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Circles of Health: Towards an advanced social network about disabilities of neurological origin



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ABSTRACT

Objectives: This research is concerned with the study of a new social-network platform, which (1) provides people with disabilities of neurological origin, their relatives, health professionals, therapists, carers and institutions with an interoperable platform that supports standard indicators, (2) promotes knowledge democratization and user empowerment, and (3) allows making decisions with a more informed opinion. **Methods:** A new social network, Circles of Health, has been designed, developed and tested by end-users. To allow monitoring the evolution of people's health status and comparing it with other users and with their cohort, anonymized data of 2675 people from comprehensive and multidimensional medical evaluations, carried out yearly from 2006 to 2010, have been standardized to the International Classification of Functioning, Disability and Health, integrated into the corresponding medical health records and then used to automatically generate and graphically represent multidimensional indicators. These indicators have been integrated into Circles of Health's social environment, which has been then evaluated via expert and user-experience analyses.

Results: Patients used Circles of Health to exchange bio-psycho-social information (medical and otherwise) about their everyday lives. Health professionals remarked that the use of color-coding in graphical representations is useful to quickly diagnose deficiencies, difficulties or barriers in rehabilitation. Most people with disabilities complained about the excessive amount of information and the difficulty in interpreting graphical representations.

Conclusions: Health professionals found Circles of Health useful to generate a more integrative understanding of health based on a comprehensive profile of individuals instead of being focused on patient's diseases and injuries. People with disabilities found enriching personal knowledge with the experiences of other users helpful. The number of descriptors used at the same time in the graphical interface should be reduced in future versions of the social-network platform.

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1. Introduction

A disease or injury may have multiple disabling effects of various levels of severity, and cause varying degrees of health problems. The *global burden of disease* (GBD) links average loss of health to disease and injury's causes through *disability-adjusted life years* (DALYs) [1] and disability weight factors. The DALY extends

the concept of potential years of life lost due to premature death to include equivalent years of healthy life lost by virtue of being in states of poor health or disability. The weight factor reflects the severity of the disease on a scale from 0 (perfect health) to 1 (death). The term *disability* has a number of different meanings and, in particular, is not seen by some as a synonym or proxy for loss of health. However, the *World Health Organization* (WHO) uses the term *disability* to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing and vision, and we adopt this use for the term. According to the WHO, of the world's population of 6.5 billion in 2004, 19 million (3%) were severely disabled and another 80 million (12%) had moderate longterm disability, which is a barrier for personal development as well as social integration. People with disabilities of neurological origin are mainly people

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Table 1

Comparison of existing tools which integrate bio-psycho-social information in the healthcare domain.

Tool	Data	Interoperability based on:	Social	Graphical representation of:
Circles of Health	MHR	Ontology	Yes	Individuals and population
Patients Like Me [26]	Patient health record (PHR)	No	Yes	Individuals and population
I'm too young for this [29]	Text	No	Yes	Individual
Forumclinic [30]	Text	No	Yes	Individual
Vivu [31]	Text	No	Yes	Individual
HealthVault [32]	PHR	Continuity of care record	Yes	Individual
Aptic [28]	Text	No	Yes	Individual
Mora et al.'s middleware [17]	MHR	Ontology	No	No

Table 2

Questionnaires administered in the PCE, indicating the profile to whom they are administered and if people can self-administer them.

Questionnaire	Profile	Self-administer
Institut Guttmann social scale (ESIG), Personal well being index (PWI), Community integration questionnaire (CIQ)	SCI and ABD	Yes
Craig Hospital inventory of environmental factors (CHIEF), Hospital Anxiety and depression (HAD), Patient health questionnaire (PHQ9), WHO quality of life questionnaire (WHOQOL)	SCI	Yes
Functional independence measure (FIM), Spinal cord injury measure (SCIM), ASIA scale	SCI	No
Patient competency rating scale (PCRS)	ABD	Yes
Behavioral scale, PCRSi (informer), Rancho scale levels of cognitive functioning, Barthel index, Disability rating scale (DRS), Extended Glasgow outcome scale (GOSE)	ABD	No

with *spinal cord injuries* (SCIs) and people with *acquired brain damage* (ABD). SCIs correspond to classes S14.0–S14.1, S24.0–S24.1, S34.0–S34.1 and T09.3 of the *international classification of diseases version 10* (ICD-10) [2], while ABD (which includes non-traumatic ABD or stroke, and traumatic brain injury), corresponds to classes I60–I69 of the ICD-10. In Catalonia (Spain), 50% of people with traumatic SCI are 16–30 years old; and 60% of the ones with *traumatic brain injury* (TBI) (the most common cause of ABD, mostly due to road traffic accidents) are younger than 25 [3]. It is reasonable to assume that similar figures are valid in general for high-income countries.

Because a relevant percentage of people with disabilities of neurological origin is young and, supposedly, used to social networks, in their broadest definition, these networks may be adapted or made accessible to these people, and then used to generate a positive impact on their health [4]. Furthermore, previous research [5] suggests that a significant number of patients with disabilities of neurological origin would benefit from accessible information that is relevant to them, and social networks can be providers of such information.

The objectives of the research described in this paper are:

- To provide stakeholders (people with disabilities, their family, health professionals and therapists, carers and institutions) with the Circles of Health social-network platform from now on Circles of Health, aimed at supporting multicenter studies using standard indicators. These multicenter studies use a data set that is collected periodically and forms the basis of rehabilitation processes. Standardized, multidimensional indicators are automatically and dynamically collected, transformed, represented and shared.
- To promote knowledge democratization, user empowerment and making decisions with a more informed opinion, with Circles of Health that allows people to monitor their evolution and compare with others, and which is not limited to people with disabilities (participation of other stakeholders is encouraged). This facilitates the e-inclusion of people with disabilities of neurological origin.

The rest of the paper is organized as follows. In this section, some background is provided on Circles of Health, the generation

Table 3

Patient's data from MHR.

Descriptor	Value
Number of people	2675
Frequency	Yearly
Range of years	2006–2010
Number of people with SCI	1815
Number of people with ABD	860

of indicators, knowledge democratization and user empowerment. Section 1.1 presents the people with disabilities' data used for the study and the users of Circles of Health. Section 2 describes technically Circles of Health and the methods for its evaluation. Section 3 describes Circles of Health functionalities and results of its evaluation. Section 4 discusses results obtained and usefulness; and future work is detailed at Section 5. Finally, conclusions are drawn in Section 6.

1.1. Circles of Health

In Qvidlab framework [6] carried out at Institut Guttmann, a committee of experts in sociology, psychology, neuropsychology, social work and neurorehabilitation from several institutions identified a set of evaluation questionnaires for describing the bio-psycho-social profile of SCI and brain-injury people, which are the core of *periodic, comprehensive evaluations* (PCEs). This led to an improvement of the information about the problems of people with disabilities, which can have an impact on new laws, decision policies, knowledge democratization, and promotion of research and funding.

In addition, a Ministerial European Conference [7] identified the following needs: (1) achieving the inclusion of each and every individual and community in each and every aspect of the information society; (2) achieving a level of access to information that leads to knowledge democratization and user empowerment; (3) building a global community of support to allow immediate access to

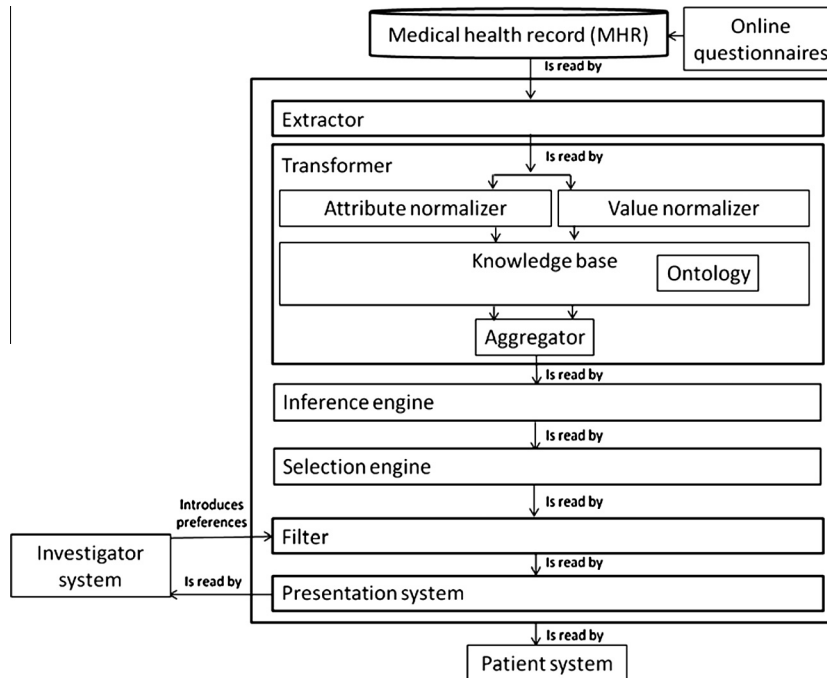


Fig. 1. Architecture of the automatic generation of multidimensional indicators.

resources for people with disabilities and other people in a similar situation so as to encourage them to talk openly about their problems and help to: avoid isolation, alleviate suffering, and build and cement relationships.

Following the idea of using social networks to understand better the specific problems faced by people with certain illnesses or disabilities and to facilitate e-inclusion of people with disabilities of neurological origin, this study develops Circles of Health, which allows belonging to a community of people associated by the same problem, with whom to share knowledge and experiences. Furthermore, Circles of Health allows people with disabilities to monitor their individualized, standardized, multidimensional health indicators, extracted from *medical health records* (MHRs) or online self-administrable questionnaires, and compare themselves with other people in similar situations. In addition, Circles of Health provides personalized access to resources (about medical advances, symptoms, financial support and volunteering) supervised by professionals of healthcare institutions. Circles of Health is centered on people with disabilities of neurological origin, but it also includes other stakeholder. In fact, users of Circles of Health are all people interested in disability, and more specifically:

- People with disabilities, who will be able to access personalized representations of indicators about themselves and people like them, and share information in a social environment: population representations are automatically personalized allowing them to compare themselves to people with similar personal factors, such as disease, cause of disease and lesion level. A real scenario would be the following. Pol is a man who suffered an accident 47 years ago while driving to Barcelona. Pol's accident resulted in paraplegia with a severe lifelong disability, which changed his life dramatically. After finishing his rehabilitation in Institut Guttmann, he returned to his hometown, but once a year he returns to Institut Guttmann to perform PCE. At home he does not meet new people who share his problems. Furthermore, he finds it difficult to access updated and reliable infor-

mation from experts. For this reason, he is very enthusiastic when he finds out about Circles of Health and he starts looking at his bio-psycho-social information.

- The family of people with disabilities, who has, depending on the disability, a different degree of access to resources.
- Health professionals, such as doctors, psychologists, neuropsychologists, psychotherapists and social workers, who will be able to administer questionnaires, and access individual and population representations of indicators. They will be able to filter population representations by disease, cause of disease, lesion level and gender.
- Healthcare institutions, which will be able to: (1) access population representations of indicators and read and share information in a social environment; (2) filter population representations by disease, cause of disease, lesion level and gender.

