Personalized Emergency Medical Assistance for Disabled People

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Abstract. Emergency medical services (EMS) rely on well established operational instructions and predefined procedures allowing to promptly and accurately choose a proper course of action in the field. The procedures, on which medical first responders are specifically trained, target the most frequently occurring cases and do not include special cases concerning (sensory, motor or cognitive) disabled persons. As a result, they may not be optimal and require changes and additions for the various types of disabilities. This paper proposes both a detailed user model for EMS that can account for peculiar aspects of the many existing disabilities and an adaptive information system called PRESYDIUM (Personalized Emergency System for Disabled Humans) that provides tailored instructions in the field for helping EMS nurses and volunteers in dealing with disabled persons. More precisely, we will illustrate and discuss: (i) the design and development process of the system, (ii) the user model, which is partly based on the ICF (International Classification of Functioning, Disability and Health) standard proposed by the World Health Organization, (iii) the knowledge base used by the system to provide tailored instructions, (iv) the Web-based architecture of the system, (v) the different interfaces – including one for mobile devices – the system provides to enable all the identified stakeholders (disabled persons, their families, clinicians, EMS call center operators, medical first responders in ambulances) to easily contribute data and/or receive personalized instructions, (vi) the evaluation of the validity of the user model and of the usability of PRESYDIUM which have been conducted with end users.

Keywords: *personalized e-Health information systems, patient models, disabled patients, tailored instructions, first responders, emergency medical services, tailored decision support, knowledge-based systems, Web-based systems, mobile applications*

1 Introduction

Being able to promptly and accurately choose a proper course of action in the field is a crucial aspect of emergency response. For this reason, emergency medical services (EMS) rely on well established procedures that apply to the most frequent cases first responders encounter in their practice, but do not include special cases concerning (sensory, motor or cognitive) disabled persons. In these cases, first responders may end up applying suboptimal or possibly wrong procedures or lose precious time trying to adapt on-the-fly to the special case. Adaptive systems could thus be employed to generate personalized instructions for medical first responders, taking into account a model of the disabled person involved. For example, an adaptive system could consider the presence of chronic pain or pre-existing paralysis in specific parts of the body to instruct first responders – while they are traveling in the ambulance to the patient location – about changes to the standard procedures. For example, the question “Do you feel pain here?” should be substituted with “Do you feel more pain than usual here?”, manual procedures to immobilize the patient and to transfer her to a stretcher should treat paralyzed body parts with extra care (e.g., loads and tractions), and specific instructions to properly manage infrequent acute conditions (e.g. autonomic dysreflexia) that can affect people with certain disabilities should be provided.

Our work focuses on providing personalized operating instructions concerning disabled persons, by exploiting a detailed patient model that can account for the peculiar aspects of the many existing disabilities, a knowledge base containing the rules to generate personalized operating instructions, and a Web-based system that allows different categories of users (disabled persons, their families, clinicians, EMS call center operators, medical first responders) to access and possibly provide data to the system through appropriate user interfaces. After an analysis of related work (Section 2), we illustrate the knowledge acquisition process (Section 3), the detailed patient model (Section 4), the knowledge base (Section 5), and the PRESYDIUM (Personalized Emergency System for Disabled Humans) Web-based system (Section 6). In Section 7, we present the user study we carried out to assess the adequacy of the patient model and of the functionalities provided by PRESYDIUM to manage patient models. Finally, Section 8 concludes the paper and illustrates future work.

2 Related Work

To the best of our knowledge, no research has been devoted to using adaptive or knowledge-based systems for helping EMS nurses and volunteers in dealing with disabled persons by tailoring instructions to individual needs.

In the medical emergency response domain, a few knowledge-based systems have been proposed for information and resources management in mass casualty incidents or crises: for example, R-CAST-MED (Zhu et al., 2007) is a system that uses an agent-based architecture to manage information sharing among geographically-dispersed teams to improve collaboration and coordination in mass casualty incidents, and iRevive (Gaynor et al., 2005) is a system that includes also a mobile component to handle coordination among ambulance teams, local site management and a distributed collection of hospitals. Other knowledge-based systems focus on triage in EMS: for example, Mobile Emergency Triage (Michalowski et al., 2003) is a mobile application that can be used to triage a child based on identified symptoms, while Automated Triage Management is a system that assists healthcare practitioners in finding patients' chief complaints (Guterman et al., 1993). Gertner and Webber (1998) proposed instead the TraumaTIQ knowledge-based system to support physicians in trauma management. Their approach is based on evaluating rather than recommending plans: the system aims at recognizing what plan the physician is following, evaluates it and provides a user-focused critique to the course of actions chosen by the physician when it detects possible problems. Comments presented by the system are sorted by order of importance and topic.

The generation of personalized health content has been explored in the literature in non-emergency contexts - see Cawsey et al. (2007) for an introduction. Adaptive systems have been applied successfully to inform patients about their conditions, enable them to take decisions, and persuade them to be compliant with care plans. Different diseases, such as diabetes (Binsted et al., 1995), cardiovascular disease (Davis & Abidi, 2006), cancer (Cawsey et al., 2000), and asthma (Osman et al., 1994) have been addressed. The PULSE project (Davis & Abidi, 2006) combines patient data acquired from paper-based medical records with adaptive Web-based presentation techniques to provide personalized education materials about cardiovascular risk. The personalized materials address medical and psychosocial aspects together with clinical guidelines to motivate people to take care of their health. The PIGLIT (Binsted et al., 1995; Cawsey et al., 2000) system also focuses on health education materials, aiming at providing users with personalized hypertext explanations of their conditions, exploiting information from the patient's health record, a medical knowledge base and a natural language generator.

Computer Decision Support Systems that support physicians in their activities - see Berlin et al. (2006) for a survey - share with adaptive systems the need for integrating medical knowledge bases, electronic medical records and computer-interpretable clinical guidelines. Relevant patient data can be acquired from Electronic Health Records (EHR), which unfortunately still have usage and adoption issues as discussed in (Berlin et al., 2006). While EHRs are typically managed by clinicians and staff of health care institutions, the idea of Personal Health Records (PHR) – i.e. an health record that conforms to recognized standards and is managed by the individual – is becoming popular, also thanks to Web-based applications such as Google Health (Google Inc., 2010) and Microsoft Health Vault (Microsoft Corp., 2010). Web-based PHRs are particularly interesting from a personalization point of view, since they offer: (i) standards upon which to build user models and health personalization applications, (ii) more access and control on what personal information is contained in and shared by the PHR, thus contributing to address some of the crucial privacy and trust issues highlighted in (Binsted et al., 1995).

PHRs can also be stored on USB keys, which people could always carry with them to make personal emergency medical information available to first responders. Some companies, e.g (Elderluxe, 2010; InfoVivo, 2010; Vital Record corp., 2010) , sell solutions which include a software allowing one to manage the medical information by means of a PC and store it on a USB key that can be attached to key chains or integrated into bracelets and necklaces (Safe Guard Medi-Systems corp., 2010). These solutions are a digital evolution of more traditional bracelets and necklaces which carry engraved medical alert information, such as illnesses or chronic conditions (e.g. diabetes, epilepsy), allergies (e.g. to penicillin) and in some cases the number of a call center for additional information (MedicAlert Foundation, 2010). The main advantage of USB keys with respect to engraved bracelets and necklaces is the availability of more medical information. Nevertheless, they still have several limitations, such as:

- data cannot be acquired until first responders meet the patient and, at that time, first responders often do not have enough time to acquire and manage the digital data, e.g. due to the patient's critical conditions;
- although first responders are trained to look for medical alerts and the bracelets and necklaces carrying such information are clearly labeled, it is possible that they are not available for several reasons, e.g. the patient forgot to wear or carry the USB key or it was lost or damaged during an accident;
- even if the USB key is available and there is enough time to retrieve and examine the data stored on it, first responders need the proper hardware and software configuration to access the files on that key;
- despite most companies claim to be compliant with international standards, the data stored in different USB key solutions could differ greatly in terms of both details and presentation formats and this could significantly slow down first responders while they are trying to collect the most relevant information in a short time.

3 Requirement Analysis

We started our project by conducting focus groups that involved: (i) EMS physicians and nurses, (ii) rehabilitation clinicians specialized in disabilities, and

(iii) representatives of various Italian associations of disabled persons[1]. We summarize in the following the main findings that emerged from the focus groups:

- Although knowing the general class of (sensory, motor, cognitive) disability to which the patient belongs already allows to provide some disability-related advice, for each class there are a large number of descriptive attributes (e.g., detailed anatomical descriptions of motor disabilities) that would allow the system to provide advice which is tailored to the single patient. Therefore, the system needs a detailed representation of the patient's disabilities that comprises all those attributes. From this point of view, our work shares some similarities with the problem of generating personalized information using medical records that has been explored in non-emergency domains, e.g. (Binsted et al., 1995).
- Since every second counts in EMS operations, it is not conceivable to acquire the detailed description of patient's disabilities during the emergency: the information is needed beforehand, also taking into account that determining the value of the different attributes can require considerable time to an experienced clinician.
- The disabled person and her family should be actively involved in the management of the information stored in the system: although some attributes can be provided only by doctors, allowing the disabled to access their full record and keep some personal fields (e.g. contact information) up-to-date contributes to build trust in the system and make patients aware (for privacy and legal reasons) of the data stored about them and who can access it.
- The system should provide advice to the phone operators of the EMS call center (to help them choose which team and which ambulance is most appropriate to the context) as well as to the EMS first responders on the field (to provide advice about the course of actions to take). For this reason, the system should run on desktop as well as mobile devices, and

[1] Association of the Blind and Visually impaired (UICI), Association of the Deaf and Mute-Deaf (ENS), Autism association (PROGETTO AUTISMO FVG), Dystrophy Association (UILDM), Regional Council of the Disabled (CONSULTA FVG), Spilimbergo Center for the Motor Disabled (PROGETTO SPILIMBERGO).

the mobile interface should take into account peculiar limitations of mobile data visualization (Chittaro, 2006).

