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Specification of linguistic schema

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ABSTRACT:

This deliverable concerns the nature of the interaction between health institutions and individuals, particularly the communicative relation among professionals working on separate health fields and the communicative relation between physicians and patients.

To exchange information amongst heterogeneous community of participants, i.e. clinicians, researchers, patients, care professionals, psychologists, etc., it is crucial to have a common basis for transferring knowledge attached to the meaning of the linguistic expressions used for representing relevant information.

In p-medicine we consider a linguistic structure organised on three levels in which users can communicate with each other according to their preferences and abilities.

We focus here on the descriptive level on which concepts and linguistic expressions identified as being crucial for expert-patient-communication are structured into a linguistic schema that provides a description of their intended use (and meaning) together with a description of their place in the overall semantic framework of p-medicine provided by the Health Data Ontology Trunk.

This deliverable outlines the linguistic schema used by health professionals and that could be transferred to the patients.

KEYWORD LIST: p-medicine, linguistic schema, ontology, patient's language

[1] **R**=Report, **P**=Prototype, **D**=Demonstrator, **O**=Other

[2] **PU**=Public, **PP**=Restricted to other programme participants (including the Commission Services), **RE**=Restricted to a group specified by the consortium (including the Commission Services), **CO**=Confidential, only for members of the consortium (including the Commission Services)

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1 Executive Summary

The main objective of this deliverable is to integrate linguistic schema of patients into p-medicine's general semantic framework. In order to facilitate users in the development of individual Health Data Ontology Trunk (HDOT) modules according to their specific needs, we provide p-medicine with an Ontology Aggregator Tool (OAT) with which even non-expert users in ontological engineering have the possibility to take advantage of the plethora semantic technologies in biomedicine.

The OAT is currently under development and a first prototype will be available for testing next year.

In the present deliverable we present an initial prototype of the module originated from the integration of concepts derived from ALGA Questionnaire.

The result is a linguistic schema containing terms, their ontological mapping to owl-classes, definitions (or comments) and some relational properties. All specifications will be integrated into the HDOT-PM.

2 Introduction

2.1 Purpose of this document

To exchange information amongst heterogeneous community of participants, i.e. clinicians, researchers, patients, care professionals, psychologists, etc., it is crucial to have a common basis for transferring knowledge attached to the meaning of the linguistic expressions used for representing relevant information.

In p-medicine we consider a linguistic structure organised on three levels in which users can communicate with each other according to their preferences and abilities.

We focus here on the descriptive level on which concepts and linguistic expressions identified as being crucial for expert-patient-communication are gathered and then structured in a linguistic schema that provides a description of their intended use (and meaning) together with a description of their place in the overall semantic framework of p-medicine provided by the Health Data Ontology Trunk.

The first level is the technical one, built from medical reports and by various clinically objective parameters;

The second level is the conceptual one, in which the most important concepts and related terms, implicated by the first level, are pointed out;

The third level is the descriptive one, in which concepts and terms of the second level are integrated into a logical-descriptive frame for which the p-medicine ontological framework, the Heath Data Ontology Trunk (HDOT) provides the background; within this frame the patient may navigate with the IEmS to understand the actual state of his/her own health, to evaluate outcomes, to consider treatments, preventive measures and follow up arrangements.

Linguistic analysis of information needs within the p-medicine scenarios will be carried out with videos and questionnaires (ALGA), which in turn will form the basis for a patient and physicians language schema for testing the selected cases, and the basis for the development of the Patient View in WP4 task 4.4.

We would like patients to be empowered to believe in themselves and their abilities so that they can take charge of their health, but even our diagnostic terminology can sometimes undermine their confidence. Medical expert language consists to a high degree in expressions which are very hard to understand by lay persons, and even if they are widely understood some of these expressions are commonly associated with negative connotations.

That is why we not only would like to provide information in a patient friendly way, but also to pay particular attention to the treatment of problem-oriented terms and their possible replacement or supplementation with encouraging positive diagnostic expressions with foci reflecting health assests (Rotegaard AK, Ruland, 2010).

3 Specification of psychological linguistic schema characterizing patient's profile

3.1 Introduction

In order to make psychological language understandable by other fields present in the project, a linguistic schema of the psychological constructs used in ALGA questionnaire that are used for the creation of the patient profile are described below.

The cancer patient profile created from ALGA questionnaire refers to 4 main areas: 1) perceived health state, 2) psycho-social aspects, 3) psychological aspects, 4) cognitive aspects.