Circles of Health intends to set up easy-to-use communication, participation and access to information to people who suffer from a disability of a neurological origin. Table 1 shows a comparison between Circles of Health and existing tools which integrate bio-psycho-social information in the healthcare domain.

1.2. Generation of interoperable, multidimensional indicators

Today, most healthcare organizations systematically collect relevant information derived from each clinical event in their MHRs [8]. An MHR is a set of both written and graphical documents, referring to information on health and illness of a patient, and on the healthcare activity related to this information, stored in electronic form. Therefore, a MHR can be associated to the concept of a patient's profile and is taken into account in the identification of the necessary and sufficient indicators to describe patients' health status. Questionnaires (sometimes self-administered) are often used to gather part of the information on the status of a patient or an activity; are in general validated by a healthcare institution; and then are stored in MHRs. Questionnaires are usually tailored to specific problems or patients. Moreover, their selection

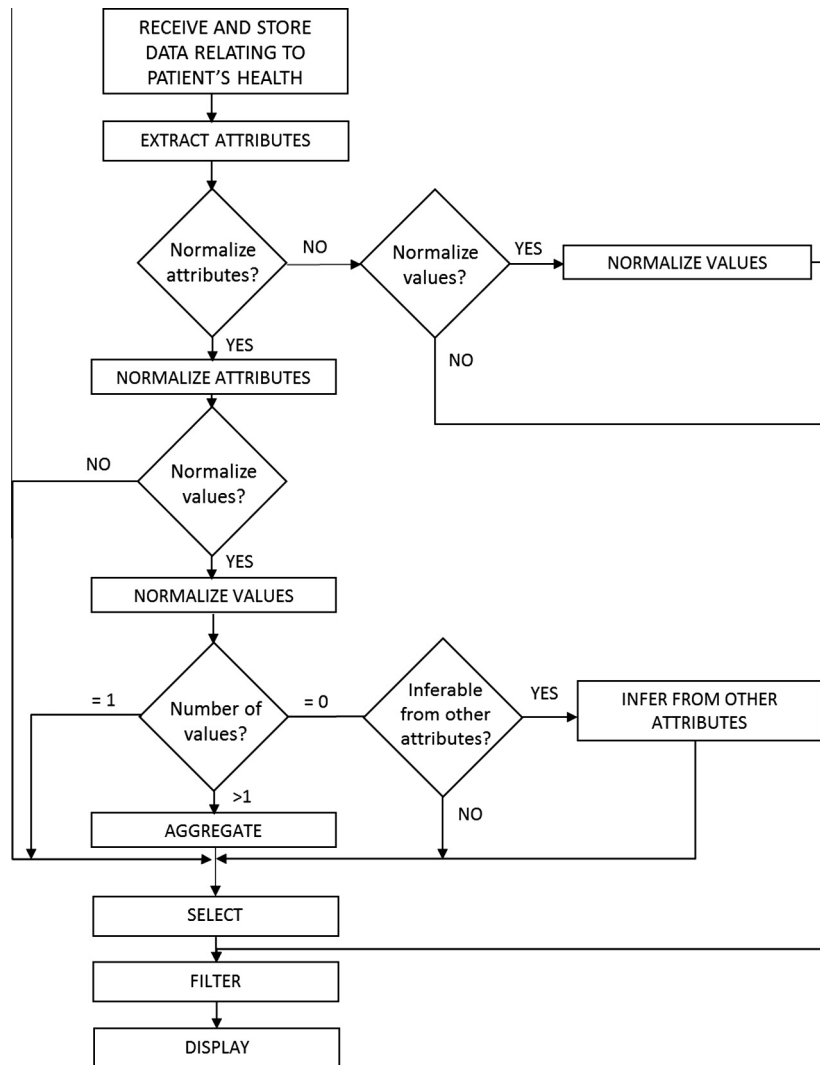


Fig. 2. Flow diagram of the automatic generation of multidimensional indicators.

depends on cultural aspects, organizations and countries. Consequently, there are often different, conflicting instruments for capturing the same type of information, with a consequent lack of interoperability. Minimum standardized data sets exist, called core sets, but their introduction implies changes in the way each organization represents knowledge, and changes in established protocols for patient's assessment may be costly. Furthermore, changes in assessment tools often result in the loss or devaluation of historical MHRs, so that organizations can be reluctant to change. Core sets have been created as a selection of indicators of international standards such as the *International Classification of Functionality, Disability and Health (ICF)* [9] or the *Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT)* [10], relevant to patients affected by specific diseases. Specific studies exist about SCI and ABD core sets [11–13] and about putting ICF into practice [14].

Currently, the monitoring of a patient's health status and evolution is based on a bio-psycho-social model, in which the physical, psychological and social aspect of the patient and environmental factors are considered as facilitators or barriers (see, for example, Schalock and Verdugo's model [15]). Implementations of multidimensional, standard-based bio-psycho-social indicators have been proposed [16], but they lack the automatic aggregation and the monitoring of the generated information. Recently a unified view

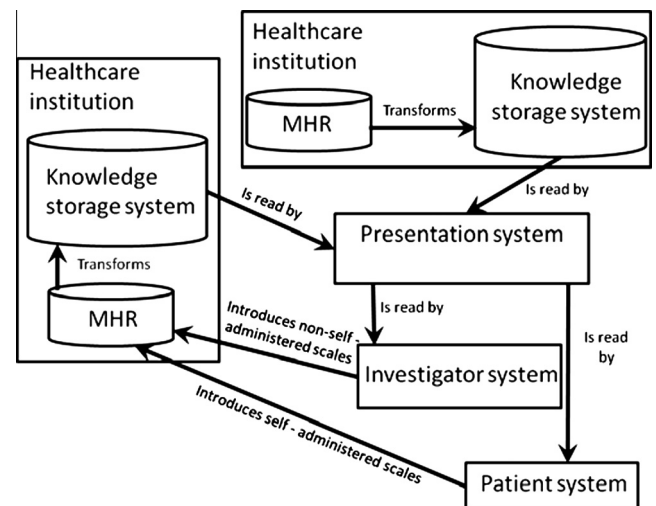


Fig. 3. Interaction of healthcare institutions in the automatic generation of multidimensional indicators.

of a federated environment of multi-scale biomedical data sources has been introduced [17,18]. Nevertheless, they do not deal with

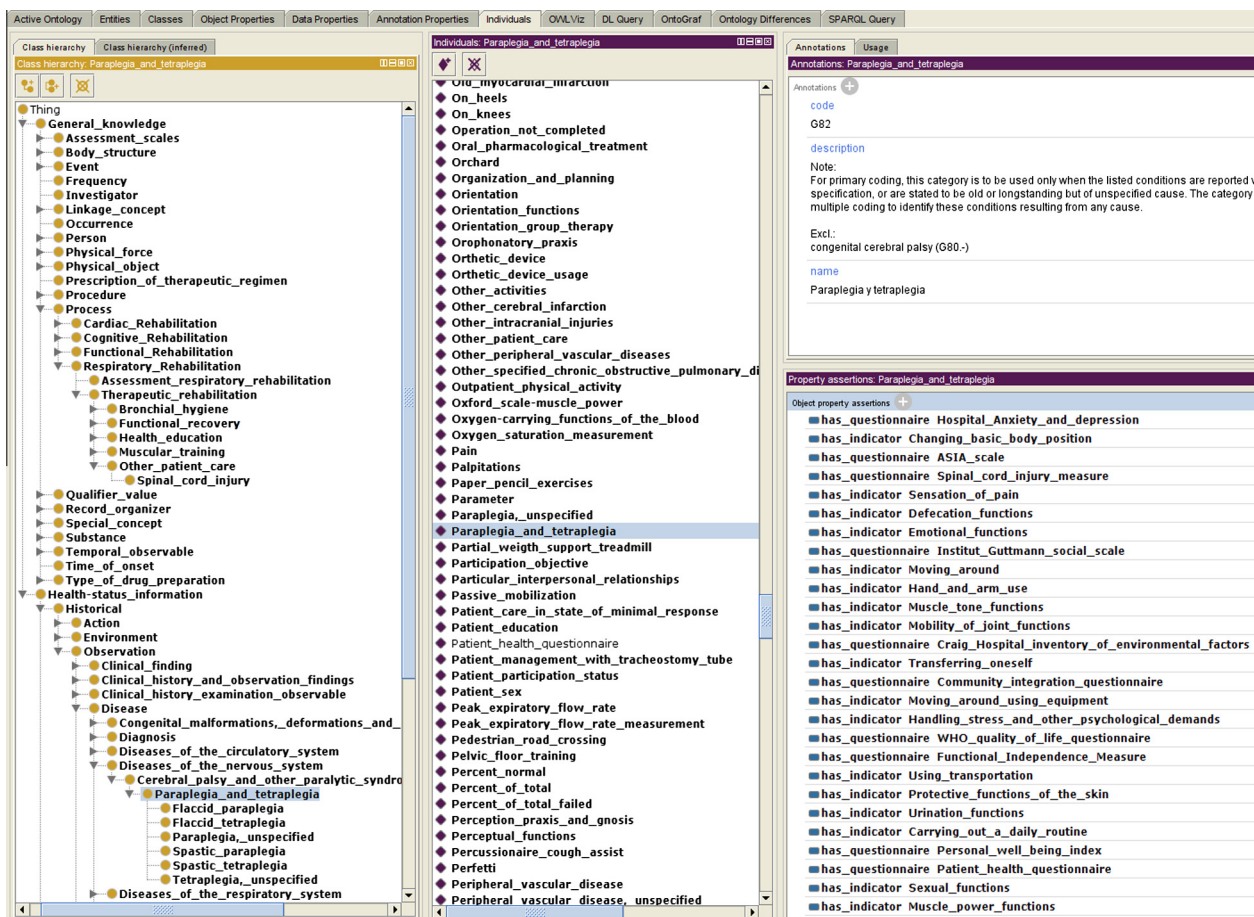


Fig. 4. Ontological representation of people who has SCI.

the particularities of the ICF standard (which require a normalization of both attributes and values), the integration with MHRs, nor the integration of several standards, such as ICF and SNOMED CT. Although relationships of the concepts of ICF have been explored [19], an implementation of automatic generation of interoperable and multidimensional data has not been provided.

1.3. Social environment for knowledge democratization and user empowerment

The adoption of *information and communication technologies* (ICTs) is one of the aspects which will link the e-inclusion of the person with his empowerment. New technologies (and especially the Internet) can facilitate the creation of a communication environment that enables knowledge democratization, empowerment [20] and participation. Currently, there is a lack of visual and personalized comparison involving individuals and populations, showing personal factors and their evolution in an indicator-driven representation, although there are already some initiatives for representing semantic similarity in biomedical ontologies [21] and for extracting knowledge from data sets over time [22]. This potentially involves the comparison of the functioning of a patient (represented by ICF) with anonymous people with similar factors such as disease, cause of disease, lesion level or gender, among others.