- An important contextual factor to be taken into account is the severity of the emergency, which is formalized by EMS with standard codes (e.g., the standard employed by all Italian EMS is based on 4 codes of increasing severity: white, green, yellow, red). As severity increases, the system should give priority to those recommendations which are crucial to preserve life.
- The advice provided to different classes of medical first responders (physicians, nurses, volunteers) should not necessarily be the same, since members of each class have different roles, tasks and responsibilities, which are based on their skills and background. For instance, advice about extra care to take in mobilizing parts of the body when it is known that they are impaired is appropriate for volunteers who are helping nurses, but the same advice would be considered obvious and redundant by nurses. On the contrary, advice such as "Consider the occurrence of autonomic dysreflexia[2]" is appropriate for nurses (and only for them), since volunteers would not have enough knowledge to handle the situation and would not be allowed to perform the operations needed to manage it.

4 Modeling disabled persons

As stated by the World Health Organization (WHO, 2010), disability is "an umbrella term, covering impairments, activity limitations, and participation restrictions". An impairment is "a problem in body function or structure", an activity limitation is "a difficulty encountered by an individual in executing a task or action", a participation restriction is "a problem experienced by an individual in involvement in life situations".

According to such definition, identifying and modeling all the impairments of each disabled person to personalize EMS operations is a challenging task, because severely disabled people can be affected by many different and unrelated conditions which are not taken into account by generic disability stereotypes (e.g.,

[2] Individuals with spinal cord injury (SCI) at or above T6 level are at risk of autonomic dysreflexia, which is an acute and life-threatening condition More specifically, autonomic dysreflexia is an excessive autonomic response to stimuli below the level of the SCI, e.g. those caused by a blocked catheter or faecal impaction. (Gall and Turner-Stokes, 2008).

blind, deaf, …). Moreover, current EHR and PHR standards do not support detailed specification of disabilities. However, starting from scratch without relying on any standard makes it much more difficult to propose a disabled person profile as well as having it adopted by clinicians.

4.1 The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is an initiative that is particularly relevant for our project, because it focuses specifically on disabilities. The ICF is the World Health Organization (WHO) international standard for measuring health and disability at both individual and population levels and is endorsed by all WHO member states since 2001. A literature review on ICF adoption is provided by Bruyère et al. (2005). The ICF organizes information in two parts. Part 1 concerns Functioning and Disability, and is structured into two components:

- *Body Functions and Structures*, to classify functions of body systems (e.g., Mental Functions, Sensory Functions, and Pain) and body structures (e.g., the Nervous System, The Eye, Ear and Related Structures);
- *Activities and Participation*, to cover functioning from both an individual (e.g., Communication, Mobility) and a societal (e.g., Interpersonal Interactions and Relationships) perspective.

Part 2 covers Contextual Factors, and is structured into two components:

- *Environmental Factors*, organized from the individual's most immediate environment (e.g., Products and Technology) to the general environment (e.g. Services, Systems and Policies);
- *Personal Factors*: they include gender, age, race, fitness, lifestyle, habits, coping styles, and other such factors.

Each of the above components consists of various *domains* (e.g. Sensory Functions and Pain is a domain of the component Body Functions and Structures). Within each domain, *categories* are the units of classification and are arranged hierarchically (e.g. the domain of Sensory Functions and Pain has nested categories such as Seeing Functions, Quality of Vision, and Light Sensitivity). Health and health-related states of an individual are recorded by selecting the appropriate category code and then adding *qualifiers*, which are numeric codes that specify the extent or the magnitude of the functioning or disability in that category, or the extent to which an environmental factor is a facilitator or barrier. For instance, the code b210.4 indicates a complete impairment of seeing functions: the “b” prefix identifies the Body Functions component, the “210” code identifies the Seeing Functions category of the Sensory Functions and Pain domain, and the “.4” identifies the “complete impairment” value of the impairment category qualifier.

Since the ICF contains over 1400 categories, efforts to facilitate its use in clinical practice are underway. In particular, the ICF Checklist (WHO, 2003) consists of a selection of 125 ICF categories of more frequent use in clinical practice, and provides a questionnaire that can be filled out by a health professional to generate a disability profile of a patient.

4.2 Disabled Person Profile (DPP)

To develop a Disabled Person Profile (DPP) that describes the disabilities of an individual which are most relevant in the context of EMS, we conducted meetings which included the authors of this paper and involved a total of 4 computer scientists, 3 clinicians working with disabled patients, and an emergency medicine doctor. The ICF Checklist was identified as a starting point, and each of its categories was evaluated for appropriateness in the EMS context. The analysis pointed out that the DPP could be built by making some changes and extensions to the ICF Checklist. PHR data was also considered, since the availability of (parts of) the detailed medical history of patients might be useful. The meetings focused on identifying which fields of PHRs are crucial for the EMS context, considering that the time to analyze patient data in emergencies is limited and thus one has to concentrate on the most relevant information.

The DPP is organized into 12 sections (some of which have subsections) that group different sets of related fields, leveraging the domains and categories of ICF wherever possible. In the following, we list and briefly describe all DPP sections and subsections, grouping them to highlight common aspects (for a full description, see the Appendix of this paper):

- Sections containing general data about the disabled person:

- *Personal data*: information to identify the disabled person (e.g. social security number, name and surname, address, phone numbers);
  - *Contact persons*: contact information of relatives and/or representatives to be called or who may call in case of emergency.
  - *User requests*: particular notes (in free text form) about some specific requests made by the disabled person, which cannot be expressed by means of any other field.
- Sections containing PHR data that capture medical information which does not belong to the ICF, but is relevant in EMS operations for any individual (we will refer to these sections as *PHR sections*):
  - *Diagnoses and comorbidities*: includes two subsections, one for the main disability *Diagnoses* (e.g. paraplegia, blindness, deafness, autism,…) and one containing the list of *Comorbidities*[3] (e.g. diabetes, asthma, epilepsy,…), if any;
  - *Allergies*: list of allergies (to drugs, food or other);
  - *Medications and medical devices*: includes two subsections, one containing the list of the *Medications* regularly taken by the disabled person and the other listing the *medical devices* (e.g., mechanical ventilator, catheters,…) that the patient needs, if any;
- Sections containing ICF data (37 ICF categories: 20 from the ICF Checklist, 17 from the full ICF) and 3 additional fields selected by the domain experts based on relevance in the context of EMS (we will refer to these sections as *ICF sections*):
  - *Cognitive functions*: includes three subsections, one grouping *Mental functions* (i.e. *Consciousness, Orientation, Intellectual, Memory* and *Language*) impairments, and two grouping *Communication* abilities in receiving and producing messages (verbal and non-verbal);
  - *Body functions*: includes different subsections, each one grouping together the impairments to the functions of a different body

[3] Comorbidity is the presence of one or more disorders (or diseases) in addition to a primary disease or disorder.

system (i.e. *Sensory*, *Cardiovascular*, *Respiratory*, *Gastrointestinal* and *Urinary functions*);

  - *Mobility of joints*: describes impairments to the mobility of joints;
  - *Motor control*: includes three subsections, one for impairments to motor control of body parts, one for *Mobility* abilities (i.e. Walking and Moving around using equipment), and one for *Muscle tone* impairments (i.e. Hypertone and Hypotone), if any;
  - *Pain*: body parts in which the disabled person chronically feels a sensation of pain;
  - *Involuntary movements*: parts of the body exhibiting involuntary contractions of muscles.

With respect to ICF categories and qualifiers, we made the following changes:

- Since some ICF categories (i.e., b280-Pain, b710-Mobility of joints, b760-Motor control, b765-Involuntary movements) do not include the precise identification of the body parts affected by impairments, which is needed for our purposes, we extended them using a 27-parts graphical representation of the human body; examples of such representations for a real quadriplegic person is provided in Figure 1.

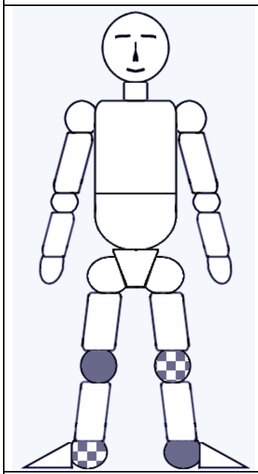
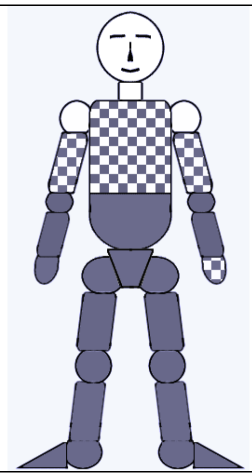
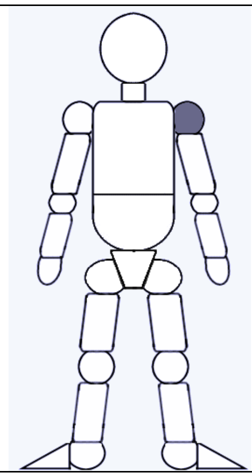
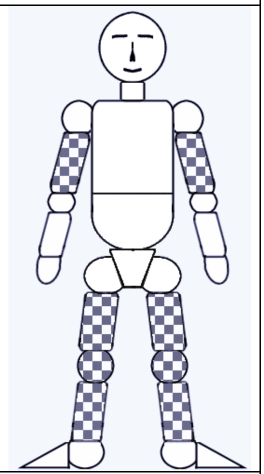
Mobility of joints	**Motor control**	**Pain (rear view)**	**Involuntary movements**
			
☐ No Impairment	☐ Full Control	☐ No pain	☐ No involuntary movements
Moderate Impairment	Partial Control		Rare involuntary movements
Serious Impairment	No Control	Pain	Frequent involuntary movements

Figure 1. Examples of the 27-parts graphical representations of the human body used in the DPP, showing the impairments of a quadriplegic person in a real clinical case.