Each of these four areas are characterized by few more subareas, which constructs are specified below. The choice for these specific constructs are described in the deliverable D2.5.

With purpose of clarity, in psychology the term "construct" generally refers to a latent variable (e.g., a specific personality trait) manifested through several aspects associated with one another in a meaningful way. In the following chapter, we will use the term "construct" with this meaning.

3.2 Definition of constructs originating from ALGA.

The constructs measured by ALGA Questionnaire are constant between patients. The profile of each patient, therefore, will be characterized by the same components at different levels.

3.2.1 Perceived Health State

In ALGA questionnaire Perceived Health State construct is defined by 6 components (or variables, statistically speaking): Global Self-Rated Health (GSRH), Fatigue, Pain, Physical Abilities, Appetite.

3.2.1.1 Self-Rated Health (GSRH)

This component refers to the subjective perception of one's own health, in other words, it is relative to how the patient believes his/her health state is. As previous studies showed, the self-rated health is a predictor of mortality (Nguyen, Donesky-Cuenco, Carrieri-Kohlman, 2008). People who report poor health have two to three times the risk of dying compared to those who report good or better health. The prognostic power of global self-rated health (GSRH) has also been reported in patients with various cancers.

Participants with worse self-rated health had a significantly higher risk for mortality even after adjusting for physician perception of their health and an array of objective health data. It is important to note that physician-assessed health and GSRH may not always be concordant, especially if physicians do not consider nonclinical psychosocial information such as quality of life, income, and education (DeSalvo, Muntner, 2011). Therefore, it is considered GSRH provides important patient-centered information in addition to that readily available to clinicians, such as emotional health (depression, anxiety), advancing age, and lower socioeconomic status (Zastrow, Faude, Seyboth, Niehoff, Herzog, Loewe, 2008).

3.2.1.2 Fatigue

Fatigue can be described as a subjective and multidimensional concept with several modes of expression (Servaes, Verhagen, & Bleijenberg, 2002). It is a physiological and psychological state characterized by a diminished capacity to perform and accompanied by a feeling of tiredness. Accordingly, it can be measured at the physical level, referring to diminished energy and the need to rest, the affective level, considering lack of motivation and interest and low mood (depression), or the cognitive level, with impairment of cognitive function such as diminished memory capacity and attention and, finally, at the social level, with a reduced ability to sustain social relationships (Morrow, 2007).

Fatigue is one of the most common and debilitating symptoms experienced by patients with cancer. Cancer-related fatigue (CRF) is characterized by feelings of tiredness, weakness, and lack of energy, and is distinct from the “normal” drowsiness experienced by healthy individuals in that it is not relieved by rest or sleep (Hoffman et al., 2007).

This condition may be related directly to the cancer or its treatment and may continue for years after treatment is completed (Wang, 2008). Fatigue may occur as an isolated symptom or as one element in a cluster of symptoms such as pain, depression, sleep disturbance, and anemia (NCCN, 2008).

3.2.1.3 Pain

Pain can be defined as a multidimensional phenomenon that is the result of a complex interaction between physiological, psychological, cognitive, social, and other factors. It is the result of a physiological series of electrical and chemical events that occur in the body. The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (Merskey, Bogduk, 1994).

It has been demonstrated an association between cancer pain and psychological distress, including mood disturbance, emotional distress, psychological well-being, depressive feelings, fear, anxiety, worry, irritability, and energy level. Higher levels of pain are also associated with decreased social activities (Zaza & Baine, 2002).

Relatively to chronic pain, it ceases to serve a protective function, degrading health and functional capability, through sleep disturbance, fatigue, mood changes (Chapman & Stillman, 1996).

High levels of pain and depression are generally associated with poor cognitive functioning (attention, information processing speed, working memory capacity, reasoning ability, and verbal memory). It seems that depression mediates the relationship between pain and cognitive functioning (Brown et al., 2002). In other words, chronic pain causes depression, which causes impairment in cognitive functioning.

Patients with chronic pain conditions often report anxiety levels that do not fall within the normal range, suggesting, as a study from Keogh and colleagues demonstrated (2001) that anxiety may predispose to have negative responses to painful events.

3.2.1.4 Physical abilities

Physical abilities are relative to the ability to perform some physical acts, that allow the individual to deal with the needs of every-day life. Impairment in physical abilities decreases the quality of life of the individual, both because of a concrete impossibility to perform an action, and because of the consequences this inability may have on personal emotional state (depression, anxiety).

