable a comfortable death at home, including patients who cannot communicate anymore and who are in their most vulnerable stage of life.

The innovative character of the proposal is in the combination of recent scientific evidence regarding the subjective experience of pain and distress in (non-communicative) dying patients, the use of patient-centred information (subjective experiences and preferences), advanced technology such as bio-sensors as objective indicators of comfort, especially in non-communicative patients, and ICT to ensure continuous remote monitoring of these patients.

Our project is truly interdisciplinary by combining methods from 'positive' sciences (medicine, engineering) with methods from the humanities (qualitative research about the preferences and perspectives of patients and their family).

#### 5. Applicable IPR rules

We are working on algorithms for measurement of pain and these will be protected. However in principle all our other findings and insights will be published and be made available to the widest possible audience.

#### 6. Information on the partners

The applicant, Prof. **Reginald Deschepper**, is an anthropologist with expertise in end-of-life care and qualitative methods. He is now working at the Mental Health and Wellbeing Research Group (Vrije Universiteit Brussel), together with **Prof. Johan Bilsen** (nursing, health sciences) and a team of about 10 researchers (psychologists, sociologists, a neurologist, ethicist...). For this project they cooperate with:

**Prof. Steven Laureys** leads the Coma Science Group at the Cyclotron Research Centre at the University of Liege (ULg) (> 300 publications). His expertise is on residual brain function in coma and other non-communicative patients, including experience of pain and quality of life. His research confronts clinical expertise and bedside behavioral evaluation of consciousness with state-of-the-art multimodal imaging, including EEG.



**Prof. Sabine Van Huffel**, KULeuven, is a world expert in biomedical signal processing, (multi)linear algebra, (non)linear signal analysis, classifications and system identification, with special focus on the development of numerically reliable and robust algorithms for improving medical diagnostics. She leads the research group BIOMED (> 500 publications).

**Prof. Stefaan Vandenberghe** works in the MEDISIP research group in Ghent University, where a variety of topics is covered: Monte Carlo simulations, rotating slat SPECT, Time-of-Flight PET, PET-MRI and quantification for radionuclide dosimetry. He co-authored about 80 scientific journal papers and is coinventor of four patents. During the last years his research has focused on the EEG source localisation, SPECT imaging, the development of attenuation correction and PET system design simulations for PET-MR in two EU-FP7 projects.

**Jan Poelaert** is head of the dep. Anesthesiology (Vrije Universiteit Brussel en UZBrussel) and has a large and long clinical experience in acute and chronic pain treatment, including use of BIS monitors. His research includes topics that are pivotal for this project such as intra-operative awareness, cerebral neurobiology and administration of Propofol in patients with Brugada Syndrome.

**Nicole Vandeweghe** is a physiotherapist and trainer in stress regulation and biofeedback. She is director the Association for Biofeedback and Self-regulation. She has 25 years of experience with psychophysiological monitoring.

## Main References

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## Addendum: Contact information

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