A general need exists for specific tools and services which offer social networking [23], participation, guidance to high quality information, collaboration and openness in medicine [24]. There are some initiatives which share biomedical information in a social environment such as the popular social network PatientsLikeMe

[25,26]; others which analyze biomedical information disclosed in YouTube [27]; and some others which aim to improve patients' *quality of life* (QoL) [28]. However, none of them integrates standardized and multidimensional data nor allows automatic personalization of visualization of biomedical information depending on the patient's profile.

2. Methods

This section describes technically Circles of Health and the methods for its evaluation.

2.1. Technical description of Circles of Health

Circles of Health is developed in Liferay Portal CE [40], which is available under the Lesser GNU Public License (LGPL) v2.1 at absolutely no cost. Liferay is a content management system (CMS) written in Java with certain *portlets* preinstalled which cover most of the functionalities (described in Section 3.1) required in Circles of Health. New portlets for the automatic generation of interoperable, multidimensional and holistic indicators of MHRs, developed using Matlab, are available upon request. Nowadays, Circles of Health is not publicly available because the business model to ensure sustainability of Circles of Health is still under study and a patent has been published [41]. The rest of the section describes the automatic generation of interoperable, multidimensional and holistic indicators of MHRs; knowledge representation; and accessibility of Circles of Health.

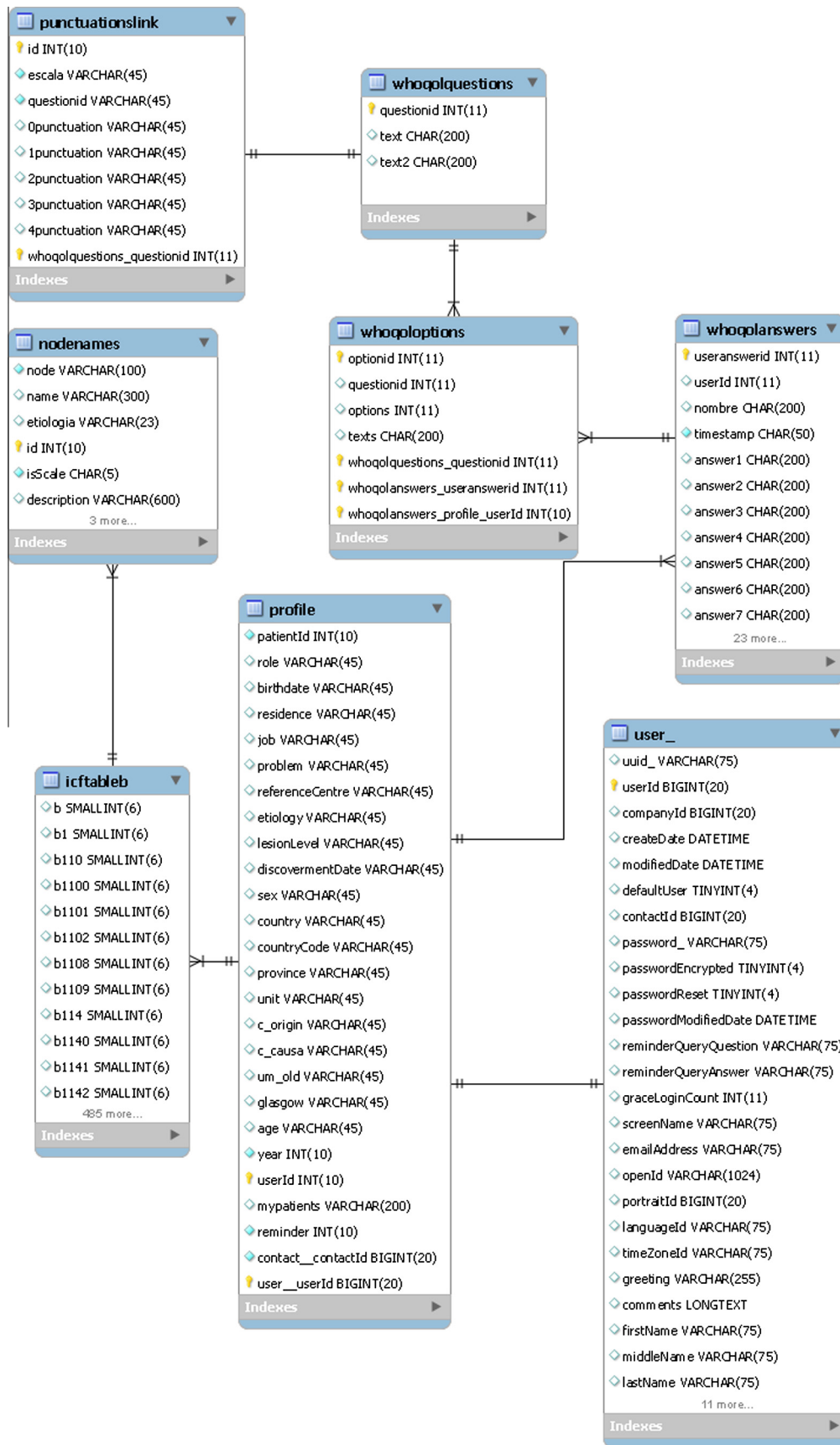


Fig. 5. Entity relationship modeling.

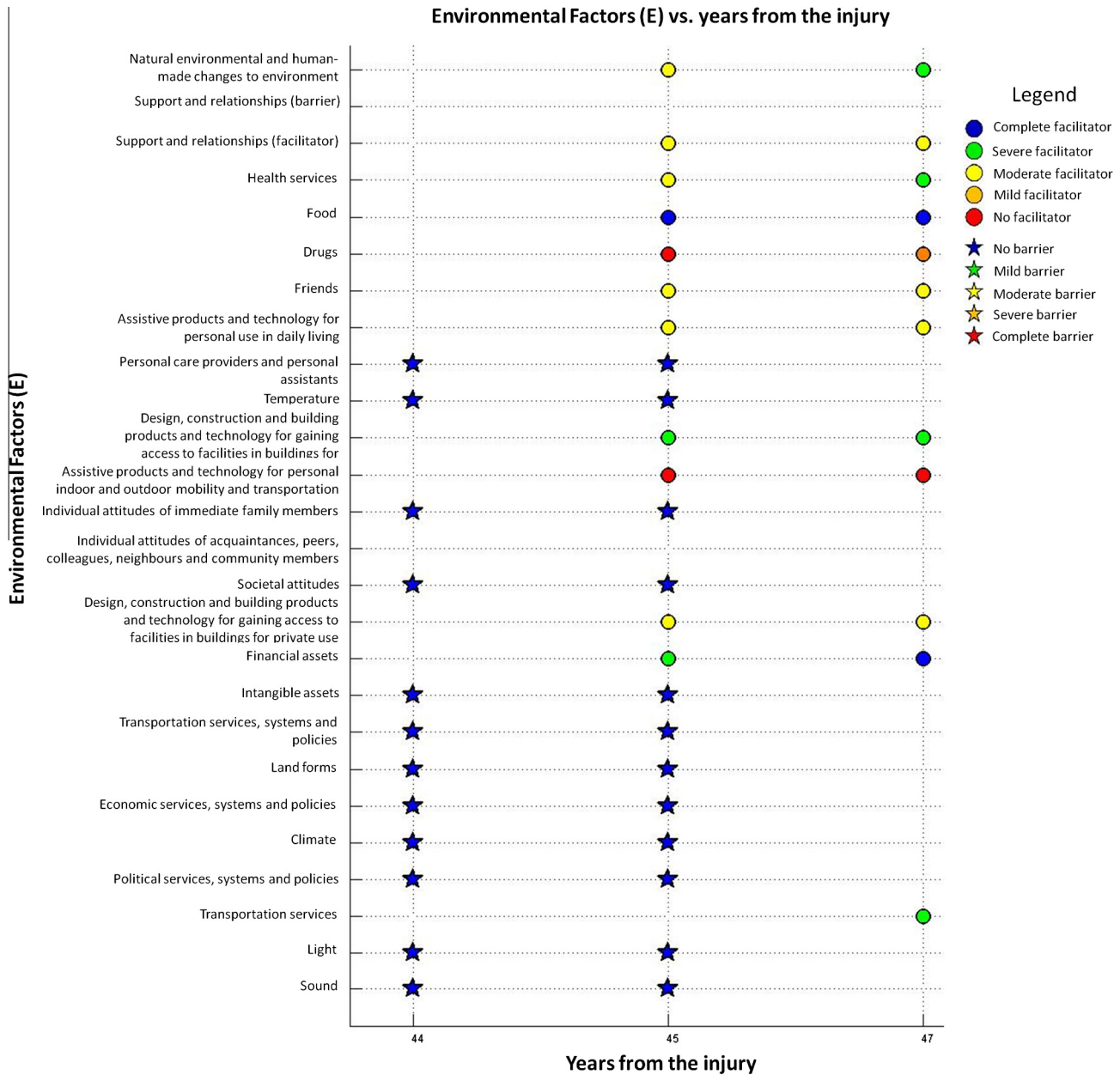


Fig. 6. Graphical representation of the evolution of an individual across categories of the ICF. ICF values of difficulty, deficiency or barrier are represented with red/4 in complete levels, orange/3 in severe levels, yellow/2 in moderate levels, green/1 in mild levels and blue/0 in no difficulty, deficiency or environmental factors. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

2.1.1. Automatic generation of interoperable, multidimensional and holistic indicators of MHRs

An indicator is as a measure used to evaluate, qualitatively or quantitatively, some aspect of the functioning or health of a person (including the level of autonomy, personal satisfaction and QoL). The *Laboratory of autonomy-enhancing measures, personal satisfaction and quality of life (Qvidlab)* [6] defines a set of indicators for the comprehensive evaluation of people with SCI or ABD. For this study, follow up data after clinical discharge of patients treated at Institut Guttmann have been used. All of them are re-assessed every 12 or 18 months in *periodic, comprehensive evaluations (PCEs)*. A PCE is conducted to allow early detection of some pathologies which, because of a baseline neurological lesion, might be asymptomatic till advanced phases. Early detection can decrease complications, preventing long hospitalizations, or even death.

The PCE also aims to improve autonomy levels, QoL and the e-inclusion of the patients as much as possible. Questionnaires administered in PCEs are listed in [Table 2](#); some of them can be self-administered by the people with disabilities (SA questionnaires). This research uses MHRs, whose data are summarized in [Table 3](#). These data are anonymous, confidential and only shared when the owner authorize it. Qvidlab indicators have been translated to ICF following the methodology of Cieza et al. [33,34]. Every time data of questionnaires are introduced, deleted or updated, indicators are updated automatically.

[Fig. 1](#) depicts the architecture of Circles of Health, which is comprised of an extractor, a transformer, an inference engine, a selector, a filter and a presentation system.