3.2.1.5 Appetite

Appetite is the natural desire for food. Cancer-associated loss or reduction in appetite can result from medical conditions, such as from local effects of a tumour, the host response to the tumour and anticancer therapies.

Loss of appetite may lead to malnutrition, which in turn has consequences such as impairment of immune functions, performance status, muscle function, and quality of life. Furthermore, responses to chemotherapy are decreased, chemotherapy-induced toxicity and complications are more frequent and severe, and survival times are shortened (Cutsem, Arends, 2005).

A loss or reduction in appetite may be due also to psychological conditions, such as emotional or mental symptoms. More specifically, depression, anxiety, fatigue and malaise can lead to decreased appetite or other changes in eating habits, that also significantly impact on patient well-being and recovery.

3.2.2 Psychological Aspects

Psychological Aspects are features that, even though physiological symptoms can be present, primarily involve the mind and the way people interpret situations, events, behaviours. In general, the meaning people give to the specific event is the trigger for physiological and behavioural reaction. This category includes 3 components: Anxiety, Depression and self efficacy.

3.2.2.1

Anxiety can be defined as “an intense emotional response caused by the preconscious recognition that a repressed conflict is about to emerge into consciousness” (Gerrig, Zimbardo, 2002). This emotional state includes feelings of apprehension, tension, nervousness, and worry accompanied by physiological arousal related to future danger events, in which an unpleasant specific future crisis is fairly likely. More specifically, it is a condition of persistent and uncontrollable nervousness, stress, and worry that is triggered by anticipation of future events, memories of past events, or ruminations over day-to-day events, both trivial and major, with disproportionate fears of catastrophic consequences.

Low level of anxiety is adaptive in motivating behaviour that helped individuals cope with threatening situations. Accordingly, it is a normal body's response to stress, which

allows you to cope with threats or dangers. However, high level of anxiety can interfere with everyday life, causing panic attacks, depression, sleeplessness, fatigue, distractibility, digestive problems, decreased appetite or other changes in eating habits, and lowered resistance to infection.

High level of anxiety can negatively impact working memory and information processing (Ikeda, Iwanaga, Seiwa, 1996), learning and memory (Wetherell, Reynolds, Gatz, et al., 2002), abstraction and problem-solving (Fisher, Allen, Kose, 1996), suggesting that subclinical levels of anxiety can be sufficient to interfere with normal functioning.

High correlation in co-morbidity between anxiety and depression has been found (Clark & Watson, 1991).

3.2.2.2 Depression (depressive symptoms)

Depression is defined as a psychophysical condition associated with loss events (e.g., loss through death of a loved one; loss of one's physical health), in which something or someone that is valued is lost and perceived as hard or impossible to regain.

The duration (at least two-week period) and the number of symptoms are generally used to distinguish depression from a normal sadness and grief by requiring a certain duration.

Depression is considered a heterogeneous condition (Gelenberg, 2010) in which different biologic abnormalities may be present such as a significant weight loss or gain, too little or too much sleep, physical agitation or slowing down, fatigue or loss of energy, feelings of worthlessness or excessive guilt, feelings of hopelessness and helplessness, lowered ability to think, to concentrate or make decisions and recurrent thoughts of death or suicide.

A wide variety of clinical pictures can be observed especially in depressed cancer patients that often tend to be underestimated, such as symptoms as anger, irritability, and hostility (Pasquini, Biondi, 2007).

The importance to take into account depressive symptoms in cancer patients is driven by the awareness that depression can adversely affect a cancer patient in many ways: interfering with cancer treatment, increasing length of hospital stay, reducing ability to care for oneself, impairing quality of life, and possibly reducing overall survival time (McDaniel, Musselman, Porter, Reed, Nemeroff, 1995).

3.2.2.3 Self-Efficacy

Self-efficacy pertains to a sense of control over one’s environment and behaviour. It can be otherwise described as the subjective perception (or belief) to be able to cope with life problems and to reach success. Being a subjective perception, or belief, patients are aware of their own competences. This awareness affects whether or not health behaviour change will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and failures. In particular, it influences the processes of planning, taking initiative, maintaining behavior change, and managing relapses (see Luszczynska & Schwarzer, 2003; Marlatt, Baer, & Quigley, 1995; Sutton, 2005).

Individuals with strong self-efficacy select more challenging goals (DeVellis & DeVellis, 2000), focusing on opportunities and not on obstacles.

Although fatigue is most commonly thought of as a physical problem requiring physical intervention, self-efficacy may have a mediating role on fatigue and consequently on QOL (Haas, 2011).

