



# **Guidelines for training**

**links United for Coma  
Awakenings**

**L.U.C.A.**



With the support of the Lifelong Learning programme  
of the European Union



## Participating organisations

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- \* **Coma Science Group**, GIGA & CHU Sart Tilman Department of Neurology, University of Liege, **Belgium**
- \* NGO “**My world**”, Harmanli, **Bulgaria**
- \* **National Technical University of Athens** (NTUA) - Intelligent Systems, Content and Interaction - Laboratory (ISCIL), **Greece**
- \* **Spanish Society of Health and Social Care** (SEAS), Valencia, **Spain**

## Supporting organisations

- \* **Gli amici di Luca**, Bologna, Italy
- \* **Nueva Opción**, Valencia, Spain

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## **Introduction**

### **1.1 L.U.C.A. Project – Links United for Coma Awakenings**

These guidelines are one of the main results of L.U.C.A. project, a Grundtvig partnership funded with support from the European Commission within the Lifelong Learning Programme. The coordinator is Futura Soc. Cons. r.l., Italy, in collaboration with the Association “Gli Amici di Luca”, the partners are the Coma Science Group, GIGA & CHU Sart Tilman Department of Neurology, University of Liege - Belgium, the Spanish Society of Health and Social Care (SEAS) - Spain, the Association “Moyat Svyat” (NGO “My Worl”) - Bulgaria, the National Technical University of Athens (NTUA) with the Intelligent Systems, Content and Interaction Laboratory (ISCIL) – Greece. The partnership was aimed at exchanging experience and good practices in the field of formal, non-formal or informal learning of people awakened from a coma with acquired brain injury and people accompanying them in their new project of life (family members, volunteers, experts).

L.U.C.A. partners are subjects (training institutions, research centers, associations and groups of family members and volunteers) that accompany people with acquired brain injuries (in particular after a coma) to redesign their own family, social and work life. They also teach to family members, professionals, volunteers and, more generally, citizenship and institutions, to play an active role for promoting the citizenship rights of people with disabilities. Starting from the comparison of best practices, implemented by

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partners, these common Guidelines were produced for training, consulting and coaching of people awakened from a coma as well as for their family members/caregivers and volunteers. In particular, the partners focused the discussion and these common guidelines on the issues of the rights of persons with acquired brain injury, the role of associations representing the family, the quality standards in the therapeutic facilities as well as when returning at home, and finally the methodologies for social and employment reintegration.

### **1.2 Key points**

Some “key points” were shared by the partnership during the project development: important elements to be considered, related in a general sense to the target audience, not only in training activities addressed to them.

1. **Different needs:** in the acute phase, the family caregivers usually go through an emergency or crisis state, including despair, confusion, and disorientation. In the post-acute phase, usually with the patient in a rehabilitation unit, uncertainty about the future dominates. The burden for the family increases because of the efforts involved in ensuring constant attention, and coping with the unavoidable changes in the family routine, including less time for themselves. Furthermore, patients’ problems and difficulties can cause stress, burn out, depression and anxiety in the families. They most commonly need information about prognosis, treatments, and services, as well as

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emotional and social support. The family expresses the need to be informed on matters related to the coma outcomes and the possibility of re-socialization and rehabilitation interventions.

- 2. Consequential care project and system:** in order to help the families of patients with severe acquired brain injury, it is important to evaluate daily practical problems, the emotional burden, problems in dealing with the patient's disability, and the needs of family caregivers. Health professional, non-health professionals (e.g., social workers, educators, social operators) and volunteer/non-profit associations (both those including volunteers and paid workers) must be involved to provide support for the families of patients with severe acquired brain injury, to explore their opinions, needs, activities. Medical staff and caregivers operate in a complementary way on the basis of an explicit formal "care contract" that is amended from time to time. A multidisciplinary training group allows the creation of a professional team in constant evolution with a positive impact to meet the patients and their families' needs.
- 3. Economic burden:** After the patient returns to home, the family must support many expenses that affect the family budget, such as a professional caregiver with a category contract (e.g., nurse, physical therapist), pharmaceutical

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costs, increases in utilities (water, electricity, gas), arrangement of the house with removal of architectural barriers and installation of lifters, possible purchase of a suitable mean of transport, and specialized medical analyses. The actions are activated in a flexible way according to specific needs, based on a personalized program that is defined by the social and health services in the area. These measures can be of economic nature:

- Welfare benefits
- Tax incentives
- Economic support
- Education and training
- Respite or support services
- Promotion of leisure activities, subsidized holidays, ...
- Discounts on public transport, etc.

4. **Inter/multidisciplinary team:** The partnership shares the importance of interdisciplinary working group in the path during and after the coma.

- **Different experts: health professionals** (doctors, neurologists, psychologist neuropsychologist, physiotherapists, speech therapists, nurses, occupational therapist) and **non-health professionals** (social workers, educators, music therapists, art therapists, social pedagogist).
- **Families:** families of patients with acquired brain injury are involved in

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the training process in order to evaluate daily practical problems, but also to help them increase their knowledge on matters related to the coma outcomes, decrease their emotional burden, and showing them the possibility of re-socialization and rehabilitation interventions.

- **Associations:** working with and without volunteers and who provide information, orientation and council to the patients and their families and carry out projects to provide occupational therapy, leisure activities, in-home and hospital-based assistance, training to the families and principal caregivers, fight for the right of patients, preventing programs and development of research.

5. **The importance of developing an active and conscious role of family:** the relatives' support must be positive and profitable and in line with the advices of the operators; if possible, it will be useful to alternate their own availability and get away according to the times and the ways suggested, especially with the volunteers' activities and stimulation sessions. In some countries, the cooperation between the Local Health Authority and the Associations offers a theoretic and practical training to the families in order to grow up a conscious role of caregivers in the path of rehabilitation.



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6. **Public and private domains:** In the relationship between local government and central government, the role of associations can be very important as mediators of an "action of proximity" and as promoters of projects of analysis and evaluation of the problems, especially in those contexts with less public services supporting integrated care. Tools for the action are: conventions and partnerships with health institutions and local administrations.
  
7. **Hospital/rehabilitation centre/home:** The family is the 'hub of care' for patients with severe acquired brain injury once discharged after the acute and post-acute period in the hospital. The family expresses the need to be informed on matters related to the coma outcomes and the different possibilities after the hospital: rehabilitation centers, residential facilities, assistance at home, services provided by private companies, associations or NGO's etc. and on the possibility of re-socialization and rehabilitation interventions.
  