- The qualifiers used to specify the magnitude of an impairment in the different categories have been simplified, by including only 3 of the 7 ICF values. More specifically, we kept the values *No impairment*, *Moderate impairment* and *Complete impairment*, while we discarded the values: (i) *Mild impairment* and *Severe impairment* to reduce subjectivity in the assignment and interpretation of impairment, and (ii) *Not specified* and *Not applicable*, since they were useless in our considered categories. We also added a *Not evaluated* value to be used when the field has not been explicitly evaluated. This value is useful when the clinician who is filling the DPP of a disabled person does not have enough information or does not have proper expertise to set an explicit value for a specific field.
- For the qualifiers of some categories, domain experts identified the need of using specific terms (e.g. Hypoventilation, Normal, Hyperventilation for the category b440 Respiration) to make the values more precise for physicians and first responders, in particular where the above ICF values could lead to ambiguous interpretations (e.g. Moderate impairment of the category b420 Blood pressure could mean Hypotension as well as Hypertension).
- Notes fields have been associated to most DPP fields (in particular, to all fields that do not identify a body part) to allow physicians to provide additional details about each impairment, if they would like to.

5 Generating tailored operating instructions

To collect *operating instructions* (including warnings, procedures and recommendations) for personalizing EMS operations based on the DPP, the knowledge acquisition process has been organized to take advantage of three different kinds of knowledge sources:

- Available general documents about safety response concerning the disabled, produced by different organizations, e.g. the National Department of Firefighters in Italy and the Center for Development and Disability in the US (2010). The analysis of such documents allowed us to derive basic rules about how to communicate and behave with blind, deaf, mute people or people with mental disorders, and how to transport motor-impaired persons in emergency situations such as fires or underground train evacuations. This knowledge was not specific to EMS so it was reviewed with clinicians to adapt it to the EMS context, e.g. some recommendations were considered to be trivial for professional EMS personnel.

- Expert knowledge, provided by the above mentioned medical experts. Each expert analyzed the problem from a different perspective, the acquired rules were formulated in natural language in a draft document and we carried out periodical panel meetings involving all the experts to review the individually proposed rules. These panel meetings helped point out and correct some differences in the terminology used by the different experts. Changes in rules were typically made to reconcile the clinical approach of thoroughly reasoning from very precise diagnoses with the EMS approach where priority is given to preserve life, stabilizing the patient and transporting him quickly and safely to the hospital. When the two approaches could not be reconciled, the rule was rejected: it would indeed be impossible in the field to carry out evaluations which require considerable time and are technically more appropriate for a hospital environment.
- Knowledge acquired from representatives of the associations of disabled persons. Semi-structured interviews were carried out to gather information about previous experiences (if any) as EMS patients or let them imagine (as a role-playing exercise) being rescued and think about which kind of first responders' actions should be avoided or should be undertaken to make the whole operation more acceptable and comfortable to them. This was especially useful to more thoroughly investigate communication-related and social aspects of the interaction between first responders and disabled persons (e.g., ways to appropriately get the attention of a deaf person, verbal expressions that should be avoided with blind persons,…). The acquired knowledge was always presented to clinicians for review and final approval.

The collected operating instructions are mainly textual, but in some cases can be enriched by graphical representations of impairments (or even audio and video

clips). We represent the knowledge acquired from experts as frames that contain the slots described in
Table 1. For example, the following frame concerns an operating instruction that applies to motor disabilities:

- *DPP Conditions*: there is a joint part `J` in the anatomical representation of the patient for which `b710 Mobility of joint` is equal to `Moderate impairment` or `Complete impairment`
- *Operating Instructions*:
  - Text – recommend to avoid forced movement of `J`;
  - Graphics – graphical anatomical representation with `J` highlighted
- *Activity*: transportation
- *Emergency Codes*: yellow and lower
- *Suitable For*: volunteers, relatives
- *Priority*: 4

Table 1. Description of slots for frames in the Knowledge Base.

Slot	Description
DPP Conditions	Conditions on DPP attributes that make the frame applicable
Operating Instructions	The warnings, procedures and recommendations, provided in textual version and possibly with graphic, audio, and/or video additions
Activity	The kind of first responder activities to which the Operating Instructions refer (e.g., communication with the patient, resuscitation, transportation,…)
Emergency Codes	Codes used in ambulance dispatch (to quickly convey essential information about the expected severity of an emergency) to which the Operating Instructions are appropriate; for example, the codes for Italian EMS are (from lowest to highest severity): white, green, yellow, and red
Suitable For	Categories of system users to which the Operating Instructions are useful (physicians, nurses, volunteers, phone operators of the EMS call center, patients, relatives)
Priority	An integer number to encode possible precedence levels among applicable frames (1 = lowest, 5 = highest)

Given a DPP, the reasoning activities that the system carries out to provide personalized operating instructions are: (i) use the *DPP Conditions* slots to identify the frames that apply to the given DPP; (ii) filter out those frames which are not suitable for the current emergency code and category of user (e.g. nurse, volunteer); (iii) present the operating instructions of the remaining frames. For presentation, the system currently employs a simple approach based on first grouping the operating instructions by *Activity*, then ordering them by *Priority* inside each activity. The only adaptive aspect of presentation currently concerns the device used to access the system (mobile or desktop). Given the small screen size of mobile devices, operating instructions are organized into pages to minimize the need of scrolling and different versions of graphics are used.

The reasoning activities above described, which rely on standard techniques for expressing rules in knowledge bases, are aimed to the following goals: (i) limit the number of operating instructions for each disabled person, by selecting only the correct instructions based on the actual values of a patient's DPP; (ii) provide only the operating instructions which are really relevant for a specific emergency and for a user in a specific category, thanks to the filtering mechanism; (iii) present the operating instructions by grouping and ordering them according to criteria which are familiar to first responders.

6 The PRESYDIUM System

PRESYDIUM (Personalized Emergency System for Disabled Humans) is a Web-based system that allows users to manage DPPs and to receive tailored instructions in the field when dealing with emergencies involving the disabled persons described by those DPPs. Disabled persons, their relatives and physicians can use PRESYDIUM through a Web Portal, whose user interface adapts to user category as well as user disabilities by exploiting stereotypes. Moreover, PRESYDIUM provides a Web Service, which is accessed by EMS call center operators through a desktop client, and by first responders in the field through a mobile client, to retrieve tailored operating instructions.

In the following sections, we describe the system architecture and we illustrate how the system is used. The screenshots are taken from a real case involving a patient with hemiparesis and hypertonia of the right side of the body, total paralysis of the right foot, and impairment of urination functions.

6.1 System architecture

We built PRESYDIUM using the open source JBoss Web application framework (JBoss, 2010), which includes Drools (2010), a Rule Management System based on the well-known RETE algorithm (Charles, 1982). The high-level architecture of PRESYDIUM (illustrated in Figure 2) follows a 3-tier Web application approach. The main components of each tier are described in the following.
The data layer of PRESYDIUM is composed by five databases:

- *User Stereotypes*: contains a set of user stereotypes, which refer to categories of users (e.g. general practitioner, clinician), or general classes of disability (e.g. visually impaired, blind, hearing impaired). Stereotypes are used to determine access privileges to the system, functionalities offered and user interface adaptations.
- *System Users*: contains user account data and associations between accounts and user stereotypes.
- *User Interface Templates*: contains the page templates used to adapt the interface.
- *Disabled Person Profiles*: contains the DPPs.
- *Medical Knowledge Base*: contains the frames described in Section 5, used to generate personalized operating instructions.

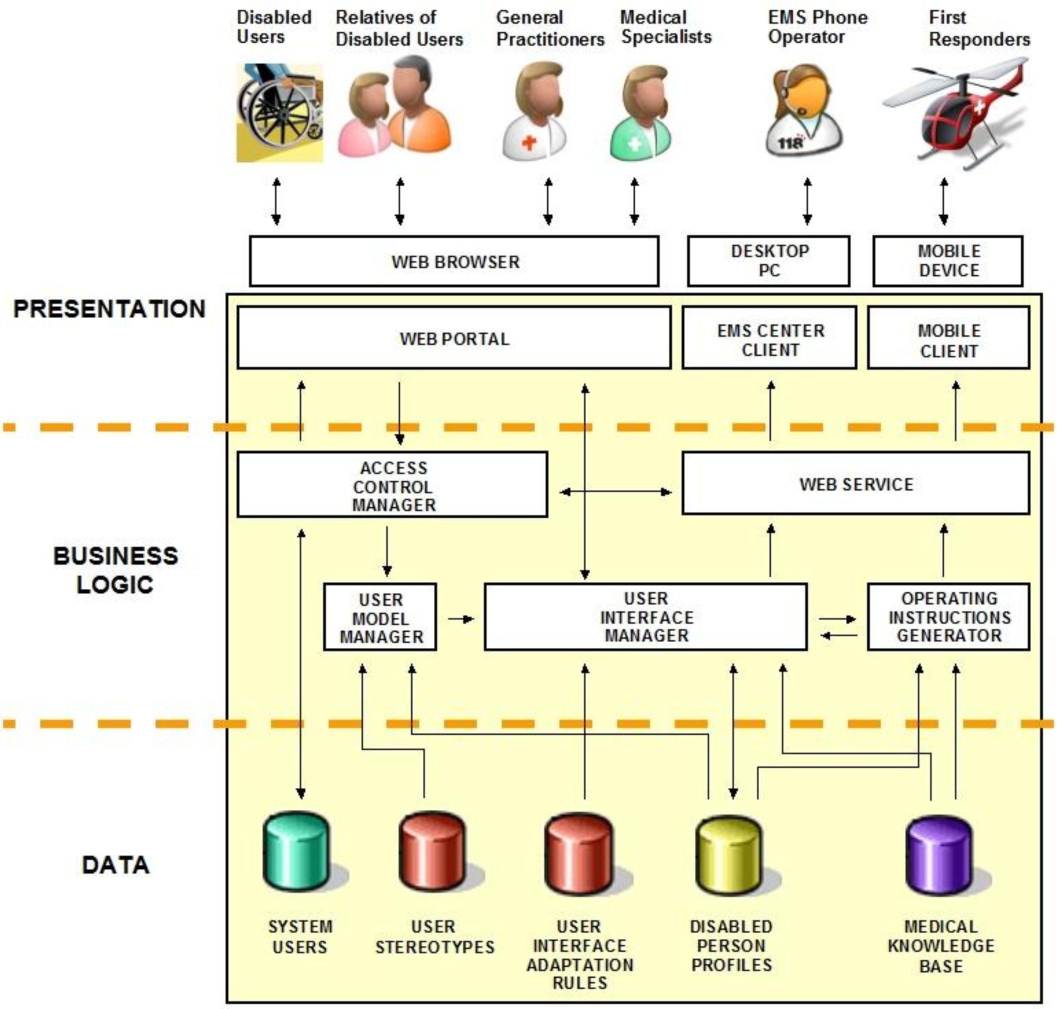


Figure 2. The PRESYDIUM system architecture.