3.2.3 Psycho-Social Aspects

Psycho-Social Aspects are factors that affect a person psychologically and socially, and in interaction with the social environment. This category includes 3 components: Social Abilities, Sexual Problems, Body Image.

3.2.3.1 abilities

This component of psycho-social aspects is relative to the ability to communicate and interact with other member of the society.

In particular, being integrated in social life is an important factor to determining the patients' functional response to their illness and its treatment (Schipper, Clinch, McMurray, Levitt, 1984).

A decrease propensity to communicate and interact with other people or decrement of social life may be associated with medical (e.g., pain) and psycho-social factors (e.g., fatigue, depression, low self esteem, distorted body image, financial problems) related to the cancer condition.

3.2.3.2 Sexual problems

This component is relative to dysfunction in the sexual life of a person, which can be due to physical, psychological, and behavioural aspects.

Often sexual dysfunctions are characterized by both physical and psychological factors. The most common sexual problems for people who have cancer are loss of desire for sexual activity in both men and women, achieving and maintaining an erection in men, and pain with intercourse in women. Men may also experience inability to ejaculate, ejaculation going backward into the bladder, or the inability to reach orgasm. Women may experience a change in genital sensations due to pain, loss of sensation and numbness, or decreased ability to reach orgasm (Schover, Montague, Lakin, 1997).

Other factors that may contribute to sexual dysfunction and lack of desire include pain medications, anxiety, depression, feelings of guilt from misbelieves about the origin of the cancer, and changes in body image after surgery.

3.2.3.3 Body image

Body Image is defined as someone's perceptions, thoughts, and feelings about his or her body (Grogan, 2008). It is considered as a component of psychosocial aspects (and not merely a cognitive aspect), since the body is seen as the vehicle toward social acceptance. It is no longer seen in simple biological terms, but an instrument for self-expression in the society, cultural capital, and political resistance (Nicholls & Gibson, 2010). It is a site over which individuals can exert control, in an increasingly complex and uncertain world (Shilling, 2003; Grogan, 2008).

Changes in Body Image, as often happens in cancer patients, have adverse implications for self-esteem and adjustment (Fan & Eiser, 2009), for sexual life and emotional reactions (e.g., depression, anxiety).

3.2.4 Cognitive Aspects

Cognitive Aspects are factors that affect the way a person think, process information, use, store and build knowledge. While the influence of environment on information processing and knowledge is generally acknowledged, the aspects described below are not considered among the psychosocial aspects since they are cross-situation skill. Furthermore, they are distinct by psychological aspects, since they not involve personality and emotional or mood states. This category includes 3 components: Attention and memory, Rumination, and Cognitive Closure.

3.2.4.1 and memory

Attention is a cognitive process that selectively concentrates on one aspect of the environment while ignoring other things.

Memory is the cognitive process that stores, retains, and recall information.

Attention and memory are processes that frequently are impaired in cancer patients, with dysfunction on the domains of attention and concentration, verbal and visual memory, and information processing speed.

This cognitive deficits has consequences on general executive functions, which includes the mental skills that help the individual adjust to the environment and organize goal-oriented behaviour, such as problem solving, multitasking, planning, making adjustments.

Effects to attention include forgetfulness, distraction, inconsistency, and lack of follow-through.

Memory changes include forgetfulness, word loss, difficulty learning new things, and losing track.

In all these types of cognition, information processing speed can slow down, leading to inefficient thinking and decision making (Vardy, Wefel, Ahles, Tannock, Schagen, 2008).

3.2.4.2 Rumination

It refers to the tendency to focus repetitively on the meaning, causes, and consequences of a problem or a negative event.

More specifically, people with a ruminative response style think repetitively and passively about their negative emotions, focusing on their symptoms and worrying about the meanings of their situation (Lyubomirsky, Cadwell, & Nolen-Hoeksema, 1998; Nolen-Hoeksema, 1991). People who engage in ruminative responses when they are sad, or depressed have higher levels of depressive symptoms over time. Accordingly, a chain of ruminative thoughts may be symptomatic of depression and may be cause of a delay recovery from depression. Moreover, rumination is associated

with other negative outcomes, such as negatively biased thinking, poor problem-solving, impaired motivation and inhibition of instrumental behaviour, impaired concentration and cognition.