8. **Social reintegration and personal autonomy:** To support a positive outcome of the rehabilitation path, a personal autonomy and a social reintegration of the people with severe acquired brain injury and training activities must be developed through occupational therapy and workshops of rehabilitation including several activities such as using no-

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verbal means of communication (e.g., theatre, music, arts), relational and social skills laboratories/workshops, overcoming emotional blocks and expressive tensions, and raising awareness of their situation (psycho-educational interventions). These activities should be developed by interdisciplinary teams of professionals such as psychologists, physiotherapists, occupational therapists, etc.

9. **Unresponsive does not mean vegetative!:** The term "vegetative state" is misleading, risks to lead to think about the person who lives this situation by assimilating her/him to a vegetable. To dispel this mental association, the partnership prefers to use the term "unresponsive". The number of people who have been diagnosed with this condition has significantly decreased over time and current diagnostic tools and current knowledge lead to find more often situations of minimally conscious state <sup>1</sup>. Provocatively Professor Giuliano Dolce member of the group on the vegetative states at the Italian Ministry of Health asks the question: the unresponsive state really exists?

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<sup>1</sup> **Minimally conscious state (MCS):** a clinical disorder of consciousness wherein patients are awake but show fluctuating signs of awareness without being able to functionally communicate with their surroundings.

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10. **Misdiagnosis:** Another important issue raised and shared by the partnership is related to misdiagnosis. The clinical assessment of consciousness is primarily based on observation of spontaneous and stimulus-evoked behaviours. Arousal is measured by eye opening and awareness is assessed by command-following or the search for other non-reflexive behaviours such as visual pursuit or localization to pain. Misdiagnosis is unfortunately very frequent when based on clinical consensus. According to a European study (Schnakers et al., 2009<sup>2</sup>), the misdiagnosis of the people with Unresponsive Wakefulness Syndrome<sup>3</sup> stands at a figure of 41%. The most sensitive scale to differentiate conscious from unconscious patients is, to date, the revised version of the Coma Recovery Scale (CRS-R)<sup>4</sup>. In the intensive care unit, a

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<sup>2</sup> Schnakers C, Vanhaudenhuyse A, Giacino J, Ventura M, Boly M, Majerus S, Moonen G, Laureys S. Diagnostic accuracy of the vegetative and minimally conscious state: clinical consensus versus standardized neurobehavioral assessment. *BMC Neurol.* 2009 Jul 21;9:35. doi: 10.1186/1471-2377-9-35.

<sup>3</sup> **Unresponsive wakefulness syndrome (UWS):** a clinical disorder of consciousness wherein patients are awake but not aware of themselves and their surroundings.

<sup>4</sup> **Coma Recovery Scale-Revised (CRS-R):** behavioural scale developed to assess the level of consciousness in patients recovering from coma. This scale has been specifically introduced to differentiate unresponsive from minimally

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routine use of the Full Outline of Unresponsiveness scale, faster to administered, is also recommended. Specific assessment material (e.g., a mirror, the patient's own name) should also be employed to increase sensitivity. On the patient side, some factors potentially causing decreased responsiveness should be taken into account: motor impairment, aphasia, agnosia, blindness or deafness, fluctuation of vigilance, and the presence of pain. Other medical complications (e.g., infections) and sedating medications might also complicate the assessment of patients with brain injuries. These elements should be investigated during the assessment of the level of consciousness in patients suffering from brain injuries.

In these clinical situations in particular there is the need to ensure the highest degree of diagnostic accuracy since this is an area with still many elements of uncertainty.

In Italy 24 Medical Associations have developed a study "VESTA" (Vegetative States) coordinated by prof. Roberto Piperno director of the House of Awakenings Luca de Nigris to increase knowledge on the unresponsive wakefulness syndrome for the impact it has on patients and on the Code of Ethics. This is the first systematic survey in Italy on diagnostic aspects of unresponsive wakefulness syndrome

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conscious patients and it tests auditory, visual, motor, communication and arousal functions.

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and minimally conscious state, understood as conditions of extreme disability. The study aimed primarily to evaluate the influence of the misdiagnosis in the clinical Italian context: it found that this is placed on the lowest values (31%) compared to those found in other European countries. The study also promotes the growth of community's attention to the problem of clinical diagnostic accuracy and dissemination of "best practices" in the path of diagnostic tests.

Second, the project VESTA analyses the possible change in the phases considered of irreversible chronicity. Minor modifications of behavioural and relational framework, although with no substantial significance in terms of personal autonomy, however, can bring about a change in the perception of family members, constituting a primary factor in the overall wellbeing of the family unit.

### **1.3 Training - general presentation**

These guidelines intend to offer useful information and key points shared and considered essential by the L.U.C.A. project partnership to anyone who wants to organize a training course for:

- persons with acquired brain injury, especially after a coma
- family members/caregivers and volunteers
- health and non-health professionals

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The aim of the courses is to facilitate a positive outcome of the rehabilitation path, social reintegration and employment of people who have acquired brain injury, acting on the social context, through awareness-raising and cultural promotion, enhancing the value of acceptance and respect for the dignity of the person in the community.

The learning of personal, relational and social skills necessary to tackle the acquired disability interests both the person who has suffered brain injury, the family and the network of volunteers and operators. For this reason it is necessary to propose an adequate training specific to each type of stakeholders, including professionals and volunteers who work with them.

- Training for people with acquired disabilities: individual psychological support, cognitive and behavioural support (neuropsychological approach), reintegration and social experiences (i.e., theatre workshops).
- Training for families: the best approach in the structured training is determined by listening, by searching for balance and relationship activities, communication and self-expression with each other.
- Training for volunteers: presentation of the various topics concerning the rehabilitation path taught by the operators; practical activities coordinated by the clinic educator.
- Training for operators: meetings and conferences are held, with lectures made by researchers and professionals involved in post-

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coma rehabilitation facilities to disclose their studies and experiences.

The ongoing training facilitates and stimulates the contact with the outside world for the person awakened from coma; supports the family in the difficult path of needs' and resources' awareness in their own context and in their relationship with the outside world. Training activities improve the work of the operators and volunteers, and contribute to create a network of experiences in the field of rehabilitation after brain injury.