The *extractor* is configured to access databases and to selectively fetch information. Each time a value or piece of information is

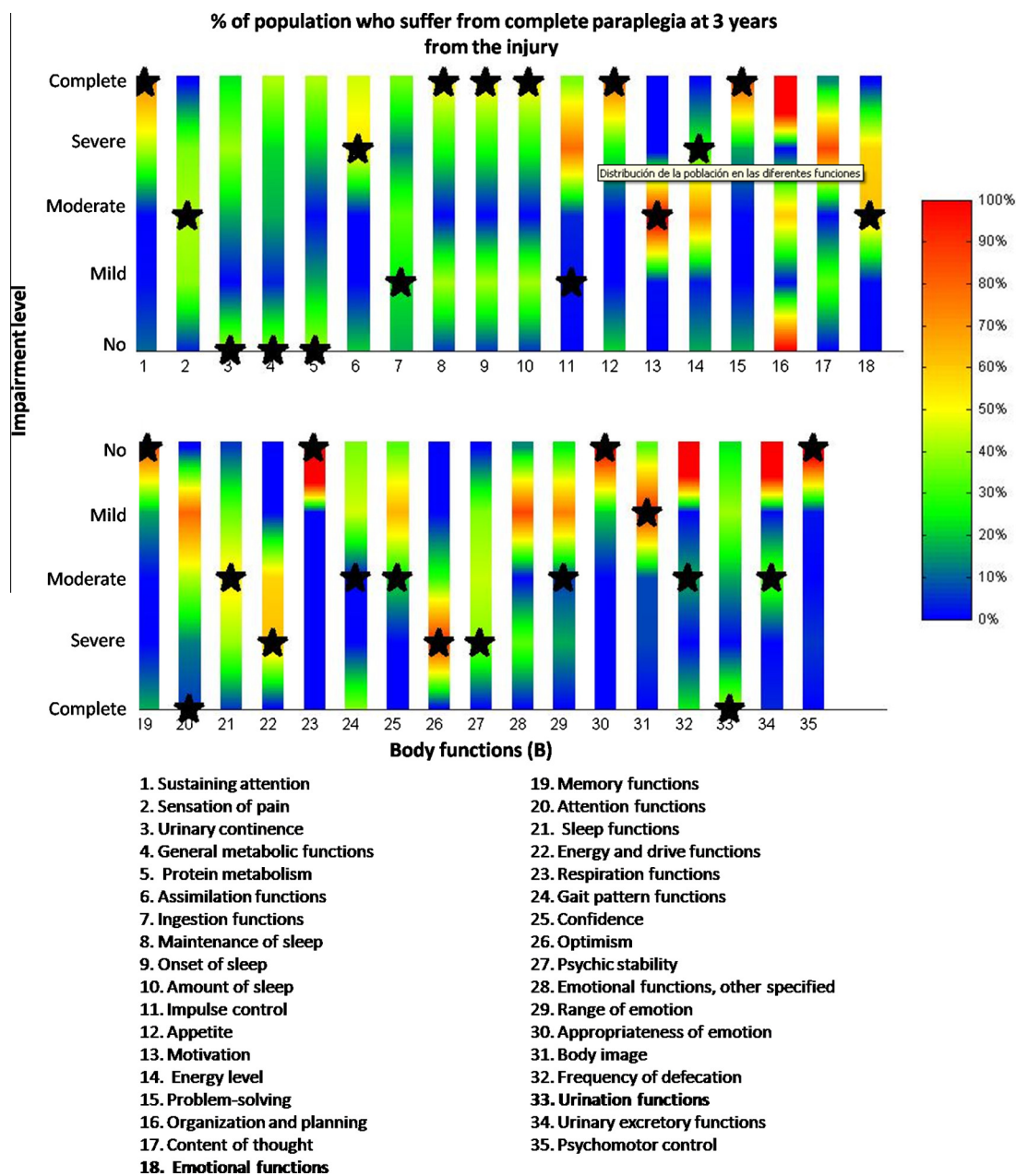


Fig. 7. Graphic representation of the status of populations and individuals across categories of the ICF.

modified in a database, the extractor automatically updates the transformer, inference engine and selector. In the extraction of the information, patient-specific profiles are created. Patients profiles can be based, for example, on diseases. The extractor then provides data to the transformer.

The *transformer* comprises an attribute normalizer, a value normalizer, and an aggregator. The normalizer however is not applied when standards such as SNOMED CT, which does not specify the range of values of the attributes, are used. In the same way, the aggregator is not used if there are not overlaps in collected data from questionnaires.

The *attribute normalizer* maps each extracted attribute to one or more normalized attributes. For this mapping one or a combination of international standards are selected (such as ICF or SNOMED CT). The mapping of extracted attributes to such systematic medical terminologies enables the recording of clinical data effectively and in a harmonized manner recognizable worldwide.

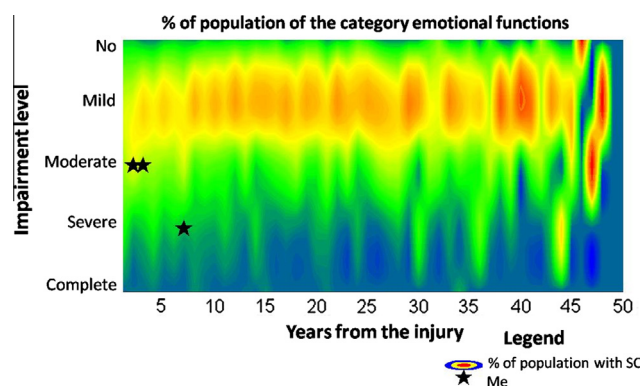


Fig. 8. Graphical representation of the evolution of a population across categories of the ICF.

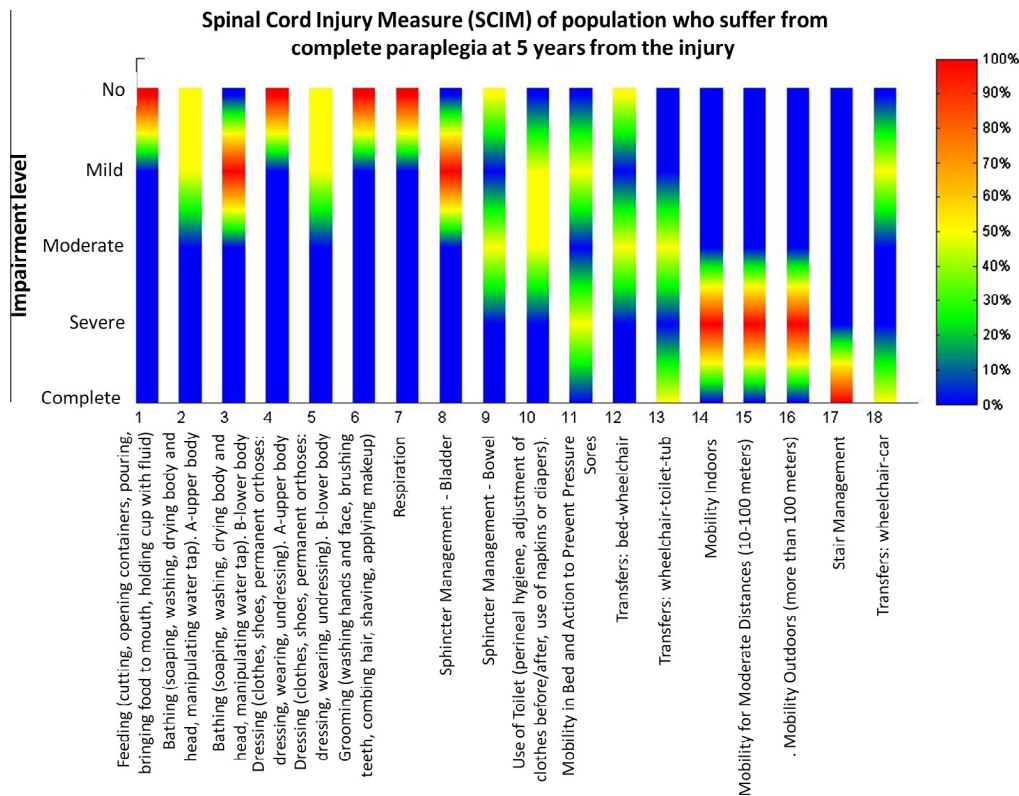


Fig. 9. Graphic representation of the status of populations and individuals through the spinal cord injury measure (SCIM).

The *value normalizer* also receives the attributes from the extractor and proceeds to normalize their values to a standard scale. Values of attributes are normalized to values between 0 and 4, representing degrees of deficiency, from no deficiency to complete deficiency, respectively. This value normalization enables all patient-data to be evaluated on the same scale. Standards such as SNOMED CT do not specify a range of values in their attributes. In this case, it is not necessary and the original value type of the attribute is maintained. Not normalizing values has the advantage of not introducing potential artificial distortions in the original measurement, especially when they are represented as Booleans or strings. After normalization, an attribute can contain zero or more values, is classified into three classes, and is processed differently depending on its class.

- A normalized attribute of type-1 comprises no values.
- A normalized attribute of type-2 comprises only one value.
- A normalized attribute of type-3 comprises more than one value. In the case of the type-3, the pluralities of values are combined by aggregator automatically. This is done because although questionnaires are optimized for the problem they evaluate, there are overlaps in the normalized data collected from several questionnaires.

Questionnaires attributes can be normalized to one or more attributes of the selected nomenclature or nomenclatures. Therefore, using the appropriate aggregation function for a normalized attribute, the values of questionnaires attributes are combined into a single value providing the optimized representation of the information contained originally within the plurality of attributes. In the state representation of a person, each standardized attribute can have only one value.

Therefore, the *aggregator* manages overlaps among items which have been measured through different questionnaire questions.

Table 4 Efficiency.

Representation/standardization	Response time (s)
Individual evolution of body functions ICF categories	4
Status of populations and individuals across categories of the ICF	20
Evolution of populations and individuals of the category body image of ICF	18
Status of populations and an individual of WHOQOL	14
Automatically standardize WHOQOL to ICF	3

The aggregating function can follow different approaches. In a statistic approach, the aggregating function would be the average, the median or the mode value. In another, more optimistic approach, the best value; while, in a more pessimistic approach, the worst value. Furthermore, not all attributes need to have the same aggregating function. Depending on the nature of the attribute, one aggregation function can be more appropriate. The *aggregator* could be located in an external component, for instance, in an external presentation system. This enables centralized aggregation of data located in different health institutions. On the other hand, not all questionnaires are administered in the same time, therefore, an interval of study of the status of the patient is chosen. In this field, the interval chosen was a year, as questionnaires are administered in the PCE once a year. In the case of type-2, a single value complies with the minimum information necessary for evaluation. In the case of type-1, the problem exists that an empty entry can cause that the final evaluation of the patient's health is incomplete and even erroneous. In order to maximize the probability of correct health evaluation, inference engine is used to determine a value from related attributes, which are structured in a hierarchy. The aim of the inference engine is to perform, when necessary and

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Rol Persona con discapacidad

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Nombre

Problema Parapleja completa

Apellidos

Año De La Lesión 2010

Nombre de usuario

Causa Traumática

Fecha de nacimiento
enero 1 1970

Hombre
Mujer

Texto de verificación A715

Enviar formulario de alta

Acceder Olvidó su contraseña

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Fig. A.1. Identity management, creation of an account.

possible, the inference of the value of type-1 attributes from other attributes. After attribute normalization, the value of more general attributes can be inferred from more specific attributes. After completing the processing of the normalized attributes according to their type, *selector* selects the relevant information depending on the particular profile being analyzed. Examples of relevant attributes that depend on each patient's values are non-empty values, extreme values, values which change over time, and values which are relevant for classifying patients in dysfunctional profiles. In addition, users are able to personalize the attributes they want to monitor depending on their personal experience or preferences.