3.2.4.3 Cognitive Closure

The need for cognitive closure is a dispositional construct, i.e., a personality trait that influences the knowledge acquisition process in rather stable ways across various situations. As construct, it is treated as a latent variable manifested through several aspects, such as desire for predictability, preference for order and structure, discomfort with ambiguity, decisiveness, and close-mindedness (Webster, Kruglanski, 1994).

In other word, it may be defined as a general tendency of urgency and permanence. The urgency represents an individual's inclination to attain closure as soon as possible, and the permanence tendency represents an individual's inclination to maintain it for as long as possible (Kruglanski, Webster, 1996).

It is typical of patients that need to reduce the uncertainty. The possible consequence of cognitive closure (closing down the process of thinking-through), is that the individual may become intellectually passive, rather than developing a persistent and tenacious stance toward problem-solving. Thinking through multiple potentially correct answers requires a stick-with-it mentality, that when dealing with cancer might lead some patients to think too much to the negative events of having a cancer (a possible link with rumination, depression, anxiety).

4 The Health Data Ontology Trunk (HDOT) as the semantic backbone of p-medicine

4.1

In the following chapter we present the method and the obtained results for the integration of the patient language linguistic schema into p-medicine's general semantic framework. In performing this integration we paid particular attention to incorporating all kinds of information associated with linguistic expressions which are suitable for being captured in an axiomatic, owl2 based representational structure. Thus we include different labels for owl-classes (synonyms), natural language definitions (for experts and where necessary and possible for lay persons), helpful comments and logical axioms.

We released the Health Data Ontology Trunk (HDOT) as the semantic backbone of p-medicine in the deliverable D4.1 - List of domain quality-checked ontologies and initial release of HDOT and its Glass Box Evaluation. One the main objectives of the semantic interoperability work package in p-medicine (WP4) is the development and the further extension of HDOT in a modular design fashion, so that instead of creating an unique large ontology for the needs of the project, which we would consider hard to handle for both humans and machines, we create and maintain different purpose driven modules as members of the same semantic and axiomatic frame. HDOT has been conceived since its first release as a middle-layer ontology aiming at representing biomedical information in a very general axiomatic structure, i.e. its nodes are intentionally created to be further extended within one and the same semantic and axiomatic frame.

In order to facilitate users in the development of individual HDOT modules according to their specific needs, we provide p-medicine with an Ontology Aggregator Tool (OAT) with which even non-expert users in ontological engineering have the possibility to take advantage of the plethora semantic technologies in biomedicine. The OAT is currently under development and a first prototype will be available for testing next year. It is worth noting that the modular approach is widely recognized in the ontological engineering community as the best solution for the management of large quantities of data which constantly undergo changes (Stuckenschmidt, Parent, Spaccapietra, 2008).

The results of the ALGA questionnaire presented in the previous chapter are going to be integrated in a new HDOT owl2-module called 'patient module' (HDOT-PM). Of course, these results do not constitute the whole module, but only a small part. The design of the module is patient-driven, i.e. within a patient-empowerment frame it aims at helping patients to understand clearly their clinical history. Indeed, in a recent paper (Beck et al., 2012) it has been noted that there is a big gap between the research about ICT technologies for the biomedical domain and their exploitation in daily contexts and work-flows. Several times researches are far away to know what really happens in the daily work-flow of hospitals and single physicians, as well as physicians and health care providers are sometimes reluctant to exploit technologies that seem to be very complex to use. We have reasons to think that this gap is going to increase if the results of researchers is presented not only to domain experts, but also to patients, who in many cases ignore the complexity of both biomedicine and computer science applications. The HDOT-PM aims at covering this gap.

The main advantages of including the results of the ALGA questionnaire under HDOT regard:

1. From the human perspective: the disambiguation of complex terms among the community of p-medicine, in the sense that everyone using p-medicine architecture will share the same semantic descriptions in order to avoid the problem of exploiting the same terms with different meanings.

2. From the machine perspective: the axiomatization of such information in owl2 aims at making the data computable with a high degree of precision. Indeed, it is widely recognized by the scientific community that if the information is structured using the ontology web language as a knowledge representation language, a machine acts as an agent able to “understand” the meanings of the information and is thus enabled to perform reasoning on them (OWL 2, http://www.w3.org/TR/owl2-overview/).

We are confident that we can strictly follow p-medicine's DoW and the development of the HDOT-PM is planned for the end of the 2nd year of the project.