These guidelines have been built up by the L.U.C.A. partners considering all the key points included in section 1.2 and based on the experience of this interdisciplinary team.

### **2. Definitions**

#### **2.1 Disorders of consciousness<sup>5</sup>**

At present, there is no universal definition of consciousness that covers all essential characteristics. In a clinical setting, consciousness is reduced into two main components: wakefulness and awareness (Posner, Saper, Schiff et al., 2007)<sup>6</sup>. Wakefulness refers to the level of vigilance or arousal. Awareness is related to subjective experiences and can be subdivided into awareness of the external world (i.e., sensory or perception of the environment) and of the internal world (i.e., stimulus-independent thoughts, such as mental imagery and inner speech).

Survivors of severe brain damage classically go through different clinical entities before partially or fully recovering consciousness. Although the majority of these patients recover from coma within the first days after the injury, some permanently lose all brain functions (brain death), while others evolve to an unresponsive wakefulness syndrome (previously vegetative state - VS) or minimally conscious state (MCS). Exceptionally, patients may awaken from their coma fully aware but unable to move or speak – their

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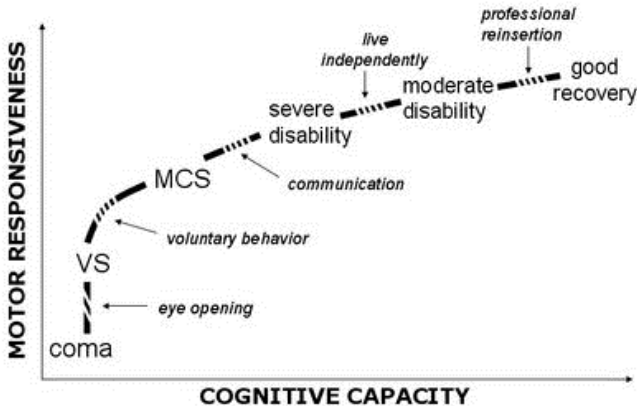
<sup>5</sup> **Disorders of consciousness (DOC):** this term refers to altered states of consciousness as a result of severe acquired brain injuries and describes patients in coma, vegetative state/unresponsive wakefulness syndrome, and minimally conscious states.

<sup>6</sup> Posner, J. B., Saper, C. B., Schiff, N. D., et al. (2007). Plum and Posner's diagnosis of stupor and coma. (4th ed.). New York: Oxford University Press.



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only way to communicate is via small eye movements (locked-in syndrome<sup>7</sup>).



*Different clinical entities encountered on the gradual recovery from coma, illustrated as a function of cognitive and motor capacities. Restoration of spontaneous or elicited eye-opening, in the absence of voluntary motor activity, marks the transition from coma to unresponsive wakefulness syndrome (UWS) (previously vegetative state, VS). The passage from the UWS to the minimally conscious state (MCS) is marked by reproducible evidence of “voluntary behaviour” on command following. Emergence from MCS is signalled*

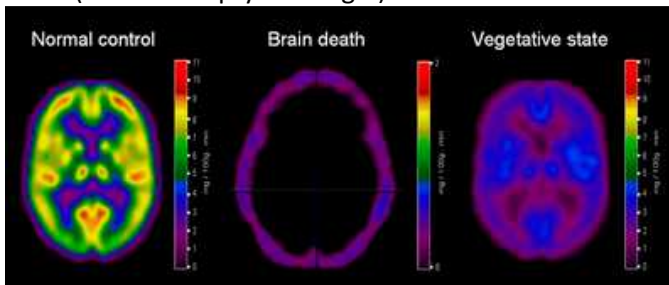
<sup>7</sup> **Locked-in syndrome (LIS):** a clinical condition wherein patients are awake and aware, but with severe motor impairments; sometimes the impairments are so severe that they cannot move any part of their body. The primary means of communication is through eye movements.

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by the return of functional communication or object use. (Taken from Laureys et al., 2005<sup>8</sup>)

### 2.2 Brain death

Brain death means death, with the absence of all brain functions. All brainstem reflexes are lost, and the patient is persistently comatose. There should be an evident cause of coma without confounding factors, such as hypothermia, drugs, electrolyte, and endocrine disturbances (Laureys et al, 2005). Behavioural and neurological testing should be performed to confirm the diagnosis. Images of the brain death show the absence of brain activity in the entirety of the patient's brain (i.e. the 'empty skull sign').



*Differences in brain metabolism measured in brain death and unresponsive wakefulness syndrome, compared with healthy subjects. Patients in brain death show an 'empty-skull sign', clearly different from what is seen in unresponsive patients, in whom brain metabolism is massively and globally decreased (to 40-*

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<sup>8</sup> Laureys S, Perrin F, Schnakers C, Boly C, Majerus S. Residual cognitive function in comatose, vegetative and minimally conscious states. *Current Opinion in Neurology*, 18 (2005) 726-733

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*50% of normal values) but not absent. (Taken from Laureys, 2005)*

Clinical entities	Definition
Brain Death	Irreversible coma
	Evidence for the cause of coma
	Irreversible loss of all functions of the brain, including brainstem reflexes
	Apnea
	Absence of confounding factors (e.g. drugs, hypothermia, electrolyte, and endocrine disturbances)

### 2.3 Coma

A coma is a transient condition: patients' eyes remain closed, even after painful stimulation and hence they remain unaware of the surroundings and of themselves. A coma must last at least one hour to be differentiated from fainting. Autonomous functions, such as breathing and thermoregulation, are reduced, which often requires respiratory assistance. Most patients recover from a coma within the first hours to weeks after injury. However, this recovery may sometimes go no further than unresponsive wakefulness syndrome or the minimally conscious state.

Clinical entities	Definition
Coma	No wakefulness
	No awareness of self or environment
	Acute state (i.e. resolves in hours to maximum 4 weeks)

### **2.4 Unresponsive wakefulness syndrome**

After a period varying from several days to weeks, comatose patients will eventually regain arousal, meaning that they show spontaneous or induced eye opening. Autonomic functions are generally preserved, and breathing occurs usually without assistance. They show no voluntary interaction with their environment, and no adapted emotional responses. The patient is able to perform a variety of movements, such as grinding teeth, blinking and moving their eyes, swallowing, yawning, crying, and smiling, but these are always reflexive movements and not related to the context (The Multi-Society Task Force of PVS, 1994)<sup>9</sup>. As mentioned in the introduction “Unresponsive wakefulness syndrome” was recently proposed as a replacement term for “vegetative state” to avoid the negative “vegetable-like” connotation and to provide a more neutral description of the behaviour profile (Laureys et al., 2010)<sup>10</sup>.