The *filter* enables filtering population's status and the representation of each patient's evolution by a plurality of parameters: disease, cause of disease, lesion level and gender. When patients read health data from the representation system, the filter is not visible for them and population data are automatically filtered with population of their profile. Without the filter, data visualization is not personalized.

Fig. 2 summarizes the described flow diagram, which is illustrated by the following real example:

- Extract attributes. One of the questionnaires people who suffer SCI are assessed is the FIM.
- Normalize attributes? Yes. The item *dressing upper body* is normalized to *dressing* (d540) and *putting on clothes* (d5400).
- Normalize values? Yes. Attributes of this scale have 7 levels for each item: complete independence, modified independence, supervision, minimal assistance, moderate assistance, maximal assistance and total assistance. As a consequence, values are normalized to the 0–4 scale of ICF. The normalization of values has been the following: 7 corresponds to 0; 5 and 6 correspond to 1; 3 and 4 correspond to 2; 2 correspond to 3; and 1 correspond to 4. The real example's value correspond to 2, so the value of the dressing is 3.

- Number of values >1? Yes. Attribute d540 is extracted also from SCIM scale. The value from SCIM scale is 2. Therefore, the value of this attribute is the average of values from both scales (2.5), which is rounded to 3.
- Select. Attribute d540 is a non-empty value, therefore it is displayed.
- Filter. In the representation, the population represented is people who suffered a complete paraplegia, therefore the example is included.

If the number of values of d540 was 0, then it would be inferred from its children attributes from the ICF taxonomy, such as *putting on clothes* (d5400), *taking off clothes* (d5401), *putting on footwear* (d5402), *taking of footwear* (d5403), *choosing appropriate clothing* (d5404), *dressing, other specified* (d5408) or *dressing, unspecified* (d5403).

The *presentation system* enables the graphical representation of all normalized data of a patient's health as well as evolution throughout time and taking into account the different profiles. It also allows patients to compare themselves with other patients with their same profile. Patients and health practitioners can select a particular time frame for which they want the data to be analyzed, for instance, a number of years that have passed since a particular lesion or discovery of the disease. The presentation system allows the visualization of aggregated data from different health institutions.

The *presentation system* is centralized and optimizes the management of patients and clinicians which could be located at different geographical locations worldwide.

Fig. 3 shows the interaction of healthcare institutions if information comes from more than one MHR.

2.1.2. Knowledge representation

As in typical, modern knowledge-based systems, an ontology is used to represent patient's information [36] and it is updated using


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Fig. A.2. Identity management, profile.

SPARQL Protocol and RDF Query Language (SPARQL) [37] and Jena [38]. Both the ontology and *OntologyInteraction* Java library are available under the LGPL at <https://code.google.com/p/circlesof-health>. If health professionals need to update the ontology, they can do it collaboratively using WebProtégé [39], which is integrated in Circles of Health. Fig. 4 depicts the ontological representation of people who suffer from a SCI, which describes their administered questionnaires (summarized at Table 2) and their ICF core sets [14]. All this information is extracted through SPARQL queries from Liferay. An example of a SPARQL query to extract indicators obtained from questionnaires administered to people who has SCI is the following:

```
PREFIX rdfs:<http://www.w3.org/2000/01/rdf-schema#>
PREFIX rdf:<http://www.w3.org/1999/02/22-rdf-syntax-ns#>
select*where {?indicator
<http://purl.bioontology.org/ontology/PMR.owl#is_indicator_of>
<http://purl.bioontology.org/ontology/PMR.owl#Paraplegia_and_tetraplegia>
```

```
?.?indicator
<http://purl.bioontology.org/ontology/PMR.owl#code>?code .?indicator
<http://purl.bioontology.org/ontology/PMR.owl#name>?name .?indicator
<http://purl.bioontology.org/ontology/PMR.owl#description>?description}
```

The ontology and the MySQL database can be easily connected as they are both accessed through Java libraries, and concepts are represented using the same ICF and SNOMED CT standard codes. Apart from Liferay tables, 57 new tables are created:

- 4 tables to represent user's ICF values, for example, in the case of body functions, in *icftableb* table;
- Table *nodenames* to help users to understand ICF categories, to which disease it can be applied, and from which scales it has been extracted;
- 5 tables to contain information of the ASIA scale;
- 3 tables to contain information of each questionnaire of Table 2 (except for ASIA scale that has more tables due to its subscales), for example, in the case of WHOQOL, in *whoqolquestions*, *whoqoloptions* and *whoqolanswers* tables;



IMÁGENES Y VÍDEOS



QUIÉNES SOMOS



CONTACTAR

Autentícate

Dirección de correo

proig@circulos.com

Contraseña

Recuérdame

Acceder

[Crear cuenta](#) | [Olvidó su contraseña](#)


Red digital avanzada dirigida, desde los principios de promoción de la **inclusión social**, a todas las personas, y centrada en los problemas de aquellas con **diversidad funcional**, **abierta a la participación** de profesionales de la salud, agentes sociales y familiares. Permite compartir experiencias, **acceder a información y conocimiento**, compartirla y potenciar sus opiniones.

Agenda

Mes

Todos los eventos

febrero, 2011

Hoy

lunes	martes	miércoles	jueves	viernes	sábado	domingo
	1	2	3	4	5	6
7	8	9 Jornadas Turismo y Accesibilidad Universal, Calidad y Oportunidad	10	11	12	13
14	15	16 15:30 Taller de búsqueda de trabajo - ASPID (Lleida)	17	18	19 10:00 Liderazgo y representación del colectivo de personas con discapacidad- ECOM	20
21	22	23 16:00 Proyecto Millú, terapia asistida con animales- ASPID	24	25	26	27
28						

Imágenes y vídeos[Batukada public](#)

Por Marta Puig | 25/01/11

[BATUKADA-Escenar](#)

Por Marta Puig | 25/01/11

[DIRGuttmannMaratoTV3](#)

Por Marta Puig | 25/01/11

[Siguiente](#)**Noticias y FAQs [ver todas]****Noticias**

- 2010-10-20 [Hijos, complemento de la pensión 1.2](#)
- 2010-08-18 [Un robot enseña a jóvenes con discapacidad a manejar la silla de ruedas 1.2](#)

Preguntas frecuentes

- [FAQ DCA 1.2](#)
- [FAQ LM 1.0](#)

Encuesta

¿Qué opinas sobre Círculos de Salud?

- a. Me parece muy útil por su parte social e informativa
 b. Me parece útil por su parte social
 c. Me parece útil por su parte informativa
 d. No me parece útil

Votar

Anuncios [ver todos]**Ayudas técnicas**

- [En venta silla de bipedestación](#)
- [En venta silla compact](#)

Demandas laborales

- [Busco trabajo de teleoperador o conserje](#)
- [Busco trabajo para hacer en casa](#)

Ofertas laborales

- [Convocatoria de la plaza de director@ financiero@ de la federació ECOM](#)
- [Administrativo especializado en el ámbito contable](#)

Vehículos

- [En venta ford mondeo familiar](#)
- [En venta scooter eléctrica](#)

Vivienda

- [En venta casa totalmente adaptada](#)
- [En venta piso adaptado](#)

Fig. A.3. Network awareness, initial page without authentication.

- Table *profile*, to specify medical information; and
- Table *punctuationslink*, to normalize values of questionnaires.

In Fig. 5, there is the entity relationship modeling of a sample of 7 of these tables and the table *user* from Liferay database (which contains user identification).

2.1.3. Accessibility

The Liferay community is making continuous improvements in accessibility and usability issues. The recommendations of the WAI (Web Accessibility Initiative) have been followed, although Double-A requirements have been not satisfied. The following general recommendations have been applied:



Te ayuda a comunicarte, a compartir información y a aprender sobre tu calidad de vida



Hola pol

Desconectar



INICIO



PERFIL



MURO



TALLER de conocimientos



NOTICIAS Y PREGUNTAS frecuentes



FORO



EVENTOS



IMÁGENES Y VÍDEOS

Noticias y FAQs [ver todas]

Noticias

- 2010-10-20 Hijos, complemento de la pensión 1.2
- 2010-08-18 Un robot enseña a jóvenes con discapacidad a manejar la silla de ruedas 1.2
- 2009-10-27 La Asociación de Familias con Ictus en Extremadura organizará el jueves una charla sobre cómo abordar la enfermedad 1.2
- 2007-02-12 Varios hospitales españoles participan en un estudio que identifica a los pacientes con ictus con mayor riesgo de muerte 1.1
- 2010-09-06 Lesionados medulares tocan el futuro 1.1

Sobre Ruedas

- Número 76 1.3
- Número 75 1.2
- Número 74 1.1
- Número 71 1.1
- Número 73 1.1

Preguntas frecuentes

- FAQ DCA 1.2
- FAQ LM 1.0
- Noticias y preguntas frecuentes 1.3 (minor-edit)

Muro [ir al muro]

No hay mensajes

Foro [ver todos]

Dolor neuropático

- Estrategias de afrontamiento
 - Estrategias de afrontamiento de la discapacidad

Grupos focales

Ocio

- RE: Club deportivo Institut Guttmann
- Viajes accesibles
- Guía de monumentos, museos y puntos de interés turístico
- Guía de restaurantes accesibles

Participación en la sociedad

- Libro Paralimpiadas

Alertas

Tiene escalas pendientes

Buscar amigos

Anuncios [ver todos]

Ayudas técnicas

- En venta silla de bipedestación
- En venta silla compact
- En venta paralelas
- En venta silla de ruedas para baño

Demandas laborales

- Busco trabajo de teleoperador o conserje
- Busco trabajo para hacer en casa
- Empleo para realizar desde casa
- Administrativa - recepcionista
- Busco trabajo

Ofertas laborales

- Convocatoria de la plaza de director@financier@ de la federació ECOM
- Administrativo especializado en el ámbito contable
- Oferta de trabajo
- Se necesita auxiliar administrativo
- Gestores/as para realizar funciones de recepción

Vehículos

- En venta ford mondeo familiar
- En venta scooter eléctrica
- En venta adaptaciones coche
- En venta BMW

Vivienda

- En venta casa totalmente adaptada
- En venta piso adaptado
- En venta casa adaptada de tres plantas
- Se alquila piso adaptado

Encuesta

¿Qué opinas sobre Círculos de Salud?

a. Me parece muy útil por su parte social e informativa
 b. Me parece útil por su parte social
 c. Me parece útil por su parte informativa
 d. No me parece útil

Eventos [ir al calendario]

Mes: Todos los eventos

febrero, 2011

Hoy

lunes	martes	miércoles	jueves	viernes	sábado	domingo
	1	2	3	4	5	6
7	8 23:00 Jornadas Turismo y Accesibilidad Universal, Calidad y Oportunidad	9	10	11	12	13
14	15	16 14:30 Taller de búsqueda de trabajo - ASPID (Lleida)	17	18	19 9:00 Liderazgo y representación del colectivo de personas con discapacidad- ECOM	20
21	22	23 15:00 Proyecto MiU, terapia asistida con animales - ASPID	24	25	26	27

Fig. A.4. Network awareness, initial page with authentication.