Here, we present an initial prototype of such a module based on the ALGA questionnaire results. It is worth noting that the development of owl-ontologies is a very expensive enterprise both in terms of human and economic resources, so that they should be developed according to specific needs and clearly stated requirements and within a continuous debate between ontology engineers and domain experts, at least if we do not want run the risk of wasting a lot of human efforts. We thus conceive the integration of the following linguistic schema into HDOT as a first prototypical effort which should be further developed and extended as the project progresses and more detailed needs become apparent.

4.2 Integration of the ALGA questionnaire results in HDOT-PM

According to the results presented by the questionnaire and aiming at their inclusion in HDOT-PM, we need to pursue the following ontology design steps:

1. Identify clearly the ALGA terms that must be included in the module;

2. Verify whether the terms are already in the specifications provided by HDOT.

When we map the ALGA terms to HDOT classes we have to consider two possible scenarios:

(a) The term is already in the HDOT ontology. In this case, we do not need to create a new HDOT class, but nevertheless we need to verify if the meaning of the term given by the questionnaire corresponds to the one given by the pre-existing specifications within HDOT. If this is not the case, we have to disambiguate the different respective meanings, i.e. we need to create different owl-classes in HDOT-PM for different meanings.

(b) The term is not in the ontology. In this case, we create a new owl-class in HDOT-PM and consider the possibility to subsume it under an already existing HDOT middle-layer class. If there is not any available HDOT middle-layer class which is adequate for the representation of the new term, we need to create it before subsuming the term under the HDOT structure;

3. Identify the logical structure of the ALGA questionnaire definitions for terms. In the deliverable D4.1 we point out that for ontological representation purposes definitions of terms should be provided using the genus-differentia form wherever possible:

'A is a B that C', where A is the new term, B is its super-type (or top class) and C states the differences between A and B in specifying a further property.

For example, “Human being (A) is a mammal (B) that is rational (C)”, or “Blood pressure (A) is a pressure (B) that occurs in blood (C)”. Following this form, ontology engineers have the possibility to identify clearly the upper-level class to which a more specific class belongs, and at the same time including their differences. Thus the design of a structure of an acyclic representational graph is guaranteed and modelling inconsistencies are avoided.

4. Create the HDOT-PM according to the definitions obtained in (3) and following ontological engineering standards. Of course, the results of the analysis of the questionnaire will be only a small sub-set of the module.

5. Evaluation of the new module. The evaluation process plays a central role in ontological engineering in order to state the quality of the ontological representation and avoid the spread of mistakes as soon as possible. It is a very complex and long-term task. In the deliverable D4.1 we state our evaluation methodology according to p-medicine needs. At the moment we cannot say anything about the patient module evaluation, because the module is under development.

6. Integration of the patient module in p-medicine architecture. Further discussions are required in order to state clearly how such integration should be pursued within p-medicine.

It is worth noting that in the current state of the art of ontological engineering a lot of work has been done in the formalization of annotations for large quantities of data coming from different resources and for different needs, i.e. what is usually accounted as ontological representation of domains. However, patient-driven or user-friendly ontologies have often been put aside.

There seems to be a clear reason for this: ontologies are computational representations of real domains and they mainly aim at the disambiguation of complex concepts among different communities of agents. This means that ontologies are computable information artefacts that lay behind those semantic-driven computational systems which aim at improving the communication between humans.

The main consequence of this view is that an ontology cannot be directly patient (user)-friendly or patient (user)-driven, but it is the whole system in which the ontology is integrated that can be as such, i.e. patient (user)-oriented. A computational ontology by itself cannot achieve anything more than the domain representation according to domain specifications and ontological engineering standards, while a whole computational system can be designed in such a way to be useful for both experts and non-experts. Nevertheless, the structure of an ontology can be designed in a way that facilitate the user-friendliness, for example adding classes definitions and synonyms that facilitate the comprehension of its specifications.

4.1.1 Initial ontological knowledge assessment according to the ALGA questionnaire results

The following terms are mentioned in the previous chapter as the results of the analysis of the questionnaire and they should be integrated within the HDOT ontology. In a first step of processing these terms we loosely group them:

Perceived health state:

- Global Self-Rated Health (GSRH);
- Fatigue;
- Pain;
- Physical abilities;
- Appetite.

Psycho-social aspects:

- Social abilities;
- Sexual problem;
- Body image.

Psychological aspects:

- Anxiety;
- Depression;
- Self-efficacy.

Cognitive aspects:

- Attention;
- Memory;
- Rumination;
- Cognitive closure.

In the following table we sum up the methodology for the development of the HDOT-PM developed the paragraph 2. The result is a linguistic schema containing terms, their ontological mapping to owl-classes, definitions (or comments) and some relational properties. All specifications will be integrated into the HDOT-PM.