The business logic layer of PRESYDIUM is composed by:

- *Access Control Manager*: this component manages user authentication, by checking credentials in the System Users database, and handles user identification based either on traditional password access or the European Health Insurance Card (EU Commission, 2009). The most recent version of the card includes a memory that contains identification data and can be read by a PC card reader which in our region is freely distributed to all households.
- *User Model Manager*: for each logged user, this component merges her associated stereotypes; if the user is a disabled person, specific attributes of her DPP (e.g. visual impairment) are used to find the proper stereotypes.

- *User Interface Manager*: starting from the user stereotype information provided by the User Stereotype Manager, this component adapts the following user interface features: (i) information and functionalities provided (e.g. medical data editing available to physicians only), (ii) presentation of elements of the user interface (e.g. bigger font size and inverted contrast for users with low vision), (iii) forms for data entry of DPPs, which show or hide some of their parts (e.g. fields, notes, schematic representations of human body) based on the values entered for specific fields.
- *Operating Instructions Generator*: this component selects, filters and formats the appropriate operating instructions as discussed in Section 5.
- *Web Service*: this component provides (to authenticated users) the methods to retrieve information about the DPPs (e.g. the list of disabled persons and relatives matching search criteria) and the operating instructions associated to each of them.

The presentation layer of PRESYDIUM is composed by three user interfaces:

- *Web Portal*: allows all kind of users who are involved in managing DPPs to access the system through any Web browser (see Figures 3 through 5).
- *EMS Center Client*: provides phone operators of the EMS call center with fast search and retrieval functionalities on DPP data (see Figure 6), and the capability of associating the DPP of the disabled person involved in the emergency to the first responders team sent to the field.
- *Mobile Client*: is used by first responders in the field (e.g., while they travel to the emergency destination) through wireless cellular networks to examine operating instructions (Figure 7) structured in sections and pages.

6.2 Using the system

Web Portal

To be used in an emergency concerning a specific disabled person, PRESYDIUM requires that a DPP for that person is available in its database. To fill in and maintain the DPP for a disabled person, PRESYDIUM encourages a shared initiative between physicians, who contribute medical data, and the disabled (or their relatives), who contribute personal information (e.g. contact information and specific requests) through the Web Portal. The DPP is thus filled before emergencies occur, e.g. during a routine medical visit, when a physician has the opportunity to gather all the information needed from the disabled person (or her relatives) and from her clinical documents.

The user interface of the Web Portal was developed in conformance with W3C Web Content Accessibility Guidelines 2.0 (W3C, 2008), allowing disabled persons to access their own DPP and inspect all the data the system stores about them. This also contributes to address trust issues.

The user interface of the Web Portal (Figure 3) provides a menu listing the main functionalities of the system (e.g. *New Patient*, *Patient Selection,…*) on the left, while most of the screen is devoted to display data (e.g. parts of the DPP of a selected patient). The DPP organization into different sections and subsections is thoroughly matched by the user interface, which provides a link for each DPP section at the top of the data area. A link to an additional *Operating instructions* section is also available, so that all users (both physicians and disabled people) can read the operating instructions that will be provided to EMS first responders on the field. Just below the sections links, the name of the currently selected DPP section is displayed followed by its fields (possibly grouped into subsections). DPP fields are normally displayed in *view mode* (i.e. read-only) to avoid unintentional changes. The “Edit data” button of a DPP section must be pressed (activating the *edit mode*) to edit its fields, whose value can be changed through: (i) comboboxes (listing the available values for each field, including the “Not evaluated” default) for most DPP fields (Figure 4), (ii) textboxes for possible additional notes (Figure 4) (iii) clickable impaired body parts in DPP sections (Figure 5) where graphical representations of the human body are available. Contextual help about how to use currently displayed controls and available functionalities (e.g. how to set fields values in edit mode) is provided within the data area, by means of focused textual instructions (Figure 5). Moreover, users can see the definition (which is directly taken from the corresponding ICF field when appropriate) of each DPP field, by pointing the mouse over the question mark icon preceding each field label (Figure 4). The Web Portal adapts the interface of the system by changing the presentation of user interface elements (e.g. bigger font size and inverted contrast for users with low vision), and by form adaptations during data entry of a DPP, to show or hide parts of the form (e.g. fields, graphical representations of the human body) based on the values entered for specific fields (e.g. notes fields are displayed only when a value has been set for the associated field).

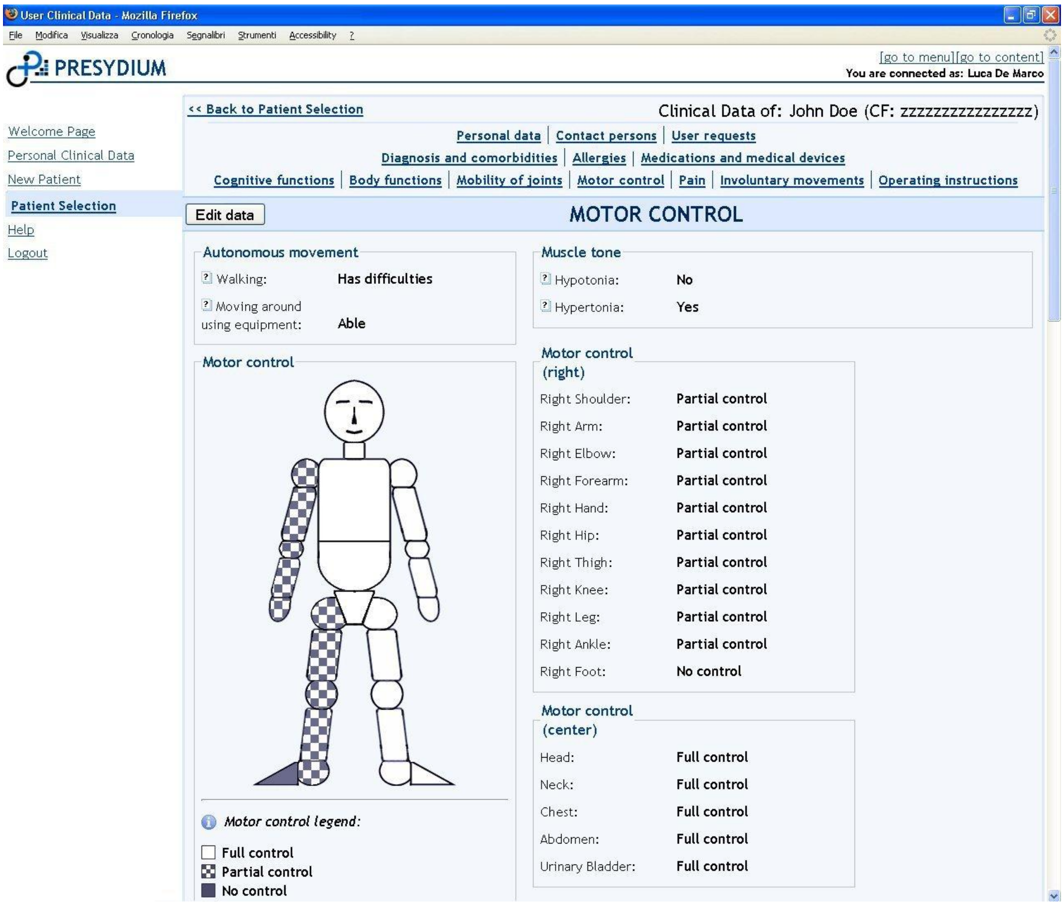


Figure 3. A sample screen of the Web Portal. The menu on the left lists the main functionalities of the system, while most of the screen is devoted to display DPP data of a selected patient. The data shown in this screen concerns motor control: information is presented graphically through patterns that indicate the level of impairment of different body parts on a representation of the human body, and also with text descriptions.

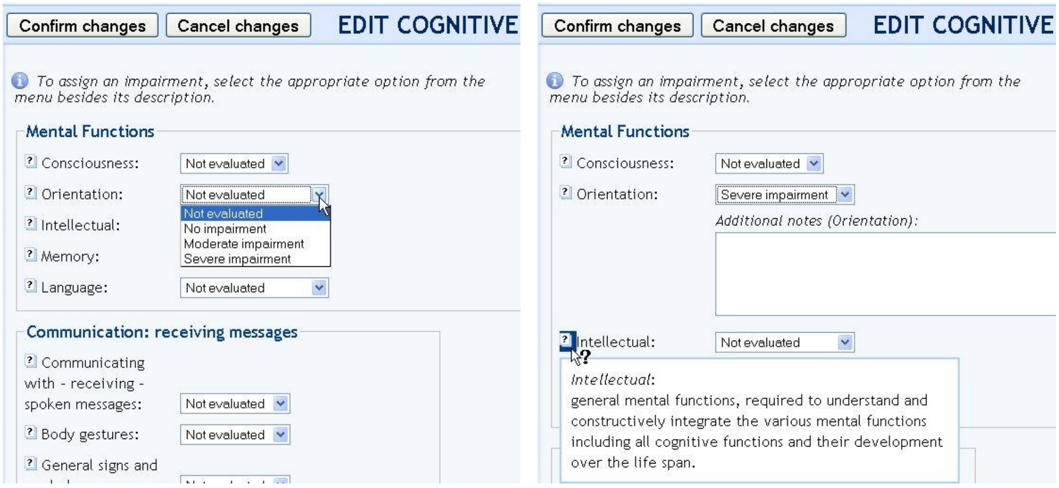


Figure 4. Entering data in PRESYDIUM Web Portal: (left) combobox values for editing a DPP field; (right) a note for a DPP field with an impairment value and DPP fields popup definitions.