UWS can be partially or totally reversible, or it may progress to a permanent unresponsive state or death. Many people in UWS regain consciousness in the first month after their brain injury. However, after a month,

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<sup>9</sup> The Multi-Society Task Force of PVS. (1994). Medical aspects of the persistent vegetative state. *New England Journal of Medicine*, 330, 1499–1508.

<sup>10</sup> Laureys S, Celesia G, Cohadon F, Lavrijsen J, Léon-Carrion J, Sannita WG, Szabon L, Schmutzhard E, von Wild KR, Zeman A, Dolce G and the European Task Force on Disorders of Consciousness. Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome. *BMC Medicine* (2010) 8: 68.

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the patient is said to be in a persistent UWS and the probability of recovery diminishes as more time passes. Generally, the UWS is thought irreversible a year after traumatic, and three months after non-traumatic (anoxic) aetiology.

<b>Clinical entities</b>	<b>Definition</b>
<b>Vegetative state/ Unresponsive wakefulness syndrome</b>	Wakefulness
	No awareness of self or environment
	No sustained, reproducible, purposeful, or voluntary behavioural responses to visual, auditory, tactile, or noxious stimuli
	No language comprehension or expression
	Relatively preserved hypothalamic and brainstem autonomic functions (e.g. respiration, digestion, thermoregulation)
	Bowel and bladder incontinence
	Variably preserved cranial-nerve and spinal reflexes
	Acute and/or chronic state

### **2.5 Minimally conscious state**

The minimally conscious state describes patients who are unable to communicate their thoughts and feelings, but who demonstrate inconsistent but reproducible behavioural evidence of awareness of self or

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environment (Giacino et al., 2002)<sup>11</sup>. For example, they might show the following signs of consciousness: command following, visual pursuit as a direct response to moving or salient stimuli, localization of noxious stimulation, as well as contingent responses to emotional stimuli. Patients in MCS are more likely to experience pain and/or suffering (Boly et al., 2008)<sup>12</sup>. MCS has been recently stratified into MCS+ (plus) and MCS-(minus) based on the complexity of behavioural responses. Like the vegetative state, the minimally conscious state may be chronic and sometimes permanent.

When patients show reliable demonstration of “functional communication” (i.e., consistently accurate yes-no responses to situational orientation questions) or “functional object use” (i.e., demonstration of the use of two different objects), they emerge from the MCS (EMCS) (Giacino et al., 2002).

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<sup>11</sup>Giacino, J. T., Ashwal, S., Childs, N., et al. (2002). The minimally conscious state: Definition and diagnostic criteria. *Neurology*, 58(3), 349.

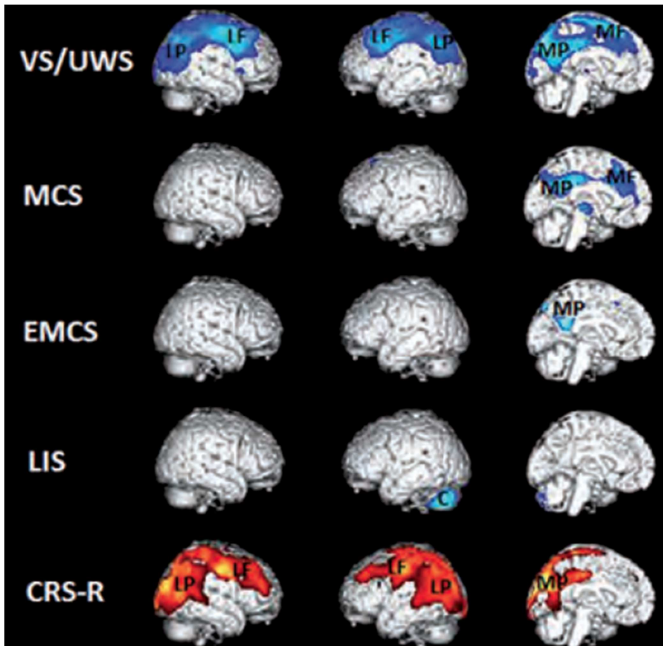
<sup>12</sup>Boly, M., Faymonville, M. E., Schnakers, C., et al. (2008). Perception of pain in the minimally conscious state with PET activation: An observational study. *Lancet Neurology*, 7(11), 1013–1020.

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<b>Clinical entities</b>	<b>Definition</b>	
<b>Minimally conscious state</b>	Wakefulness	
	Awareness is inconsistent but definite	
	<b>MINUS</b>	Visual pursuit
		Contingent behaviour
		Reaching for objects
		Orientation to noxious stimulation
	<b>PLUS</b>	Following simple commands
Intentional communication		
Intelligible verbalization		
<b>Emergence from minimally conscious state</b>	Functional communication	
	Functional object use	

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*In blue, the brain areas with significant impairment in activity compared to age-matched healthy controls. These areas consist of a widespread frontoparietal network, encompassing lateral prefrontal and posterior parietal areas as well as midline anterior cingulate/mesiofrontal and posterior cingulate/precuneal associative cortices (Thibaut et al., 2012)<sup>13</sup>. The lateral areas of this frontoparietal network*

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<sup>13</sup> Thibaut A, Bruno MA, Chatelle C, Gosseries O, Vanhaudenhuyse A, Demertzi A, Schnakers C, Thonnard M, Charland-Verville V, Bernard C, Bahri M, Phillips C, Boly M, Hustinx R, Laureys S. (2012) Metabolic Activity in external and internal awareness networks in severely brain-damaged patients. *J Rehabil Med*, 44(6):487-94.