ALGA questionnaire term	**HDOT already existing class**	**HDOT (possible) new class**[3]	**HDOT type subsuming the ALGA new class**	**Class definition according to HDOT**[4]	**Class definition according to the ALGA questionnaire**
Global Self-Rated Health (GSRH)	Missing	Further discussions are required regarding the ontological status of GSRH	-	-	This component refers to the subjective perception or believes of one's own health
Fatigue	Fatigue	-	-	-	Fatigue is characterized by feelings of tiredness, weakness, and lack of energy, and is distinct from the "normal" drowsiness experienced by healthy individuals in that it is not relieved by rest or sleep
Cancer-related fatigue[5]	Missing	Cancer Related Fatigue	Fatigue	A cancer-related fatigue is a fatigue that is quality of some organism that has part a pathological formation	Cancer-related fatigue (CRF) is characterized by feelings of tiredness, weakness, and lack of energy, and is distinct from the "normal" drowsiness experienced by healthy individuals in that it is not relieved by rest or sleep
Perceived health state	Missing	No need (it is only a category of a particular questionnaire)	-	-	-

[3] We create a new HDOT class only if the actual HDOT structure does not contain any possible class able to represent the new ALGA term. At the current state of the development of the patient module, the new classes are accounted as "possible" in the sense that we need to put more efforts into the semantic structure of these new terms.

[4] It is very probable that the following definitions will undergo a process of evaluation according to the further development of the patient module. They must be considered as initial definitions.

[5] This term is not direcly present in the ALGA questionnaire results, but it is meantioned as a kind of fatigue that occurs in those patients who suffer from cancer.

Physical abilities	Physical Functioning Ability	-	-	-	Physical abilities are relative to the ability to perform some physical acts, that allow the individual to deal with the needs of every-day life
Pain	Missing	Physical Pain	Organismal Condition	Physical pain is an organismal condition that is the result of a physiological series of electrical and chemical events that occur in the body	An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage
Cancer Pain[6]	Missing	Physical Pain	Organismal Condition	Cancer Pain is an organismal condition that occurs in a organism that has part a pathological formation	-
Appetite	Appetite	-	-	-	This concept is relative to the natural desire for food
Cancer-associated appetite[7]	Missing	Cancer Associated Appetite	Appetite	Cancer associated appetite is an appetite that is quality of some organism that has part a pathological	Cancer-associated loss or reduction in appetite can result from medical conditions, such as from local effects of a tumour, the host response to the tumour and anticancer therapies, other than psychological and

[6] The same as the 3rd footnote

[7] The same as the 3rd footnote

				formation	emotional symptoms
Psycho-social aspects	Missing	No need (it is only a category of a particular questionnaire)	-	-	-
Social abilities	Social Functioning Ability	-	-	-	This construct is relative to the ability to communicate and interact with other member of the society
Sexual problems	Missing	Sexual Dysfunction	Malfunction	Sexual dysfunction is a malfunction of the sexual apparatus due to physical and psychological factors	Physicial dysfunction and loss of desire for sexual activity in both men and women
Body image	Missing	Further discussions is required regarding the ontological status of Patient Body Image	-	-	Body Image is defined as someone's perceptions, thoughts, and feelings about his or her body
Psychological aspects	Missing	No need (it is only a category of a particular questionnaire)	-	-	-
Anxiety	Missing	Anxiety	Organismal condition	Anxiety is an organismal condition that causes some physiological and	Anxiety can be defined as an emotional state that included feelings of apprehension, tension, nervousness, and worry accompanied by physiological arousal related to a future

				psychological processes	danger events, in which an unpleasant specific future crisis is fairly likely
Depression	Depression	-	-	-	Depression is defined as a psychophysical condition associated with loss events in which something or someone that is valued is lost and perceived as hard or impossible to regain
Self-efficacy	Missing	Self Efficacy	Psychological functioning ability	Self-efficacy is a psychological functioning ability that causes some psychological and behavioral processes	Self-efficacy pertains to a sense of control over one's environment and behaviour
Cognitive aspects	Missing	No need (it is only a category of a particular questionnaire)	-	-	-
Attention	Missing	Attention	Cognitive faculty	Attention is a cognitive faculty that is realized by cognition (i.e. a cognitive process)	Attention is a cognitive process, that selectively concentrates on one aspect of the environment while ignoring other things
Memory	Memory	-	-	-	Memory is the cognitive process, that stores, retains, and recall information
Rumination	Missing	Rumination	Cognitive faculty	Rumination is a cognitive faculty that causes some	It refers to the tendency to focus repetitively on the meaning, causes, and consequences of a distress

				psychological and behavioral processes	
Cognitive closure	Missing	Cognitive Closure	Cognitive faculty	Cognitive closure is a cognitive faculty that causes some psychological and behavioral processes	Cognitive closure is a dispositional construct that is treated as a latent variable manifested through several different aspects, such as desire for predictability, preference for order and structure, discomfort with ambiguity, decisiveness, and close-mindedness