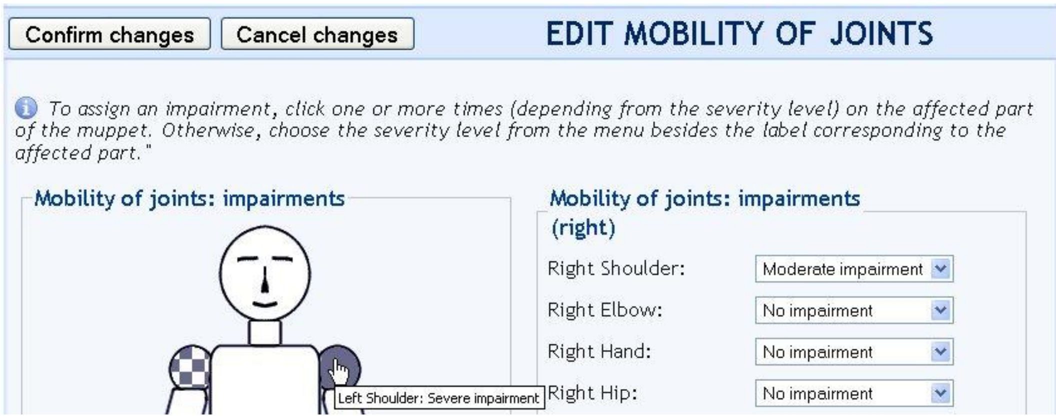


Figure 5. Clickable graphical representations of the human body and contextual help providing focused textual instructions at the top of the section (marked by the “i” – information – icon).

EMS Center Client

When the phone operator in the EMS call center receives an emergency call, the system first tries to match the calling number with the DPP database to automatically display the caller’s personal data on the phone operator’s screen. If caller’s automatic identification fails, the system provides the phone operator with a quick search functionality (Figure 6) to retrieve the DPP from the typical information that is requested anyway during an emergency call (such as the name and surname of the disabled person involved and the phone number of the calling person). On average, an emergency call to the EMS center lasts only one minute and a half to collect all the information needed from the calling person, since EMS center operators are specifically trained to manage calls as quickly as possible. At the end of the call, the phone operator dispatches an ambulance to the emergency destination and assigns the appropriate DPP to that ambulance run. Moreover, the EMS Center Client shows information about the contact persons of the disabled (Figure 6) allowing operators to quickly and easily contact them if needed (e.g. if the disabled person is alone and is temporarily unable to open the door, or if the communication is interrupted, e.g. because the caller phone runs out of battery).

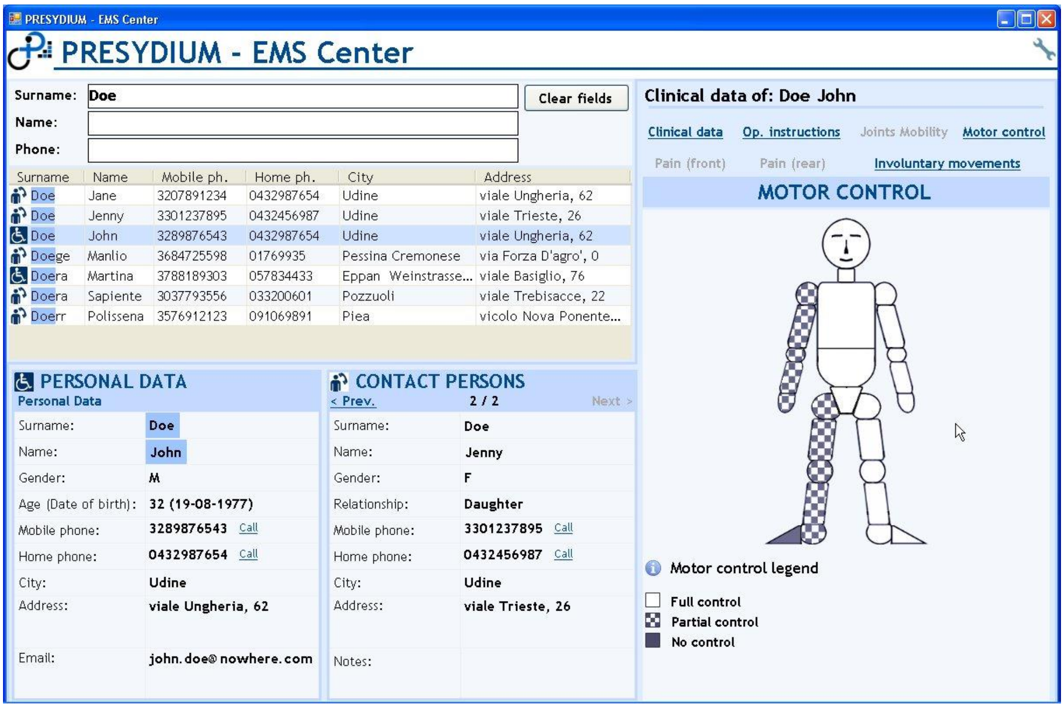


Figure 6. Searching for the DPP of a disabled person with the PRESYDIUM desktop client for EMS call center operators.

Mobile Client

Once a DPP has been assigned to a team of first responders in an ambulance, they become able to read the generated operating instructions from their mobile devices. Figure 7 shows three screens (corresponding to different pages) of the mobile interface used in the field: the screen on the left shows data contained within the PHR sections of the DPP (i.e. Diagnoses and comorbidities, Allergies, Medications and medical devices sections), the screen in the center displays the operating instructions, organized into sections by Activity and ordered according to their Priority, the screen on the right displays the motor control graphical representation for the considered patient. Moreover, the name, surname, gender and age of the patient are always visible in all sections at the top of the screen, as shown in Figure 7. Team members can thus examine operating instructions while traveling to the emergency destination. Moreover, to improve usability in a mobile context, the user interface of the Mobile Client has been designed to be fully operable with a single hand and by means of the device buttons (i.e. up and down arrows to scroll text, left and right arrows to browse pages), so that using the stylus is not necessary. In preliminary trials of the system, nurses spent from two to three minutes to examine DPP data, reading all the operating instructions and visualizing the graphical representations of the human body.

Figure 7. Mobile Client for EMS first responders: (left) PHR data (e.g. Diagnosis and Medications); (center) operating instructions, organized into sections (e.g. mobilization) and ordered according to their priority; (right) graphical representation of the motor control impairments (e.g. right hemiparesis).

7 DPP and Web Portal Evaluation

To assess the validity of the user model and the PRESYDIUM Web Portal, we carried out an evaluation organized in two distinct stages, both involving experienced clinicians specialized in disabilities. In the first stage, a group of clinicians was asked to fill in the DPPs of a given set of realistic cases, with the main goal of assessing the consistency of the data entered into the proposed user model by different clinicians. In the second stage, we asked a different group of clinicians to fill in the DPPs of a set of disabled persons who voluntarily participated to our study, to assess the adequacy and completeness of the DPP in describing a broad set of disabilities. In both stages, we also collected data and users’ feedback about the usability of the PRESYDIUM Web Portal.

7.1 First Stage

In the first stage, we asked a group of clinicians to fill in the DPPs of a given set of realistic cases, by means of the Web Portal of the PRESYDIUM system, with the following main goals: (i) assessing the consistency of the data entered by different clinicians about the same cases; (ii) collecting users' feedback about the usability of both the DPP and the Web Portal.

Participants

All 10 participants (5 male, 5 female) were experienced clinicians with different specializations (neurology, physiatry, radiology, rheumatology, sports medicine). Participants' age varied between 30 and 56 years, averaging at 42. All participants were familiar with electronic clinical data entry systems, which they used daily, but none of them had seen the PRESYDIUM system or the DPP before.

Pilot Study

A preliminary small-scale pilot evaluation was conducted, in which 5 of the 10 clinicians used the Web Portal to fill in the DPP of two of their patients (whose personal data were not collected for privacy reasons). The results of this pilot study allowed us to identify some limitations of the DPP (i.e. the absence of a Comorbidity subsection and the need to specify more detailed notes for some specific fields, in particular, in the Functions of the cardiovascular system and Functions of the respiratory system subsections), which were addressed and solved before proceeding with the evaluation.

Cases Creation

Another preliminary activity was the definition of 10 cases to be used in the evaluation. The cases were based on real patient data selected to be representative of a wide range of disabilities (sensory, motor, and cognitive). The cases were defined by two clinicians who participated in the design of PRESYDIUM and were not involved as subjects in the evaluation: for each case, they wrote down a natural-language description which included all the relevant clinical information, and filled in a *reference DPP* to indicate which DPP values best described the corresponding case. The reference DPPs were later used for assessing correctness and consistency of the data entered by different clinicians by comparing the values of each DPP filled in by a study participant with the corresponding reference DPP. Finally, the 10 cases were split into two sets of 5 cases each, taking care of balancing them in complexity and relevance to different disability types.

Procedure

The experimenter initially briefed participants about the nature of the study. Then, participants were instructed about the functionalities of the Web Portal during a hands-on session with a case prepared for training purposes. After the training phase, one of the two above mentioned sets of cases was assigned to each clinician, who had to fill in the DPP for each of its 5 cases by means of the PRESYDIUM Web Portal, whose user interface was fully localized in their language (Italian). This lead to a total of 50 DPPs entered in the system. Participants' comments were collected by note taking during and at the end of the session.

Results

Analyzing a patient case and entering the data into the system required a time varying between 10 and 22 minutes, depending on case complexity. All participants were able to successfully fill in most sections of DPPs, and were satisfied with respect to the completeness of the DPP in describing patient disabilities for medical emergency purposes. Participants were also generally satisfied of the usability of the Web Portal and reported only a minor problem in the procedure to insert medications, which was found to be boring because medications had to be inserted one-by-one, repeatedly switching between the edit and view modes of the user interface.
We performed an analysis of the consistency of the data entered by different clinicians about the same cases. In particular, for each case, the values assigned by the clinicians to represent impairments were compared to those of the corresponding reference DPP. For free text fields, different wordings for describing the same impairment (e.g. "Alzheimer's disease", "Alzheimer disease", "Alzheimer's") were considered equivalent. The results of the comparison are illustrated in Table 2, which shows that the data entered by the different clinicians was overall consistent (only 28 out of 355 – less then 8% – filled-in sections

contained deviations). In the following, we describe in more detail the results summarized in Table 2, focusing especially on deviations from the reference DPPs.