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*are considered to be implicated in external awareness, whereas the midline regions have been linked to internal awareness (Vanhaudenhuyse et al. 2010)<sup>14</sup>. According to this scheme, patients in MCS show higher metabolism in precuneus than patients in VS/UWS (Thibaut et al., 2012)<sup>15</sup>. The lower panel shows the areas where metabolic activity correlated with Coma Recovery Scale-Revised (CRS-R) scores (Giacino et al, 2004)<sup>16</sup>.*

### **2.6 Locked-in syndrome**

Patients suffering from a locked-in-syndrome (LIS) can be easily misdiagnosed. The locked-in syndrome describes patients who are awake and conscious but have no means of producing speech, limb, or facial movements. Brainstem lesions are its most common cause. People with such lesions often remain comatose for some days or weeks, needing artificial respiration and then gradually waking up, albeit remaining paralyzed and voiceless, superficially resembling patients with an unresponsive wakefulness syndrome.

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<sup>14</sup> Vanhaudenhuyse, A., Demertzi, A., Schabus, M., et al. (2010). Two distinct neuronal networks mediate the awareness of environment and of self. *Journal of Cognitive Neuroscience*, 23(3), 570–578.

<sup>15</sup> Thibaut, A., Bruno, M. A., Chatelle, C., et al. (2012). Metabolic activity in external and internal awareness networks in severely brain-damaged patients. *Journal of Rehabilitation Medicine*, 44(6), 487–497.

<sup>16</sup> Giacino, J. T., Kalmar, K., & Whyte, J. (2004). The JFK coma recovery scale-revised: Measurement characteristics and diagnostic utility. *Archives of Physical Medicine and Rehabilitation*, 85(12), 2020–2029.

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The primary mode of communication is via eye movements or blinking (American Congress of Rehabilitation, 1995)<sup>17</sup>. Locked-in patients can be divided into three categories: (a) classical locked-in syndrome is characterized by quadriplegia and anarthria with eye coded communication; (b) incomplete locked-in syndrome permits remnants of voluntary responsiveness other than eye movement; and (c) total locked-in syndrome consists of complete immobility including all eye movements, combined with preserved consciousness. Once a locked-in syndrome patient becomes medically stable, and given appropriate medical care, life expectancy now is several decades. Even if the chances of good motor recovery are very limited, existing eye-controlled computer-based communication technology currently allows these patients to control their environment, use a word processor coupled to a speech synthesizer and access the world wide web.

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<sup>17</sup> American Congress of Rehabilitation Medicine. (1995). Recommendations for use of uniform nomenclature pertinent to patients with severe alterations of consciousness. Archives of Physical Medicine and Rehabilitation, 76, 205–209.

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<b>Clinical entities</b>	<b>Definition</b>
<b>Locked-in syndrome</b>	Wakefulness
	Awareness
	Aphonia or hypophonia
	Quadriplegia or quadriparesis
	Presence of communication via the eyes
	Preserved cognitive abilities

### **2.7 Coma outcomes: persons with acquired brain injuries**

Outcome phase and domiciliation.

The aetiology of brain injury can be traumatic or non-traumatic. Concerning the severity of brain injury, most patients have moderate or severe disability, with a low percentage with unresponsive state. About different acquired disabilities, the difficulties reported concern:

- medical issues
- motor disabilities
- cognitive disabilities
- behavioural changes
- emotional disorders
- communication limitations
- functional problems

After the post-acute rehabilitation in hospital, patients are generally discharged, although social and healthcare services are still needed to deal with the disability's chronic phase. Challenges for families include providing long-term care, support return to

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school or work, financial problems, and difficulties related to healthcare and social services.

Acquired brain injury is a significant cause of permanent physical, cognitive, psychosocial, communicative, functional and behavioural limitations that adversely affect different approaches such as the Italian paradigm of the ‘family caregiver system’.

The family caregiver is taking place in Italy an action by many organizations because it is recognized the role and commitment of family members in the care pathway. In Italy the Emilia Romagna has been the only region that has enacted a law for the recognition of this figure.

Reports on the reactions, coping ability, and needs of family caring for a patient with a severe brain injury usually describe a wide pattern of events: in the acute phase, the family carers usually go through an emergency or crisis state, including despair, confusion, and disorientation. In the post-acute phase, usually with the patient in a rehabilitation unit, uncertainty about the future dominates. The burden for the family increases because of the efforts involved in ensuring constant attention, and coping with the unavoidable changes in the family routine, including less time for themselves and economic burden. Furthermore, patients’ problems and difficulties cause stress and anxiety in the families. They most commonly need information about prognosis, treatments, and services, as well as emotional and social support. Most families experience a lack of support from the professional team, and generally have adjusting trouble to the complexity of the new situation.

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Outcomes of severe acquired brain injury includes a wide range of different situations. Even after emergence from minimally conscious state, people may experience cognitive problems involving disorders of memory, the ability to pay attention or stay focused, the opportunity to act and communicate in a functional way or even have specific disorders of language. All of these aspects can be present in different combinations and different gravity also in the case of a good or excellent motor recovery. A major obstacle to rehabilitation and/or training is represented by anosognosia (awareness of illness): it can happen that people are not aware, or are just partly aware, of their disability. This does not allow them to adhere to the program that is being offered or to benefit from interventions. For the same reason they are not able to implement the necessary strategies to compensate their difficulties. The difficulties resulting from the different cognitive deficits are often accompanied by an emotional difficulty to accept this new and different condition. For these reasons, an holistic approach must be considered mandatory to promote autonomy.

## Guidelines for training – L.U.C.A.

### 3. Training and information

#### 3.1 Training for persons with acquired disabilities after brain injuries

TARGET GROUP	
People with acquired disabilities (in particular after a coma) - (A) Minimally conscious state	People with acquired disabilities (in particular after a coma) - (B) Persons with severe or moderate acquired disabilities
SPECIFIC OBJECTIVES	
<ul style="list-style-type: none"><li>✓ To improve all the possible areas, as nonverbal means of communication, searching contacts through stimulations.</li><li>✓ To facilitate relax and a calm attitude</li></ul>	<ul style="list-style-type: none"><li>✓ To support for a positive outcome of the rehabilitation path</li><li>✓ To promote social reintegration</li><li>✓ To improve non-verbal means of communication</li><li>✓ To promote personal autonomy</li><li>✓ To improve relational and social skills</li><li>✓ To develop personal skills</li><li>✓ To overcome emotional blocks and expressive tensions</li><li>✓ To raise awareness of their situation through psycho-education</li></ul>

## Guidelines for training – L.U.C.A.

### TRAINERS

- ✓ Professional operator (doctors - physicians brain injury specialist, neuropsychologist, social educators, social workers, music & theatre therapist,...)
- ✓ Volunteers
- ✓ Families