The screenshot displays the 'Círculos de Salud' website interface. At the top, there is a logo and the text 'Te ayuda a comunicarte, a compartir información y a aprender sobre tu calidad de vida'. Below this is a navigation bar with icons for 'INICIO', 'PERFIL', 'MURO', 'TALLER de conocimientos', 'NOTICIAS Y PREGUNTAS frecuentes', 'FORO', 'EVENTOS', and 'IMÁGENES Y VÍDEOS'. The main content area is divided into several sections: 'Usuario' (User) showing a profile picture of a rabbit and the name 'Pol Roig'; 'Amigos' (Friends) showing 'Tienes 1 amigos.' and a friend named 'Leonor López'; 'Muro' (Wall) showing a post by 'Leonor López' with the text '¡Hola Pol!' and 'Publicado el día 15/03/11 14:21.'; and 'Mis actividades' (My activities) showing a list of recent actions such as 'Pol wrote a new message board post' and 'Leonor López ha escrito en el muro de Pol'.

Fig. A.5. Information exchange, wall.

- There is an accessibility section to raise awareness of the type and level of accessibility of Circles of Health. The accessibility page has the following content: navigation recommendations, browsers, document readers, type of end-user test performed and keyboard shortcuts and access keys for quicker keyboard navigation (see Fig. A.13).
- Pages are checked with speech readers such as JAWS.
- *Select boxes* are avoided when possible; and navigation is optimized through keyboard shortcuts.
- The order of the tabs (tabindex) follows a logical sequence on the pages.
- There are alternative text to images.

2.2. Evaluation

The evaluation of Circles of Health is divided into two parts: an expert and a user experience analysis with eleven users. These users are: five health professionals (a neuropsychologist, a medical doctor, a social worker, a psychologist and a psychotherapist) and six people with a disability (SCI, non-traumatic ABD and TBI).

The protocol of verbal reports [35] allowed to generate both quantitative and qualitative results. This method is chosen because

qualitative results include behavior (actions taken by the task) and literals (subjective views on the experience and interface). The main benefit of this method is to identify the user's mental model and their interaction with Circles of Health. In addition, an answer-response protocol was used to analyze user's activity and identify which parts of the interface or the system are obvious or confusing. These are the tasks of the test:

1. *Getting acquainted with Circles of Health.* Before registering, what kind of benefits did you expect to derive from joining the community? What do you think about this page? After registering, did you find the process easy? What would you change?
2. *Interpretation of the content.* Visit the Knowledge section. What do you think of the information provided in this section? Do you think it is appropriate? What would you improve? Visit the Scales section. Can you describe the type of content shown? Do you find it useful? Would you trust the data? Why?
3. *Social Network.* After visiting the Wall, Forum, News, and Events sections: Do you think it is useful to have a social network section? What kind of value do you think that brings? Would you use this kind of service? Would you trust it?

The screenshot displays the 'Circulos de Salud' website. At the top, there is a navigation bar with icons for 'INICIO', 'PERFIL', 'MURO', 'TALLER de conocimientos', 'NOTICIAS Y PREGUNTAS frecuentes', 'FORO', 'EVENTOS', and 'IMÁGENES Y VIDEOS'. Below this, a 'Galería de imágenes y videos' section is active, showing a folder named 'Batukada maratón TV 3'. A table lists three documents within this folder:

Nombre	Tamaño	Descargas	Bloqueado
Batukada public.jpg	371,0kB	1	No
BATUKADA-Escenar.jpg	247,2kB	0	No
DIRGuttmannMaratoTV3.swf	14.503,2kB	0	No

At the bottom of the page, there are links for 'Configuración' and 'Amigos online (0)'. The footer contains the text 'Circulos de Salud © 2010 | Quiénes somos | Contacta'.

Fig. A.6. Information exchange, videos.

4. *Administration* (this task is only performed by health professionals). Did you find accreditation process easy? Would you trust it? Do you understand correctly the type of information that is being provided? Would you use this kind of service?

3. Results

This section describes the functionalities of Circles of Health and an evaluation with eleven volunteers.

3.1. Functionalities of Circles of Health

Circles of Health offers the following functionalities:

- **Identity management.** Circles of Health allows managing the availability of identity information (i.e. filling in information and setting access rights). Examples for functions enabling identity management are creation of an account (Fig. A.1) and profile and community memberships to accredited professionals (Fig. A.2). Regarding the last one, once professionals have already been accepted in the community of accredited professionals, they get a new menu of people management.
- **Network awareness.** Circles of Health provides awareness of the activities and/or the current status and changes of the latter of the contacts in the personal network is supported by news feeds both without being authenticated (Fig. A.3) and being authenticated (Fig. A.4).

- **Contact management.** Contact management combines all functionalities that enable the maintenance of the (digital) personal network (Fig. A.5) and search boxes (Fig. A.4).
- **Information exchange.** Information exchange can be direct or indirect. Direct information includes wall (Fig. A.5) and chat. Indirect information comprise photos, videos (Fig. A.6), events (Fig. A.7), forums (about ads, neuropathic pain, coping strategies, focus groups, leisure and participation in society, see Fig. A.8) and wikis (where accredited professionals may consider writing relevant news and frequently asked questions (FAQs), see Fig. A.9). In addition, users can manage in their private pages questionnaires and see their graphical representation in a standardized format (Figs. A.10–A.12). This last functionality is explained in detail in this section as it is the differential characteristic of Circles of Health.

Circles of Health represents individually and comparatively people with disabilities or neurological origin. Fig. 6 depicts the information related to the evolution of the person's health and a set of attributes as a function of the time elapsed since the detection of the lesion. Regarding environmental attributes, facilitators are represented by circles while barriers are represented by stars. Looking at Fig. 6, users can quickly notice that he has a mild facilitator in drugs, and no facilitator in assistive products and technology for personal indoor and outdoor mobility and transportation. Fig. 6 depicts *person's evolution* using standardized holistic attributes. So Circles of Health helps him to improve his knowledge

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Hola pol Desconectar

[INICIO](#)
[PERFIL](#)
[MURO](#)
[TALLER de conocimientos](#)
[NOTICIAS Y PREGUNTAS frecuentes](#)
[FORO](#)
[EVENTOS](#)
[IMÁGENES Y VÍDEOS](#)

[Inicio](#) » [Eventos](#)

Eventos

Eventos Mes Todos los eventos

febrero, 2011

Hoy

lunes	martes	miércoles	jueves	viernes	sábado	domingo
	1	2	3	4	5	6
7	8 23:00 Jornadas Turismo y Accesibilidad Universal, Calidad y Oportunidad	9	10	11	12	13
14	15	16 14:30 Taller de búsqueda de trabajo - ASPID (Lleida)	17	18	19 9:00 Liderazgo y representación del colectivo de personas con discapacidad - ECOM	20
21	22	23 15:00 Proyecto Milú, terapia asistida con animales - ASPID	24	25	26	27
28						

Círculos de Salud © 2010 | [Quiénes somos](#) | [Contacta](#)

Fig. A.7. Information exchange, events.

of his health indicators. For example, he can see that he has a lack of assistive products and technology.

In Fig. 7 there are several individual and comparative representations of users. Fig. 7 is a *population's evolution of an ICF category*. It is yet another representation wherein a particular disease has been selected as well as a particular time span, and the MHR is depicted, in the top graph, in relation to a variety of body functions, such as urination and emotional functions. This graph shows the percentage of population with a certain value of deficiency of different normalized attributes, in a particular instant of time. Different colors indicate different percentage of patients with that deficiency. In his last periodic evaluation, his doctor recommended that he use a collector instead, but the patient argued that he prefers to perform intermittent self-catheterization. Doctors use the graphical representations to take a joint decision with Patients, showing them the percentage of patients that follow her recommendation of using a collector.

In Fig. 8, person's state, represented by a star, is compared to a particular *population's state* exhibiting similar profiles. The level of functional diversity is graded in relation to the number of years from the lesion. It shows the percentage of population with a level of functional diversity of one normalized attribute in time.

Different colors¹ indicate different percentages of patients with that deficiency. When the user of presentation system is a patient or a clinician who wants to monitor the evolution of one of his patients, the patient is represented by a star. Regarding the evolution of person's emotional functions, in Fig. 8, it gets worse (his impairment level goes from moderate to severe). This representation enables the comparison between him and population who suffer similar problems. The population is the set of people with an SCI, who had a traumatic injury and with the same time elapsed since the lesion. His psychologist sees then a graphical representation of person's emotional functions; as it is an abnormally severe deficiency, he derives him to an external psychological consultation.

The social worker, wants to have more information about anonymous population's evolution at 5 years from the lesion. Fig. 9 is a static representation of *population's state in SCIM*. It depicts an overview of a whole population suffering a single disease after a certain time span after the lesion, in this case 5 years. The data for this representation are extracted from the MHR and forwarded to the filter without intervention from the attribute normalizer,

¹ For interpretation of color in Figs. 7–9, the reader is referred to the web version of this article.

The screenshot displays the 'Circulos de Salud' forum interface. At the top, there is a header with the site logo and the tagline 'Te ayuda a comunicarte, a compartir información y a aprender sobre tu calidad de vida'. Below this is a navigation bar with a user greeting 'Hola admininguttmann' and a 'Desconectar' link. A row of icons provides access to various site features: INICIO, PERFIL, MURO, GESTIÓN de personas, TALLER de conocimientos, NOTICIAS Y PREGUNTAS frecuentes, FORO, EVENTOS, and IMÁGENES Y VÍDEOS. The main forum area is titled 'Viajes accesibles' and shows a post by 'Administrador Guttman' with the text: 'Hola, Para los que tienen morriña de las vacaciones de verano y ya desean preparar las próximas vacaciones, dejamos el enlace de esta agencia que organiza viajes y actividades accesibles. ¡Espero que sea de interés!'. The post includes an advertisement for 'viajes accesibles' and an attached file '20854.jpg (2,3k)'. At the bottom of the page, there is a footer with the text 'Circulos de Salud © 2010 | Quiénes somos | Contacta'.