Table 2. Deviations in impairments between DPPs entered by participants and reference DPPs. For each DPP section, the table provides the number of entered DPPs ("# DPPs") that required to set at least an impairment in that section, and the number of entered DPPs that contained K deviations in the considered section wrt the corresponding reference DPP.

		# DPPs with K deviations wrt to reference DPP section						
DPP Section	**# DPPs**	**K=0**	**K=1**	**K=2**	**K=3**	**K=4**	**K=5**	**K=6**
Diagnoses	50	50						
Comorbidities	20	20						
Medications	40	40						
Medical devices	10	10						
Mental functions	30	28	2					
Communication	30	11	4	5	2	6	1	1
Body functions	45	42	3					
Mobility	30	30						
Muscle tone	30	27	3					
Mobility of joints	15	15						
Motor control	35	35						
Pain	5	5						
Involuntary movements	15	14		1				

All clinicians described medical data contained in PHR sections in equivalent terms for all the cases where such information was needed (i.e. Diagnoses and comorbidities, Medications and medical devices). Clinicians also assigned body segment impairment values appropriately in all the sections containing graphical representations of the human body (Mobility of joints, Motor control, Pain) with just one error made in the Involuntary movements section (i.e. a clinician forgot to set the value of "frequent involuntary movements" to the legs in one case). In the Body functions, Mental functions, and Muscle tone sections, clinicians assigned values appropriately to almost all fields with the following exceptions: in a few cases, an actual impairment was not reported into the DPP (i.e. Dysphagia was not reported in 3 cases and Hypertonia was not reported in three cases), in one case a body function problem (i.e. a heart disease) was reported as a comorbidity instead of using the most appropriate field (i.e. Heart), in one case a Severe impairment instead of a Moderate impairment value was assigned to a field (Language) and in one case a Moderate impairment value has been assigned to a field (Intellectual functions) by mistake.

In the Communication section, all 5 clinicians were able to set appropriately the receiving spoken messages (ICF d310) and speaking (ICF d330) fields and they always specified, when needed, the ability of receiving or producing other message types (ICF d329 and d349, respectively). Thus, the deviations highlighted in Table 2 are due to improper assignments to the fields representing non-verbal communication channels. In particular, clinicians did not always assign a value to such fields (leaving them set to the "Not evaluated" default) when the textual description of the case did not provide explicit information about non-verbal communication. Although such information could have been inferred based on the residual cognitive, sensory and motor abilities of the patients (e.g. one of the patients was known to have no visual and mental impairments but severe motor impairments, and could be considered able to receive messages through Body gestures, Signs and symbols, Drawings and photographs, but not to produce messages through the same channels), clinicians often preferred to set values only for explicitly documented information. This points out that study participants often adopted a cautious behavior when they were not enough confident about the values to assign.

Finally, for the fields which did not require to set an impairment, an unexpected result was that all clinicians at least once (in the Body functions and Cognitive functions sections or in the Muscle tone subsection of the Motor control section) skipped a field when the case reported no problem concerning it. As a result, the skipped field contained the "Not evaluated" default instead of a specific value (which can vary as discussed in Section 4.2) to represent the fact that no impairment is present. This suggests that the "Not evaluated" value should not be used as the default one for any DPP field, so that clinicians have to explicitly set a field to "Not evaluated" when more information or expertise is necessary to choose a value.

7.2 Second Stage

In the second stage of the evaluation, we asked a different group of clinicians to use the Web Portal of the PRESYDIUM system to create the DPPs of real disabled persons, who were recruited by local associations of disabled people on a voluntary basis. The main goals of this second phase were the following: (i) assessing the adequacy and completeness of the DPP in describing real disability conditions; (ii) collecting feedback about the usability of both the DPP and the Web Portal in a real ambulatory visit context; (iii) collecting real patient data for carrying out subsequent evaluations on other parts of the PRESYDIUM system.

Participants

Several local associations of disabled people[4] helped us recruit disabled volunteers, willing to be visited by a doctor to create their DPP profile. In particular, each association provided contact information for 4-6 disabled persons (for minors and people with cognitive disabilities, also a relative had to volunteer). Moreover, 5 (out of 9) associations also recruited a clinician experienced in dealing with the specific disability of their interest. The 39 disabled participants (referred to as “patients” for brevity in the following) were representative of a wide range of (sensory, motor and cognitive) disabilities and their age ranged from 4 to 83 years, averaging at 43. The 8 clinicians (7 male, 1 female) voluntarily participating to the study had different specializations (internal medicine, respiratory pathophysiology, physiatry, neurology, psychology, sports medicine). Their age varied between 29 and 59 years, averaging at 44. All clinicians were familiar with the use of computers (in particular, Internet browsing, e-mail reading and text writing), which most of them used daily at work (with the exception of one clinician, who used it a few times a week). Patients were assigned to clinicians, by matching their primary pathology with the most appropriate clinician specialization. As a result, the number of patients per clinician varied from 3 to 6. In some cases (16 out of 39) the clinician had already seen before the patient in his/her clinical practice at the

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[4] Association of the Blind and Visually Impaired (UICI), Association of the Deaf and Mute-Deaf (ENS), Autism association (PROGETTO AUTISMO FVG), Dystrophy Association (UILDM), Regional Council of the Disabled (CONSULTA FVG), Association of Quadriplegic and Paraplegic People, Stroke Association (ALICe), National Association of Visually Impaired People’s Families (ANFaMiV), Association of the Families of Disabled People (GE.CO.).

hospital, but it turned out that having or not seen the patient before had no particular effect on task execution or task completion time.

Procedure

We initially briefed each clinician about the nature of the test. Then, before meeting patients, each clinician was instructed about the functionalities of the Web Portal during a hands-on session with two different cases (chosen among the reference ones used during the first stage of the evaluation). During this training phase, each clinician had to use the PRESYDIUM Web Portal to read the DPP of a specific case and browse through all the data contained in the different DPP sections, to become familiar with the DPP fields and structure and with the browsing functionalities of the Web Portal. Then, the clinician had to fill in the DPP of a different case starting from its textual description, to familiarize with the editing functionalities of the Web Portal. Before the beginning of the meeting with a doctor, each patient (or one of her relatives for minors and people with cognitive disabilities) had to sign an informed consent document for participating to the study and to allow us to record the session by means of a camera (only one patient did not give her consent for video recording). The camera recorded the screen of the PC used to access the PRESYDIUM Web Portal and the audio of the evaluation session. This allowed us to collect all clinicians' comments and to identify usability problems during later analysis. After patients expressed their consent, they were met in the ambulatory by the clinician who had to create their DPP. To assess the specific case, clinicians asked questions to the patient (or relative) and examined the clinical documents (s)he made available, if any. The visits assigned to a clinician were in some cases carried out in different days, due to time constraints on both clinician's and patients' sides. After seeing all the assigned patients, each clinician filled in a questionnaire to allow us collect feedback and subjective assessments about general DPP adequacy (also outside the EMS domain) and usability and usefulness of the system.

Results

All 8 clinicians were able to successfully fill in the DPPs of patients assigned to them. Average task completion time was 36 minutes for each patient (with a minimum of 15 and a maximum of 90 minutes, depending especially on the case complexity and on the patient's verbalization abilities in answering questions). These larger times with respect to the first stage of the evaluation are explained by the fact that interacting with the patient took clinicians more time than reading a textual case description.

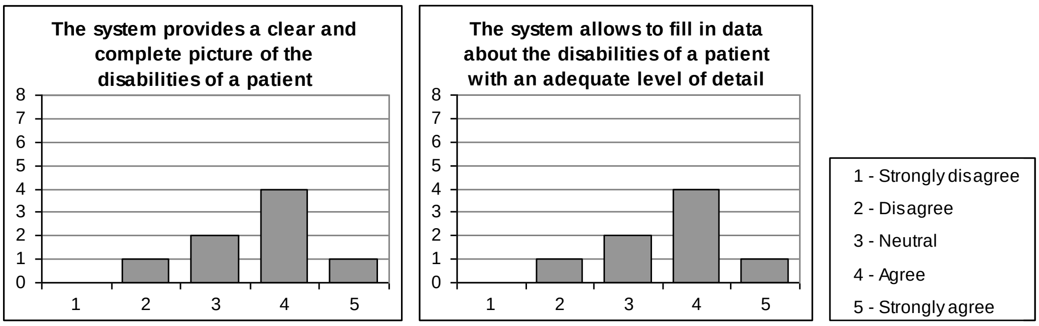

Figure 8 – Subjective assessments of the general adequacy of the DPP in describing patients disabilities

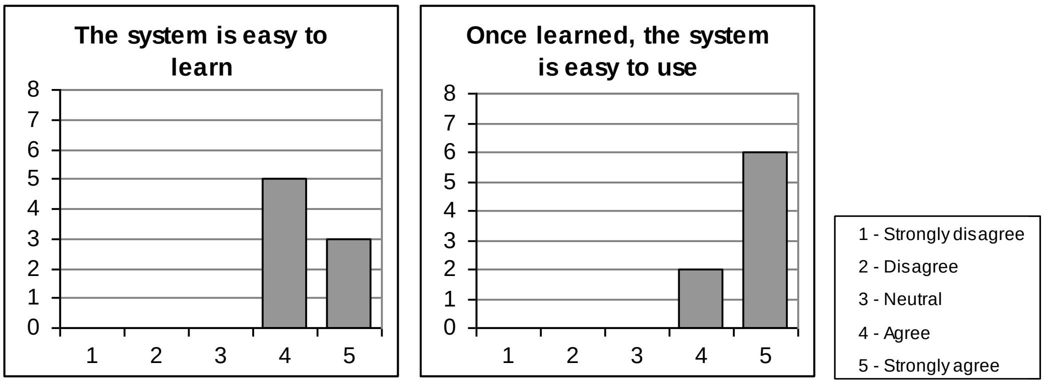

Figure 9 – Subjective assessments of the ease of learning and use of the PRESYDIUM Web Portal