### METHODOLOGY

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li>✓ Individual approach</li> <li>✓ Creating a positive emotional setting</li> <li>✓ Involvement of the families</li> <li>✓ Working with body and contact, and on the management of the emotions</li> <li>✓ ICT approach</li> </ul> | <ul style="list-style-type: none"> <li>✓ Individual approach</li> <li>✓ Group activities</li> <li>✓ Creating a positive emotional setting</li> <li>✓ Involvement of the families</li> <li>✓ Working with body and contact, and on the management of the emotions</li> <li>✓ ICT approach</li> </ul> |
|---|---|

### ASSESSMENT

With tools for evaluating the achievement of the individual initial goals

### EXAMPLES OF ACTIVITIES (SEE BEST PRACTICES COLLECTION)

- ✓ Theatre; Sport; Workshop with manual activities; Music
- ✓ Employment Guidance for both Employers and employees
- ✓ Cognitive training

## Guidelines for training – L.U.C.A.

### 3.2 Training for volunteers and families of persons with acquired disabilities after brain injuries

TARGET GROUP	
(A) Families/caregivers (you have to find the family member more adapt as referent – case manager)	(B) Volunteers
SPECIFIC OBJECTIVES	
<ul style="list-style-type: none"> <li>✓ To inform on the specific situation of the patient (in a scientific and clinical way but also on the emotional aspects).</li> <li>✓ To acquire consciousness and awareness to gain acceptance of the new family situation, not in a passive but in an active way.</li> <li>✓ To support the family during the whole path.</li> <li>✓ To educate and train on all the practical aspects on daily tasks.</li> <li>✓ To foster the personal enrichment and the expansion of the possibilities of different spheres: cognitive – emotional – relational.</li> <li>✓ To provide adequate preparation and a plan to the return at home.</li> </ul>	<ul style="list-style-type: none"> <li>✓ To establish a framework of rules and duties.</li> <li>✓ To inform on the specific situation of the patient (in a scientific and clinical way but also on the emotional aspects).</li> <li>✓ To learn how to practice contact with themselves and the other (patient, family, volunteers, operators).</li> <li>✓ To foster the personal enrichment and the expansion of the possibilities of different spheres: cognitive – emotional – relational.</li> </ul>



## Guidelines for training – L.U.C.A.

### TRAINERS

- ✓ Coordinator (could be an educator or other socio-sanitary professional).
- ✓ Professional operators (doctors - physicians brain injury specialist- neuropsychologist, social educators, social workers, music & theatre therapist,...).

### METHODOLOGY

Individual and group sessions.

To illustrate and explain (through an image) the individual brain map of their relative to the family (to understand better the consequent damages).

Role-playing on all the aspects (physical and relational, verbal and nonverbal communication). The family member acts as his/her relative, the trainers act as the family. This simulation helps the family to really understand the situation of their relative and their own behaviour and is helped in the daily life activities, less anxious and worried. This should be done by professionals once they know the family for a while so they can adjust the intervention to their needs.

Use slides – physical objects and tools as support during the presentation – active involvement - case studies with special emphasis on why and how the intervention

Group sessions.

Supported by the educators or other professionals.

Simulations.

Case studies with special emphasis on why and how the intervention in each situation needs to be carried out – particular attention to lexical aspects: simple, clear and common terms are to be preferred.

Peer to peer. Exchange of experiences (at national level).  
International mobilities.

## Guidelines for training – L.U.C.A.

<p>in each situation needs to be carried out – particular attention to lexical aspects: simple, clear and common terms are to be preferred.</p> <p>Self-aid groups (a meeting once a week – families with neuropsychologist. In ES at the beginning only in one group, then in two different groups for mother/fathers and for husbands/wives, because the approach to the person after a coma is very different).</p>	
<b>AVERAGE DURATION</b>	
<p>Minimum 1 meeting a month (4 hours), or 1 meeting a week (1 hour). Minimum 12 meetings in total. Intensified if necessary.</p>	<ul style="list-style-type: none"> <li>✓ ES 8 hours training and a week of observation.</li> <li>✓ IT 12 meetings (1 hour each)</li> <li>✓ BG one initial training 2 days (8 hours) and then subsequent 2-4 hours 2-4 times a month.</li> <li>✓ BE only individual information about multimodal assessment of the state of consciousness of their relatives (diagnosis, prognosis, therapy). Suggestion to have a psychological support (out of the Centre).</li> </ul>
<b>ASSESSMENT</b>	
<p>With tools for evaluating the achievement of the individual initial goals as questionnaires on practical skills (to improve training) and qualitative evaluation (they describe their feelings, emotions, needs).</p>	

## Guidelines for training – L.U.C.A.

### 3.3 Training for non-health professional

#### TARGET GROUP

The non-health professional staff has not a clinical function, but it is a social and educational support to the path of social reintegration. The multidisciplinary team works closely together, in a kind of therapeutic alliance that allows following people in a coma and their families in the later stages of the path after a trauma and hospitalization in the rehabilitation center. From this point of view we can say that the system of coma in the territory must develop a path “from coma to community”. The synergy among associations, personal services provided by the world of cooperation and home assistance, granted by the Integrated Health Services, must allow a wide range of interventions.

Non-health professionals operate in a complementary way on the basis of an explicit formal care contract that is amended time to time. They are part of the rehabilitation team process.

Professionals involved may be as follows: Social worker; Educators; Music Therapists; Art Therapists; Volunteers; Social pedagogic; Social assistant (one to many) and Personal assistant (one to one)

#### TRAINERS

Clinical personnel, Social workers, Therapists, Association members with experience with the specific target group

#### METHODOLOGY

Lectures and workshops, dissemination and information, visits and tours to actual rehabilitation centers, E-learning, Massive Open Online Courses (MOOC), wiki, bulletins, collaborative learning

## **Guidelines for training – L.U.C.A.**

### **CONTENT**

1. Introduction to acquired brain injury and coma
2. How to deal with the diagnosis?
3. Health aspects of coma
4. Clinical aspects and actors in coma management
5. Rehabilitation phase
6. Different approaches in therapeutic processes: art, music, animals, theater, etc.
7. The role of the family in acquired brain injury management
8. Community support in acquired brain injury handling
9. Social integration of people with acquired brain injuries (in particular after a coma).
10. Educators as social integration mediators

### **AVERAGE DURATION**

It depends on several factors that need to be defined, in particular on the previous studies of the trainees and on the regional services and facilities.