Fig. A.8. Information exchange, forums.

aggregator, or the inference engine. The level of deficiency is depicted in relation to a variety of symptoms suffered by the patient, divided into categories such as eating, hygiene, dressing, self-care, breathing, body control, physical mobility (internal/external, below/above 100 m, etc.). It also shows the percentage of population with a certain value of deficiency of different attributes, in a particular instant of time. Different colors indicate different percentages of patients with that deficiency. In Fig. 9, she can see that most people have mild facilitators for assistive products and technology for personal indoor and outdoor mobility and transportation, and moderate barriers to transportation services systems and policies and intangible assets. All this information helps her to learn that mobility is a problem for most people with this profile and that it would make a great impact to prevent it through public policies. Therefore the solution enables the social worker a straightforward, cost efficient and universal processing of health information and data, thereby allowing health practitioners and patients to ascertain their health data using common benchmarks from a wider population in a normalized and harmonized manner.

3.2. Evaluation

The evaluation methodology described in Section 2.2 is divided into two parts: an expert and a user experience analysis with eleven users. Recommendations of two usability and user experience experts were followed and helped to improve the usability, accessibility and user experience of Circles of Health before the analysis with users. The recommendations of the two experts were:

- Benefits of belonging to a community, which are interactions and access to useful information, should be explained.

- Circles of Health should carefully use vocabulary and help users in their daily life. Avoid in all profiles technicalities such as *Open Id*. In the profiles of person with disability and family, avoid medical jargon.
- The design should focus on user needs, and icons should be more serious. Excess of links and sections should be removed.
- Users should be able to navigate from static to evolution graphical representations to better understand QoL.
- Links to other social networks should be removed. The user does not need other social networks to interact with Circles of Health.

After the expert analysis and the second version of Circles of Health, there was a user experience analysis with eleven users described in Section 2.2. During the interviews, professionals indicated the graphics provided to them a lot of interesting information, and the usefulness for the professional is clear to do multidimensional studies or articles. Circles of Health helps them to compare for example, body functions of people who had non-traumatic ABD and TBI. They found it useful to make comparisons with someone from another country who uses a different scale and/or language, to know which the most important problems are, and to organize rehabilitation objectives. Regarding to users with disabilities, they said Circles of Health should be optional, users can look at it when they want and that it should be taken into account that some old people have problems using the Internet and new technologies. Some professionals indicated that although it is useful for their daily practice, sometimes they would need to have more information (for example, if someone has urination problems, it is important to know how often the leaks happen).



Círculos de Salud

Te ayuda a comunicarte, a compartir información
y a aprender sobre tu calidad de vida



Hola admringuttmann
Desconectar

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Wiki

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2010-04-20 Discapacitada, pero no para ser madre

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Las mujeres con lesión medular pueden tener hijos si reciben apoyo

Quando tenía un año y apenas se aguantaba de pie, Martí ya había desarrollado una habilidad inusual para su edad: subirse a la silla de ruedas de su madre, trepar hasta su regazo y sentarse cómodamente. Sonia Pujol dio a luz cuatro años después de haber sufrido un accidente que la dejó en silla de ruedas. Su columna quedó seccionada a la altura de la vértebra número 8. Pero eso no le impidió algo que siempre quiso: tener dos preciosos niños, Martí,

Noticias externas de interés

- Los amigos del Institut Guttmann**

11/07/12 12:19

 - [FinConsum y Fundación Adecco promoverán la integración laboral y profesional de las personas con discapacidad](#)
 - [El Institut Guttmann y Voluntarios de TMB promoverán la autonomía de las personas con discapacidad en el metro](#)
 - [El Institut Guttmann presenta nuevos servicios de telemedicina en rehabilitación en una clara apuesta por la Economía del Conocimiento](#)
- Portal SID (Servicio de Información sobre Discapacidad)**
- Aspaym Cataluña**

28/06/13 22:38

 - [Terapia sexual en una silla de ruedas - Medular Digital](#)
 - [Número 9 de la revista "Mou-te Més" de Aspaym Catalunya](#)
 - [Cena de verano de Aspaym Catalunya 2012](#)

Fig. A.9. Information exchange, wikis.

During the interviews, people with disabilities said it is very interesting to be able to bring together people with a very similar profile, is always good because you feel supported. Some of them suggested Circles of Health is useful to people who had their lesion from 1 to 3 years ago. They liked the use of use of color-coding because it is very visual. Some of them liked the comparative graphic, because it helps to know where you are in relation to the rest of the population. They said it would be interesting to have these graphs in the annual review because it is very visual and it could be a stan-

dard way of representing knowledge. This can be helpful when they travel abroad because sometimes the information is in Catalan or Spanish. However, some of them indicated that it worries them to know what their deficiency level would be in some years although there were some things that at some point they would like to see. Some of them see these graphics more professionally oriented, there is too much information and ICF concepts are difficult to understand. They suggested seeing the whole individual graphical representation in the screen, and do it larger and smaller.

The screenshot shows the 'Círculos de Salud' website. At the top, there is a logo and the text 'Te ayuda a comunicarte, a compartir información y a aprender sobre tu calidad de vida'. Below this is a navigation bar with icons for 'INICIO', 'PERFIL', 'MURO', 'TALLER de conocimientos', 'NOTICIAS Y PREGUNTAS frecuentes', 'FORO', 'EVENTOS', and 'IMÁGENES Y VÍDEOS'. A breadcrumb trail reads 'Inicio > Taller de conocimientos > Escalas'. The main content area features two tables:

Listado de escalas de paciente (autoadministrables)

Escalas	Estado	Fecha	Ver PDF	Ver gráfico	Borrar escala
Más información de las escalas					
Escala social Instituto Guttmann (ESIG)	Pendiente				
Índice de bienestar psicológico (IBP)	Acabado	07 de febrero de 2011			
Cuestionario de integración en la sociedad (CIO)	Acabado	07 de febrero de 2011			
Escala de factores ambientales hospital Craig (CHIEF)	Acabado	07 de febrero de 2011			
Escala de ansiedad-depresión (HAD)	Acabado	07 de febrero de 2011			
Cuestionario sobre la salud del paciente (PHO9)	Acabado	07 de febrero de 2011			
Escala de calidad de vida de la Organización Mundial de la Salud (WHOQOL)	Acabado	07 de febrero de 2011			

Listado de escalas a administrar por el profesional

Escalas	Estado	Fecha	Ver PDF	Ver gráfico
Más información de las escalas				
Medidas de la independencia funcional (FIM)	Acabado	07 de febrero de 2011		
Medida de la lesión de la médula espinal (SCIM)	Pendiente			
Escala de discapacidad (ASIA)	Pendiente			

At the bottom, there is a footer: 'Círculos de Salud © 2010 | [Quiénes somos](#) | [Contacta](#)'.

Fig. A.10. Information exchange, management of questionnaires.

To summarize, results obtained are:

- All professionals have noted that graphical representations of the evolution of individuals provide valuable visual feedback, e.g., for identifying categories with a high level of deficiency with the color-codification.
- 83% of the users with disabilities gave special importance to the possibility of accessing the information at any time. The type of information exchanged by people with a disability is not necessarily medical but rather about aspects of everyday life, organizations and activities of interest.
- 66% of the users with disabilities indicated that participating in a community brings many benefits and enriches personal knowledge based on the experiences of other users. They gave special importance to knowing the people or institution who is behind the management of the content and who certifies the validity of what is shown, and to access the information when they want to.
- 33% of the users with disabilities found Circles of Health useful to perform online follow up questionnaires after clinical discharge.
- 50% of the users with disabilities had problems interpreting the standardized values and indicated that graphical representations had too much information.
- 50% of the users with disabilities indicated that graphical representations are too difficult to be interpreted, and they did not want to spend time to understand them.
- 18% of the users highlighted that Circles of Health is useful to interchange information with non-Spanish speaking countries.
- Findings of usability and user experience are:
 - To strengthen the explanatory text by giving priority to the need to register and privilege to participate in Circles of Health. To include who is responsible for managing Circles of Health.
 - To explain in detail the purpose of filling in the register and the role of the user when checking the contents of Circles of Health.
 - To add contextual help text to know the content of each section before accessing it.
 - To provide information about content privacy all over the network, to inform users who is able to see their information.

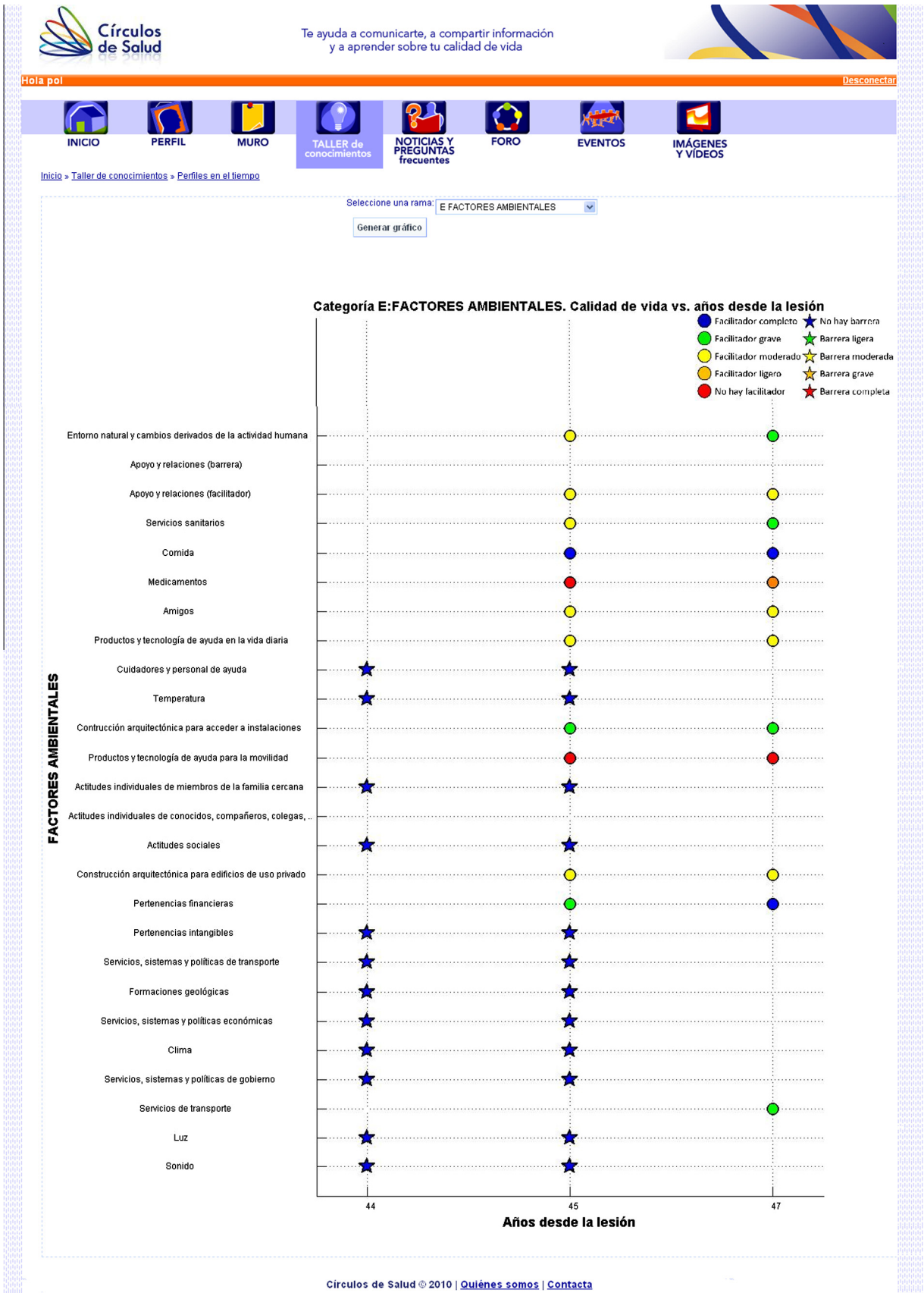


Fig. A.11. Information exchange, evolution of an individual using ICF categories.