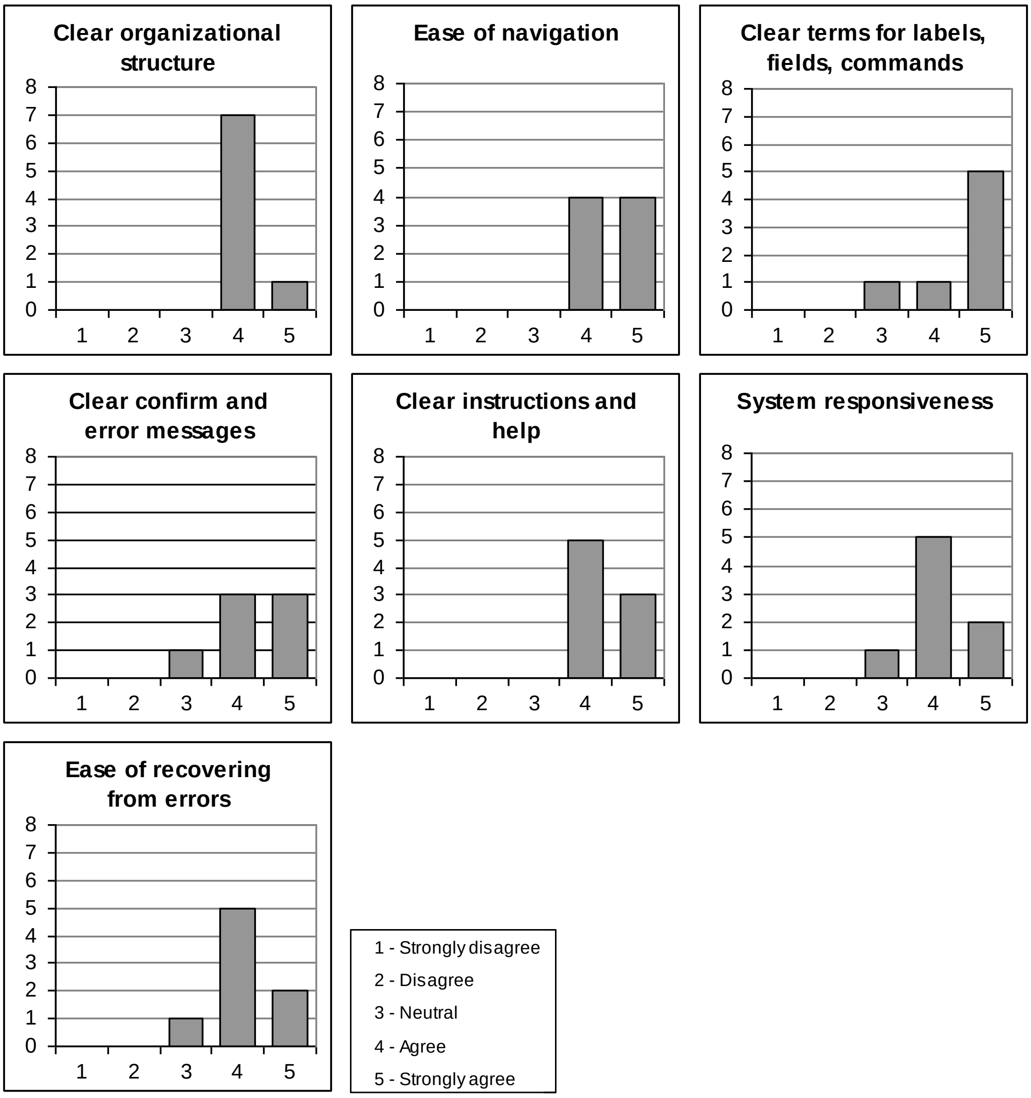

Figure 10 – Subjective assessments about the usability of the PRESYDIUM Web Portal

According to collected comments and questionnaire results, 5 out of 8 clinicians were satisfied with the general adequacy of the DPP in describing patient disabilities (both in terms of completeness and level of detail), as illustrated in Figure 8, while two clinicians gave a neutral and one a negative rating (potential improvements to the DPP pointed out are discussed in the "Lessons learned" section). Although the DPP was conceived for the specific case of EMS applications, such result of the questionnaire is encouraging in terms of building extensions of the DPP for applications outside the EMS domain.

With respect to the usability of the Web Portal, participants were satisfied (as illustrated in Figure 9 and 10) and only some minor usability problems were identified: one concerned the lack of shortcuts to assign impairments to several body parts at once (e.g. one for each individual limb), the other a small

inconsistency in the behavior of the edit mode of PHR sections with respect to the other sections.
In the following paragraphs, we describe in more detail some lessons learned about the DPP and some usability issues of the Web Portal, derived from clinicians' comments and suggestions, direct observation, video recording and notes taken during data entry sessions.

Lessons learned

Clinicians' data entry behavior. In general, all clinicians spontaneously followed the sections order proposed by the Web Portal to fill in DPP data. The different sections of the DPP and their fields were used as a sort of checklist, which allowed clinicians to focus their attention on specific aspects of the clinical data in asking questions to patients. Nevertheless, in some occasions, the clinician had to go back to a section to add data (e.g. a comorbidity or medication not previously reported by the patient), similarly to what happens in the usual practice of collecting clinical data from a new patient. Consistently with the first stage of the evaluation, all clinicians filled in PHR sections (i.e. Diagnoses and comorbidities, Allergies, Medications and medical devices sections) and sections containing graphical representations of the human body (i.e. Mobility of joints, Motor control, Pain, Involuntary movements) without problems. Overall, the DPP structure, which is reflected in the user interface of the PRESYDIUM Web Portal, allowed for a natural approach to clinical data collection.
Analogies with the first stage of the evaluation can be found in clinicians' data entry behaviors within the Body functions and Mental functions sections. In particular, although this time all clinicians were specifically instructed to fill in all the DPP fields for all sections, half of them (4 out of 8) left some fields of these sections set to the "Not evaluated" default. At times, they felt not enough confident to set "No impairment" values based only on the replies of a patient, while at other times they did not assign a value to those fields where no problem was highlighted during the visit. Although less fields were left as "Not evaluated" than in the first stage of the evaluation, the results of the second stage confirm that the "Not evaluated" value should be set explicitly by users and not be considered as a system default.

As it happened with the Communication subsection in the first stage of evaluation, the receiving spoken messages (ICF d310) and speaking (ICF d330) fields were filled in without problems and the other message types (ICF d329 and d349) were used only when needed to specify some communication mechanism peculiar of the single patient (e.g. “[the patient] sometimes prefers written messages rather than verbal ones”, “To ask for an object, [the patient] takes the person towards the wanted object”). Unlike what happened in the first stage of the evaluation, almost all clinicians (7 out of 8) assigned a value to each field representing non-verbal communication channels based on the residual cognitive, sensory and motor abilities of the patient (e.g. patients with neither visual nor mental impairments, such as deaf-mute ones, have been considered able to both receive and produce messages through Body gestures, Signs and symbols, Drawings and photographs, Written messages, while visually impaired ones have not). The more cautious approach observed in the first stage of the evaluation was adopted by only one clinician during this second stage, probably due to the fact that clinicians had the opportunity to directly interact with the patients.

Areas for possible extension. As pointed out in the Results Section, some clinicians (3 out of 8) were not fully satisfied with the adequacy of the DPP in describing patients disabilities for general (non-EMS) application. The two major reasons were: (i) they thought that the meaning of a few fields values was partly ambiguous, (ii) they were used to specify the disabilities of a patient with a greater level of detail than DPPs in their respective hospital specialty practices. We discuss the two issues separately in the following.

Considerations about the meaning of field values. We observed that clinicians were uncertain about which value to choose when they did not find any exact match between the value they had in mind and the available values for a certain field. For instance, to express a “Mild impairment” of a mental function, clinicians had to choose the available value with the nearest meaning, between two values (“No impairment” and “Moderate impairment”). Similarly, to express the meaning of “Non functional control” of a body part, clinicians had to choose between “Partial control” and “No control”. Clinicians in most (but not all) such cases opted for the more severe assignment, which was the desired behavior in DPP designers’ intentions. Nevertheless, this suggests persistence of the subjectivity problem that we tried to minimize by reducing the number of ICF qualifiers from 5 to 3 during DPP design (as described in Section 4). To solve this issue, we are extending the contextual help provided by the Web Portal user interface (i.e. popup definitions of fields, as described in Section 6) by introducing legends which make explicit also the original intended meaning of the values available for each field (e.g. “From no to negligible impairment” for No impairment; “From mild to moderate impairment” for Moderate impairment; “From severe to complete impairment” for Severe impairment). Such legends can be shown in the PRESYDIUM Web Portal as soon as a field value receives input focus or be integrated within the combobox used to select field values (i.e. each value is followed by its legend meaning).

Considerations about the detail of DPPs in describing disabilities. We noted that some clinicians described patients’ conditions at the finest level of detail, especially within the sections that more directly involved their specific expertise, although all clinicians were fully aware of the specific (EMS-related) goals of the DPP and the PRESYDIUM system. For this reason, they appreciated and (sparingly) used the note fields in all the sections (notes were available in all sections except the ones with graphical representations of the human body), since they allowed them to record very specific aspects of the associated field, e.g. clinical details about diseases such as “Mitral prolapsus” or specific temporal data such “Myocardial infarction occurred in 2004” for Heart field.

As expected, notes about communication fields were effectively used to record patient’s peculiarities (e.g., “Could be concentrated on irrelevant aspects of current context” for Consciousness field or “Inverts the pronouns You and I” for Language field) which are important for EMS applications but are too many to be captured through predefined choices. Some clinicians (3 out of 8) complained about the lack of note fields in sections containing graphical representations of the human body, since they would have liked to specify more details about the impairments associated to specific body parts (e.g. to distinguish between different impairment sources, such as blocks, dislocations or calcifications of joints, or to more precisely identify the parts where pain is located within each body part, such as the right side of the back or the shoulder-blade). These observations suggest that the availability of additional note fields could be valuable to increase clinicians acceptance of the system.

In some cases, hospital specialty practice led clinicians to suggest the introduction of extremely detailed fields (e.g. a respiratory pathophysiologist proposed to add some fields to better describe the mechanical ventilation apparatuses used by patients with respiratory impairments). However, the usefulness of such detailed fields for the considered EMS context is questionable.