### **ASSESSMENT**

The training can be evaluated through questionnaires evaluating acquired knowledge and satisfaction.

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### 3.4 Training for health professional

TARGET GROUP
<ul style="list-style-type: none"><li>✓ Health Professionals</li><li>✓ Doctors PM&amp;R/ Neurologists</li><li>✓ Psychologist</li><li>✓ Neuropsychologist</li><li>✓ Physiotherapists</li><li>✓ Speech therapists</li><li>✓ Nurses</li><li>✓ Assistant</li><li>✓ Occupational therapist</li></ul>
SPECIFIC OBJECTIVES
<ul style="list-style-type: none"><li>✓ To know the different states of the patient and the diagnosis criteria (i.e., coma, vegetative state/unresponsive wakefulness syndrome, minimally conscious state, emergence of minimally conscious state, locked-in syndrome). Evaluation of the situation of the patient using different behavioural rating scales. How to assess behaviour of the patient through specific scales (e.g. the Coma Recovery Scale-Revised – CRS-R).</li><li>✓ To present the different available tools for the assessment of consciousness (CRS-R, functional magnetic resonance imaging, electroencephalography, positron emission tomography, etc.).</li><li>✓ To know the path of the patient, starting from the acute phase to the chronic phase, from coma to community.</li><li>✓ To inform medical and paramedical staff (training) of wherever the patient will go next. Keep track of the evolution of each patient. How to plan the period after the hospital, how to create a rehabilitation plan. The role and tasks for the family, to help the patient.</li></ul>

## **Guidelines for training – L.U.C.A.**

- ✓ To recognize the situation in other countries by sharing the EU experiences and knowledge available.

### **TRAINERS**

A trainer should at least have 2 years of experience and have dealt with at least 50 patients with coma outcomes/acquired brain injuries. Trainer should also know what is the usual path of a coma patient and should be aware of the various disciplines that deal with coma population.

### **METHODOLOGY**

- ✓ Exchange of experiences through simulation, role-playing lessons and observation, through planning sessions between healthcare professionals.
- ✓ Training: face-to-face, workgroup, debate, simulation, case-studies analysis, theory, training with observation of patients.
- ✓ A first general part aimed at all professionals, to emphasize the importance of a multidisciplinary team. Then the possibility of deepening the knowledge of each profession, in particular through the support of experienced professionals, with some training through internship and observation.

### **CONTENTS**

- ✓ Psychological support for care professionals (avoid burnout). How to create a self-care program.
- ✓ How to take care of the patient (physical and psychological aspect).
- ✓ 4 out of 10 patients are misdiagnosed as being in a unresponsive wakefulness syndrome (while they are actually minimally conscious or more) so professional should be informed about that high risk of misdiagnose and all professional should use standardized and specific tools such as the CRS-R, a mirror to assess visual pursuit and the own name of the patient to assess auditory localization.
- ✓ Information about legal aspects (reimbursement of the insurance, what the family should or should not pay,

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etc).

- ✓ Information about support groups, associations,, NGO's who work with people with ABI or with the families (who support them to face the process).
- ✓ How to establish good relationship with the family of the patient.
- ✓ Questionnaires for the assessment of families' needs and suggestions.
- ✓ Multidisciplinary work for every patient (therapists, psychologists, nutritionists etc).

### **AVERAGE DURATION**

- ✓ General content for all the disciplines including basic knowledge should be 3 hours minimum (1hr of theory, 1hr clinical status, and 1hr for the behavioural scale), along with 3 hours to explain the procedure of the path of the coma patient, 30 minutes to an 1 hour of special training from each discipline, 2 hours for the relational aspect, and 2 hours for the burnout topic.
- ✓ 2 hours role-playing for the multidisciplinary team (1 case-study).
- ✓ 1 hour of presentation of new technologies.

### **EXAMPLES OF ACTIVITIES (SEE BEST PRACTICES COLLECTION)**

Assessment for professionals = case analysis.

### **3.5 Information for general population**

In addition to training the people most directly involved by the problem of acquired brain injuries, the partnership shares the importance of an information campaign aimed at the whole population, through awareness-raising and cultural actions, enhancing the value of acceptance and respect for the dignity of the person in the community.

In particular, through this project, the first **EUROPEAN DAY OF AWAKENINGS** dedicated to people with coma outcomes and acquired brain injuries will be celebrated on October 7th, 2015.

The initiative comes from the experience established by the “Amici di Luca” Association in Bologna - Italy, that from 1999 successfully promotes every year the National Day of Awakenings for Research on Coma - “Worth it”, under the High Patronage of the Italian Republic President and with the involvement of numerous associations and public institutions. This initiative, which takes place on October 7th - the date in which Luca, a 16 year boy awakened after a 8 months coma, (and whom our association and the House of Awakening is dedicated to) - gives voice to people in comas, in unresponsive state, or with different disabilities after a coma caused by a severe brain injury.

The "Day of Awakenings" has grown over time, thanks to the prestige that it has been able to acquire and to the numerous research made by the Study Centre for Research on Coma.



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The large scale vision of the "European Day of Awakenings" is to exchange various realities and experiences of those involved in order to unify different perspectives, an awareness-raising and cultural promotion event, enhancing the value of acceptance and respect for the dignity of the person in the community. This is in the effort to link various member countries of "ONU Convention on the Status of Persons with Disabilities" with the objective to provide better care, treatment, and research in this field.

The event will become the European Day of Awakenings, with the involvement of the partnership of two European projects, representing a total of 9 countries: this project L.U.C.A. and LUCAS - Links United for Coma Awakenings through Sport, both coordinated by the Italian public company Futura Soc. Cons. r.l. in collaboration with the Association "Gli Amici di Luca" and funded with support from the European Union.

LUCAS - Links United for Coma Awakenings through Sport is a Collaborative Partnership (Italy, Denmark, Spain, Belgium, Cyprus, Lithuania and Portugal) funded under the Erasmus + Programme - Sport, with the aim of creating a stable European network for sharing information, experience and best practices in terms of models of rehabilitation through sport, for the reintegration of people with acquired disability from traumatic brain injury and spinal cord injury (in particular resulting from a coma) and their families/caregivers.