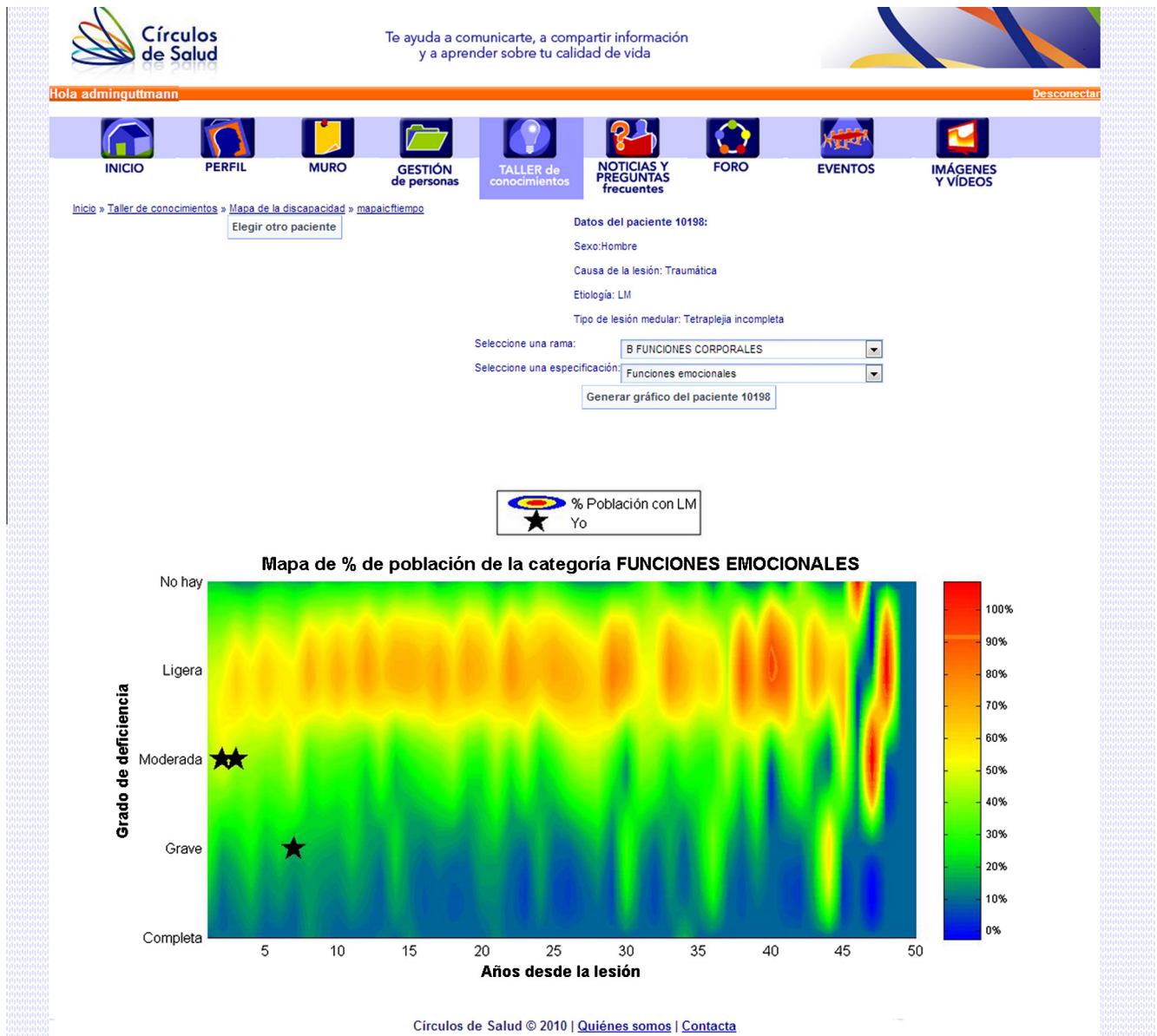


Fig. A.12. Information exchange, evolution of a population using ICF categories.

- To review the format of Circles of Health with emphasis on adding the title in all sections and to add different colors in the text.

Regarding efficiency, users were satisfied with time response of Circles of Health when generating graphical representations, and introducing and standardizing questionnaires. We show the response times of the integration of Matlab and Liferay in a X3430 (2.39 GHz, 3.99 RAM) processor (see Table 4) was acceptable by users.

4. Discussion

All professionals noted that graphical representations of the evolution of individuals provide valuable visual feedback. They also highlighted Circles of Health integrates understanding of health forming a comprehensive profile of an individual and population. Therefore, results indicate Circles of Health is useful to support multicenter studies thanks to the use of standardized knowledge. 83% of users with disabilities gave special importance

to the possibility of accessing the information at any time, 66% indicated that participating in a community brings many benefits and enriches personal knowledge based on the experiences of other users, and 33% of people with disabilities indicated Circles of Health is useful to perform online follow up questionnaires. As a consequence, Circles of Health has potential to promote knowledge democratization, user empowerment and making decisions with a more informed opinion.

However, 50% of users with disabilities remarked ICF categories obtained from PCEs provide too much information to people with disabilities. In addition, 50% of them found some categories of the ICF standard difficult to understand. Therefore, it is recommended to limit the number of ICF categories for each user's interface to no more than nine. The number nine was set due to human limits in the ability of processing information [46].

5. Future work

In the future, the usage of Circles of Health will be promoted at the *Institut Guttmann – Neurorehabilitation Hospital* among patients



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Recomendaciones para la navegación

Para navegar por el portal de "Círculos de Salud" de forma óptima, te recomendamos utilizar:

- Navegadores Mozilla [Firefox](#) 1.5 o superior, Microsoft Internet Explorer 7 o superior o Google Chrome 8 o superior.
- Una resolución mínima de pantalla de 1.024 x 768 píxeles.

Desde aquí te ofrecemos acceso directo a las páginas para que puedas bajarte los navegadores, programas y plug-ins necesarios para disfrutar de todas las funcionalidades.

Navegadores



[Mozilla Firefox](#)



[Microsoft Internet Explorer](#)



[Google Chrome](#)

Visualizador de documentos



[Adobe Acrobat Reader PDF](#)

Accesibilidad

"Círculos de Salud" se esfuerza para ser accesible utilizando como base el sistema de gestión de contenidos de [software](#) libre [Liferay](#). Se han seguido las recomendaciones del WAI (Web Accessibility Initiative), grupo de trabajo internacional perteneciente al W3C (World Wide Web Consortium), organismo que vela porque ningún colectivo sufra discriminaciones de ningún tipo que puedan ser causa de fracturas sociales en el mundo virtual. Pedimos disculpas por satisfacer los requisitos necesarios para Doble-A.

Cambios de tamaños en los principales navegadores



Mozilla

- Aumentar el tamaño del texto: CTRL + Rueda del ratón atrás, CTRL + + (tecla más) o Ver > Tamaño > Aumentar
- Reducir el tamaño del texto: CTRL + Rueda del ratón adelante, CTRL + - (tecla menos) o Ver > Tamaño > Reducir
- Recuperar la vista original: CTRL + 0 (cero) o Ver > Tamaño > Restablecer



Internet Explorer

- Aumentar el tamaño del texto: CTRL + Rueda del ratón adelante, CTRL + + (tecla más) o Ver > Tamaño del texto > Grande, Muy grande
- Reducir el tamaño del texto: CTRL + Rueda del ratón atrás, CTRL + - (tecla menos) o Ver > Tamaño del texto > Pequeño, Muy pequeño
- Recuperar la vista original: CTRL + 0 (cero, no con el teclado numérico) o Ver > Tamaño del texto > Mediano



Chrome

- Aumentar el tamaño del texto: CTRL ++ Rueda del ratón adelante, CTRL + + (tecla más) o Control de página > Tamaño > Mayor
- Reducir el tamaño del texto: CTRL + Rueda del ratón atrás, CTRL + - (tecla menos) o Control de página > Tamaño > Menor

Fig. A.13. Accessibility page.

and clinical staff (especially psychologists and social workers). It is also planned to *involve other institutions* such as other reference

healthcare centers, patient organizations, public health systems, and private enterprise; and to *conduct a benchmarking study*. For

that, information models, such as EN 13606 [44] or HL7 virtual medical record (vMR) [45], may be incorporated in order to facilitate information exchange among MHRs.

For future work, in order to improve usability and user experience of Circles of Health, the number of ICF categories for each user's interface should be reduced. In addition, as clinical decision support systems (CDSSs) have gained momentum with the emergence of biomedical ontologies [42], the inclusion of prognosis of some categories into Circles of Health may help health professionals to make decisions about changes in activities and environmental factors. There is some work done in knowledge representation of prognosis [43] we plan to incorporate into Circles of Health.

As 18% of users highlighted, internationalization is also an opportunity for Circles of Health. Although at first glance it is oriented to Spanish speaking countries, it can be extended internationally to other countries. This would be useful for governments, as it would allow get a general picture of disability and of the comparison among different regions. In addition, it would allow the creation of best practices and recommendations at the European level, with direct impact on regional policies of inclusion, support and assistance to dependence. Furthermore, this work can also be generalized to other types of disabilities or chronic conditions, the generalization to all people, and the work of internationalization described in previous sections. In addition, there are new opportunities for Circles of Health, as can be *generalized to other types of disability*. People with visual or hearing disabilities may be users of Circles of Health if questionnaires of these groups are introduced and translated to ICF. It would be interesting to generalize Circles of Health to the physical and cognitive domains, adapting the questionnaires and the information to the profile of the person.

6. Conclusions

We have presented a social-network platform called Circles of Health, focused on people with disability, open to the participation of people with disabilities, family members, health professionals, education and social services. Circles of Health uses a new methodology which automatically collects, transforms, shares and graphically represents standardized and multidimensional indicators. Circles of Health includes main aspects of a person's life (development, participation, and environment) using the ICF instead of solely focusing on his or her diagnosis. Results indicate Circles of Health has great potential for users. Professionals found Circles of Health useful to generate new knowledge. People with disabilities found helpful to enrich personal knowledge with the experiences of other users and to perform online follow up questionnaires after clinical discharge. As a consequence, Circles of Health has potential to promote knowledge democratization, user empowerment and making decisions with a more informed opinion. For future work, it would be interesting to establish no more than nine ICF categories for each user's interface and to involve other institutions.

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Appendix A. Screenshots

See Figs. A.1–A.13.

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