Broadening application scope. The attention of clinicians towards providing a detailed description of patients' conditions is clearly influenced by the specific background of each clinician and by her daily clinical practice, which are necessarily different from those of EMS, whose main focus is to concentrate on the most important parameters allowing them to preserve patient's life in emergencies while the patient is carried to the hospital. Since the PRESYDIUM system acts as a bridge between these different ways of looking at the patient (because the DPPs are created by non-EMS physicians while the end users of the DPPs are EMS physicians and nurses), we think that it could also be used to promote information sharing between the different health professionals involved, who could greatly contribute to the refinement process of both the DPP and the knowledge base. For example, during the evaluation, after completing a DPP, each clinician read also the content of the Operating instructions section. This prompted some clinicians to come up with suggestions about operating instructions (additions or changes in the priority of specific operating instructions). One could thus consider giving clinicians the opportunity to make special annotations in PRESYDIUM, concerning DPP fields and the Operating instructions section. EMS domain experts could then examine, in periodical revision sessions, the annotations provided by clinicians through the system and determine whether or not extending the DPP and the knowledge base according to their relevance in the EMS context.

8 Conclusions and Future Work

This paper proposed both a detailed user model (DPP, Disabled Person Profile) of the disabilities of an individual which are most relevant in the context of EMS, and an adaptive information system (PRESYDIUM, Personalized Emergency System for Disabled Humans) which provides tailored instructions for helping EMS nurses and volunteers in dealing with disabled persons in the field. The Web-based architecture of the system and its interfaces for different categories of users were also introduced. Finally, we described the results of the evaluation of the DPP and PRESYDIUM which assessed that: (i) the DPP supports a consistent representation of patients' disabilities by different clinicians; (ii) although the DPP has been designed to satisfy the specific needs of EMS, the majority of clinicians involved in the evaluation thought it can be used to describe the disabilities of a person in a more general context with a sufficient level of detail; (iii) the Web Portal is easy to learn and to use. Based on such results, we believe the current version of the DPP (which is fully described in the Appendix) can be used by researchers interested in modeling disabilities for personalized emergency applications and possibly extended to consider other personalized health applications for disabled persons.

We are now going to evaluate the remaining interfaces of the PRESYDIUM system in real settings. To evaluate the Web Portal with patients, all the disabled persons (and their relatives) who participated to the evaluation described in Section 7.2, will access their own DPP through the Web Portal, employing proper assistive technologies (e.g. screen readers, magnifiers) when needed; we will collect users' feedback about both the Web Portal, in terms of its ease of use and accessibility, and the DPP, in terms of its understandability, perceived adequacy in describing their conditions and usefulness of additional information (i.e. User requests and Contact persons) they can enter. To evaluate the EMS Center Client, we will have disabled volunteers make emergency calls to the EMS call center, and we will record operators' performance on the interface as well as interview the involved operators about the ease of use of the system and its usefulness in managing emergency calls. To evaluate the Mobile Client, simulations of emergency interventions on real disabled persons will be arranged in which first responders will use the mobile devices in real settings and will be interviewed about the actual usefulness of the operating instructions provided by the system and its ease of use.

Finally, to start exploring the re-use of the DPP, we have considered training applications. In particular, we have started working at the integration of the DPP and the knowledge base into an educational game (Cabas Vidani & Chittaro, 2009) that provides visual realism and user immersion to simulated EMS scenarios for nurses training. The DPP will be used to extend the game into an adaptive training system that is able to generate tailored scenarios, also based on the user's learning needs about the different DPP fields.

Appendix

In the following tables, we provide the complete list of DPP sections and their associated fields, following the same order in which they appear in the DPP. In particular, Table 3 describes each non-ICF section (i.e. sections whose fields have not been derived from the ICF); Tables 4 through 13 describe DPP sections and subsections based on the ICF, specifying for each field the associated ICF code (except for three fields which have no ICF correspondence) and its available values. Table 14 lists the names of the sections containing a graphical representation of the human body, specifying for each section the associated ICF code, the number of body parts for which the user can enter a value, and the available values for each body part (the “Not evaluated” value is not available for these sections). Table 15 lists the body parts contained in the graphical representations of the human body, specifying for each body part the associated ICF code and whether or not a value can be entered for it.

Table 3. Non-ICF sections.

Section name	**Description**
Personal data	Fields: Italian SSN, Name, Surname, Gender, Date of birth, City, Address, Home and Cellular phone numbers, E-mail
Contact persons	Fields for each contact person: Name, Surname, Relationship, Gender, City, Address, Home and Cellular phone numbers, E-mail, Notes
Diagnoses	List of diagnosis categories and subcategories to choose from, derived by the domain experts from diagnoses tables commonly used in their daily practice (Free text available if no predefined entry is suitable)
Comorbidities	Free text entries
Allergies	Free text entries
Medications	Free text entries
Medical devices	Short list of most frequently used devices to choose from, defined by the domain experts (Free text available if no predefined entry is suitable)
User requests	Free text entered by the user for communicating any specific

	requests; predefined choice for expressing the will to receive religious comfort in life threatening situations: Not expressed/No/Yes (the user can possibly specify which religion in a free text field)

Table 4. Cognitive functions section: Mental functions subsection.

ICF code	DPP field name	Available values
b110	Consciousness	Not evaluated / Normal / Altered
b114	Orientation	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment
b117	Intellectual	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment
b144	Memory	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment
b167	Language	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment

Table 5. Cognitive functions section: Communication – receiving messages subsection.

ICF code	DPP field name	Available values
d310	Spoken messages	Not evaluated / Able / Has difficulties / Unable
d3150	Body gestures	Not evaluated / Able / Has difficulties / Unable
d3151	General signs and symbols	Not evaluated / Able / Has difficulties / Unable
d3152	Drawings and photographs	Not evaluated / Able / Has difficulties / Unable
d320	Formal sign language messages	Not evaluated / Able / Has difficulties / Unable
d325	Written messages	Not evaluated / Able / Has difficulties / Unable
d329	Other message types (specify)	Free text

Table 6. Cognitive functions section: Communication – producing messages subsection.

ICF code	DPP field name	Available values
d330	Spoken messages	Not evaluated / Able / Has difficulties / Unable
d3350	Body gestures	Not evaluated / Able / Has difficulties / Unable
d3351	General signs and symbols	Not evaluated / Able / Has difficulties / Unable
d3352	Drawings and photographs	Not evaluated / Able / Has difficulties / Unable
d340	Formal sign language messages	Not evaluated / Able / Has difficulties / Unable
d345	Written messages	Not evaluated / Able / Has difficulties / Unable
d349	Other message types (specify)	Free text

Table 7. Body functions section: Sensory functions subsection.

ICF code	DPP field name	Available values
b210	Seeing	Not evaluated / No impairment / Low vision / Blindness
e350	Guide dog	Not evaluated / No / Yes
b230	Hearing	Not evaluated / No impairment / Hard-of-hearing / Deafness
b235	Vestibular functions	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment

Table 8. Body functions section: Functions of the cardiovascular system subsection.

ICF code	DPP field name	Available values
b410	Heart	Not evaluated / No Impairment / Moderate Impairment / Serious Impairment
b4101	Arrhythmia	Not evaluated / No / Yes
b4102	Diminished cardiac output	Not evaluated / No / Yes
b420	Blood pressure	Not evaluated / Hypotension / Normal /

		Hypertension

Table 9. Body functions section: Functions of the respiratory system subsection.

ICF code	DPP field name	Available values
b440	Respiration	Not evaluated / Hypoventilation / Normal / Hyperventilation
none	Domiciliary oxygen therapy	Not evaluated / No / Yes
none	Non-invasive ventilation	Not evaluated / No / Yes

Table 10. Body functions section: Functions of the digestive system subsection.

ICF code	DPP field name	Available values
b5105	Dysphagia	Not evaluated / No / Yes
none	Route of feeding	Not evaluated / By mouth / Percutaneous endoscopic gastrostomy (PEG) / Jejunostomy / Nasogastric feeding tube / Central Parenteral Nutrition (CPN) / Peripheral Parenteral Nutrition (PPN)

Table 11. Body functions section: Urinary functions subsection.

ICF code	DPP field name	Available values
b620	Urination	Not evaluated / No impairments / Impairments

Table 12. Motor control section: Mobility subsection.

ICF code	DPP field name	Available values
d450	Walking	Not evaluated / Able / Has difficulties / Unable
d465	Moving around	Not evaluated / Able / Has difficulties / Unable

Table 13. Motor control section: Muscle tone functions subsection.

ICF code	DPP field name	Available values
b735	Hypotonia	Not evaluated / No / Yes
b735	Hypertonia	Not evaluated / No / Yes

Table 14. Sections containing a graphical representation of the human body.

ICF code	Section name	Number of body parts with an associated value	Available values for each body part
b710	Mobility of joints	15: joints only (front view only)	No/Moderate/Serious Impairment
b760	Motor control	27: all (front view only)	Full/Partial/No Control
b280	Pain	54: all (front and rear view)	No pain / Pain
b765	Involuntary movements	26: all except pelvis (front view only)	No/Rare/Frequent involuntary movements

Table 15. Body parts contained in graphical representations of the human body; for each section containing a human body representation, a ✓ mark indicates that a value can be entered for the body parts in that row

ICF code	Body part(s)	Mobility of Joints	Motor control	Pain	Involuntary movements
s710	Head		✓	✓	✓
s76000	Neck	✓	✓	✓	✓
s76001	Chest		✓	✓	✓
s76002	Abdomen		✓	✓	✓
s740	Pelvis		✓	✓	
s720	Shoulder (left and right)	✓	✓	✓	✓
s7300	Arm (left and right)		✓	✓	✓
s73001	Elbow (left and right)	✓	✓	✓	✓
s7301	Forearm (left and right)		✓	✓	✓
s7302	Hand (left and right)	✓	✓	✓	✓
s75001	Hip (left and right)	✓	✓	✓	✓
s7500	Thigh (left and right)		✓	✓	✓
s75011	Knee (left and right)	✓	✓	✓	✓
s7501	Leg (left and right)		✓	✓	✓
s75021	Ankle (left and right)	✓	✓	✓	✓
s7502	Foot (left and right)	✓	✓	✓	✓

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