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We consider important a wide diffusion of communication about the conditions of people with acquired brain injuries through:

- ✓ Seminars, workshops and conferences on key issues and research linked to the assistance of these people and their family, carried out jointly in Italy and in the partner countries.
- ✓ Exchange of cultural and artistic initiatives related to their social reintegration.
- ✓ October 7<sup>th</sup>, 2015 and following years: Common actions on media and on social networks to advertise the European Day of Awakenings.

We are not only talking about the “awakenings” of people from a coma, but also about the “awakenings” of the ideas, of the will, of the capabilities both of these people and of all those who are involved in their lives. Moreover, we talk about “awakenings” of all the “not involved” ones, of the civil society, so that they support the families in their new life project. In fact, every rehabilitation program will have as its ultimate aim to form and to grow the awareness that every person, including the one with disabilities, can awaken his/her capabilities, ideas and will.

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With the support of the Lifelong Learning and the Erasmus+ Programme of the European Union

Co-funded by the Erasmus+ Programme of the European Union

**It's worth it!**

**EUROPEAN DAY OF AWAKENINGS**  
OCTOBER 7<sup>TH</sup> 2015

**COMA AND ITS OUTCOMES**

#coma #after coma #acquired\_brain\_injuries  
UEComaAwakeningsDay #

COMA MOBILAB FUTURE GINAMICI di LUGAZI CIMA S. MARIA S. MARTINO PODES SEAS

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### **3.6 ICT support for training and information**

The objective of this section is to explore engineering and imaging/clinical principles, aimed to the advancement and generation of new knowledge related to the Information Technology and Communication (ICT) in support of training and information for patients in coma, the caregivers, the family and their friends respectively. Under the framework of the LUCA project, the goal of these affective technologies is oriented in bridging the gap between engineers; scientists and medical professionals in the multidisciplinary areas of imaging systems and pattern recognition to further provide guidelines for training. Additionally, it aims to explore multifaceted design principles and new applications of imaging that would lead ultimately to novel imaging devices, modalities, techniques and technologies.

As the ability to see inside and "read" a living human brain becomes increasingly sophisticated, the ethical and social implications of image processing techniques for patients in coma grow ever greater, shaped by both the capabilities of the technology itself and the public perception of its potential. The ability to "see" the human brain in action, no matter how "clear" the brain image is or its interpretation, is of great significance for people in coma, recovering from it, their clinicians, their caregivers, families and friends respectively. There are different kinds of "seeing" human brain's images. Structural imaging offers a vision of the structure of the brain to enable diagnosis of larger-scale brain injuries. Functional imaging also allows us to visualize the relationship between activity in certain brain areas and

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specific mental functions. Functional imaging is often used in neurological and cognitive science research. Given that most ethical dilemmas addressed in this module pertain to functional imaging, henceforth the focus is given mainly on the applications and implications of technologies such as fMRI. Functional magnetic resonance imaging (fMRI) creates activation "maps" to show which parts of the brain are involved or not (in the case of coma) in a particular mental process. Recently, fMRI has become a very popular technique for imaging normal brain function and providing information on diverse topics of study, such as memory formation, language, pain, learning, emotion, and decision-making, among many others. Thus, through imaging technologies, the direct access to the cognitive information that is represented in the brain is enabled. This information can in turn be used in application and a device a caregiver, a family member of the patient during the rehabilitation process from coma, is interacting with.

Taking into account that affective states and emotions, are an integral part of human nature due to the fact that they shape our thoughts, govern our behavior and influence our interpersonal relationships, the last decades have seen a growing interest in the automatic detection of such states from voice, facial expression, and physiological signals, primarily with the goal of enhancing image technologies, particularly for brain injuries and coma, with an affective component. With the advent of imaging research, the idea of adapting and applying such technologies into cases in which patients are in coma or recovering from it, enabled the affect detection process from brain signals to increase.

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Hence, such technologies lie at the frontier between affective/cognitive neuroscience and affective computing. But what are these technologies?

Affective and cognitive phenomena are at the core of human nature and behavior, and are crucial in our interactions between each other and the external world. However, cognitive phenomena, like perception, memory, or decision-making, have long been viewed as the primary path to an understanding of the human mind. Consequently, affect and associated concepts have been rather neglected by psychologists and neuroscientists for a good part of the twentieth century—until they experienced a strong comeback in scientific interest at the end of the twentieth century. Nowadays, the relevance of affect for cognition and, vice versa, the involvement of cognitive processes in affect-generation is considered firmly established. Researchers who are working at the intersection of computer science and the affective sciences established the field of Affective Computing (AC), defined as computing that relates to, arises from, or deliberately influences emotions.

Research focused on the field are the sensing of affective states, the modeling of the processes involved in affect the synthesis of emotional expressions and behaviors, and the interaction between human and machine according to the affective context during the different “periods” of the coma. ICT originated from the field of AC as a general research program that attempts to create devices able to detect affective states from brain signals and that are able to take this information into account to advance human-computer

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interaction. Research in this domain is highly interdisciplinary, using theories and methods from psychology (concepts and protocols), neuroscience (brain functioning and signal processing), and computer science (machine learning and HCI) to induce, measure, and detect affective states and to apply the resulting information to improve interaction with machines.

Furthermore, affective phenomena (active/passive sensing) have turned out to be quite engaging to specialists from computer vision, natural language processing, and physiological computing. Therefore, researchers from the field of AC have embraced such measurements as a novel modality, delivering new and complementary insights. Affective ICT with respect to coma and other brain injuries are, of course, also an extension of the field of HCI, which itself is a multidisciplinary endeavor. Unfortunately, there are no precise definitions of affective ICT technologies with respect to coma, however, they should clearly stress the active communicative act that these systems were supposed to support, based on users', mainly patients', mental activities (depending on their coma status).

Finally, the concept of affective ICT for patients in coma is expected to lead to a new perspective on their applicability as they may serve as assessment tools to improve Human Computer Interaction (HCI) between patients in coma or patients in rehabilitation process with their family members, friends, or caregivers. However, the ideal solution of the optimal parameters is still not present. Also, it may be discussed whether the term affective ICT is appropriate or if we should find a more generic term such as affective ICT

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technologies for coma patients. Such technologies are expected to improve the quality of life of persons with such impairments and of their caregivers, by allowing the affective ICT technology user/patient to express not only content but also affect.