It is worth noting that we extract the linguistic data schema for the ontological representation out from the definitions provided by the questionnaire, even if some of them are not very useful from the ontological point of view, because they do not state clearly to which super-kind (super-class or super-type) the described terms belong (e.g. the definitions provided for Global Self-Rated Health and Fatigue). However, it is very probable that the definitions that cannot be directly exploited in the ontology as they have been provided will be integrated in the HDOT-PM as owl-class comments.

Moreover, in case we need to change the label of a provided term (e.g. 'body image' in 'patient body image'), we will reuse the questionnaire original label as an owl-class synonym. In this way, once again, we aim at developing as far as possible a user-driven module in which each class is not only designed for machine but also for human understanding.

In the further stages of the development of the HDOT-PM we will consider the possibility to extract further biomedical patient-driven knowledge out from the p-medicine tool in order to formalize and make it available among the community of p-medicine.

Particularly, we aim at stating horizontal axioms (e.g. owl:hasPart, owl:hasRole, owl:isQualityOf, etc.) between the owl-classes in the ontology and not only vertical ones (owl:isSubclassOf), so that the domain representation can be as detailed and expressive as possible relative to the targeted domain.

Here we show some possible horizontal axiomatization that are not yet part of the module because they need further discussions before they can be included in the next version of the HDOT ontology. Some of the following classes are not yet part of HDOT, but we are aware of the fact that we need to include them before assessing owl-relations.

We use in the following examples an owl2 syntax according to the specifications provided by HDOT:

• HDOT-PM:CancerRelatedFatigue isSubClassOf HDOT:Fatigue and isQualityOf some (HDOT:Organism and (hasPart some HDOT:PathologicalFormation));

• HDOT-PM:CancerPain isSubClassOf HDOT:Pain and isQualityOf some (HDOT:Organism and (hasPart some HDOT:PathologicalFormation);

• HDOT-PM:CancerPain causes some (HDOT:PsychologicalDistress or HDOT-PM:MoodDisturbance or HDOT-PM:EmotionalDistress or HDOT-PM:Fear);

• HDOT-PM:CancerRelatedAppetite causedBy some (HDOT:Chemotherapy or HDOT:PsychologicalCondition);

• HDOT-PM:CancerRelatedAnxiety causes some (HDOT-PM:PanicAttack or HDOT:Depression or HDOT:SleepDisorder or HDOT-PM:CancerRelatedFatigue or HDOT-PM CancerRelatedAppetite or HDOT:DigestiveDisorder);

• HDOT:Depression disjointWith some HDOT:Sadness.

However, it is worth noting that in the further development of HDOT and its related modules (e.g. HDOT-PM), we will re-consider the linguistic data schema that we present in the above table together with the above axioms which should be considered just as examples for the time being. The main reason for this is that we need to state

clearly the content-granularity between the middle-layer classes of HDOT and the classes belonging to its modules, considering also the case that some module-dependent class can be useful outside the single specifications of its module.

5 Conclusion

In this chapter we outline the first steps for the further development of the semantic and axiomatic structure of HDOT in a patient-driven way. Thus, we present the initial prototype of the HDOT

patient-module (HDOT-PM) according to the ALGA questionnaire results and present the core of a linguistic patient language schema.

By integrating these results in an ontological module, we ensure that this information can be shared not only amongst the p-medicine community but also p-medicine's patient communication within one and the same semantic and axiomatic structure.

However, further discussions and research about the ontological status of some results are required in order to maintain a high degree of quality in domain representations throughout p-medicine's linguistic and semantic needs.

It is worth remembering that the HDOT-PM in currently under development.

Appendix 1 - Abbreviations and acronyms

GSRH	Global Self-Rated Health
HDOT	Health Data Ontology Trunk
HDOT-PM	Health Data Ontology Trunk – Patient Module
OAT	Ontology Aggregator Tool

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