The FBE development project: toward flexible electronic standards-based bio-psycho-social individual records

Lucilla FRATTURA[a,1], Andrea SIMONCELLO[a], Giovanni BASSI[a], Andrea
SORANZIO[b], Stefano TERRENI[b], Fulvio SBROIAVACCA[b]

[a]*Central Health Directorate, Italian WHO Collaborating Center for the Family of
International Classifications, Friuli Venezia Giulia Region, Udine, Italy*
[b]*Insiel SpA, Italy*

Abstract. Under the ARCHITRAVE programme aimed at redesigning the
regional health and social information system, the alpha version of a new web
application was developed using the International Classification of Functioning,
Disability and Health (ICF) and other medical terminology systems as a basis for a
flexible electronic standards-based bio-psycho-social record. The web application
was developed in order to collect information according to a multiaxial assessment
framework consistent with the model of functioning adopted by the ICF. The web
application translates information collected in natural language into ICF and
releases outputs at different stages of the assessment process useful in evaluating
clinical and social outcomes, distinguishing between functioning and disability in
the same functioning profile and planning reasonable adaptations to overcome
disability. The alpha version works in Italian and was adapted to the Italian
welfare system/services/policies, but an international version working in other
languages/welfare systems can be designed. The first field trial is ongoing in the
Friuli Venezia Giulia Region, implementing the regional Health and Social Action
Plan 2010-2012.

Keywords. web application, ICF, information model, interoperability

Introduction

Under the ARCHITRAVE programme, the Friuli Venezia Giulia Region is
redesigning the regional health and social information system with the aim to put the
patient and his/her health status and the interventions provided by the health and social
care system at the basis of the new architecture. At the same time, the main issue is to
create an interoperable Electronic Health and Social Record (EHSR) using: (i) clinical
and social vocabularies; (ii) healthcare message exchanges; and (iii) appropriate
privacy and security standards, especially as they relate to national regulations [1].

A specific regional project was launched in 2010 aimed at creating a new
application able to describe the functioning and disability status of each patient in the
care of the health and social system and to provide suggestion for customized
intervention plans [2]. Disability does not have a unique definition although it is

---

[1] Corresponding Author.

considered to be associated with the health, functioning, and social context of an individual. To collect data valuable for planning and caring purposes, the main goal is to understand the relationships among the elements that combine to create disability and to choose a data source and measure wisely.

Two pillars were proposed: the UN Convention of the rights of persons with disabilities (UNRPD) [3] and the International Classification of Functioning Disability and Health (ICF) [4]. The ICF, provides a standard language and a bio-psycho-social framework for the description of health and health-related states. In ICF, the term *functioning* refers to all body functions, activities and participation, and it is used to describe a positive interaction between an individual and his/her contextual factors; *disability* is similarly an umbrella term for impairments, activity limitations and participation restrictions and it is proposed to describe a negative interaction between an individual and his/her contextual factors. Nevertheless, some main open issues on ICF usability in the real-world care practice have to be considered: (i) lack of operationalization of functioning as "*positive aspects of the interaction between an individual and his/her contextual factors*" and of disability as "*negative aspects of the interaction between between an individual and his/her contextual factors*"; (ii) the list of the Environmental Factors domains is too broad; (iii) in the ICF "red book" there is a lack of rules in order to have "a synthetic picture" of an individual functioning/disability ratio; (iv) and the terms functioning and disability themselves do not have the same meaning in the different languages.

1. Methods

A regional expert group was established in order to develop and test a new information system using ICF and other medical terminology systems as a basis for a flexible standards-based electronic bio-psycho-social record. The paper version of the Italian translation of the ICF [5] was transformed by the Italian WHO-FIC Collaborating Center into a ClaML format and published on the Italian Portal of Classifications [6]. The FBE conceptual design and implementation of a minimum dataset for individual records were developed in accordance with an ad hoc bio-psycho-social assessment protocol tested in more than 1,300 Italian outpatients in the past three years [7] The web application includes an information model and a description model. The information model contains concrete record entries summarized in Figure 1. Since disability lies on a continuum, there is no definitive answer to the question: "What is the level of functioning, for a specified domain below which a person can be said to have a disability?". A specific algorithm was introduced to distinguish the two conditions in the same individual description [8]. The description model provides templates for the bio-psycho-social record describing the information that can be entered, all referred to the ICF conceptual model and useful to describe the interaction between an individual and his/her environment.

The information was automatically mapped to ICF concepts, and it was specified how the concepts can be combined with natural language sentences and which concepts are mandatory or not (Figure 2). Descriptive labels were provided for the ICF categories of Environmental Factors (EFs), which are too broad for a precise description of the interaction between an individual and his/her surrounding environment, and for individual care planning purposes. To create a suitable bio-psycho-social lexicon, information was aligned with a terminology collection
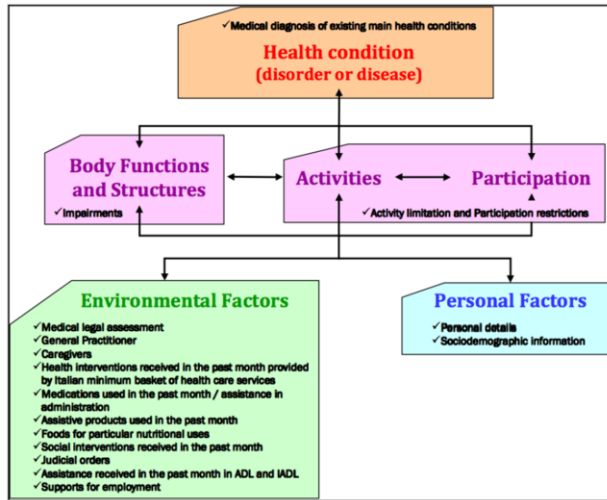
Figure 1. FBE Web application model considering the ICF model of Functioning and Disability.

containing ICF-CY, ISO9999 (1998), national nomenclatures of medical products, and social and health intervention vocabulary. A proposal of an HL7 CDA2 specification of representation of the records will be defined following the model of specification proposals for health records approved by national bodies. The web application was named FBE/electronic ICF-based individual record/FVG.
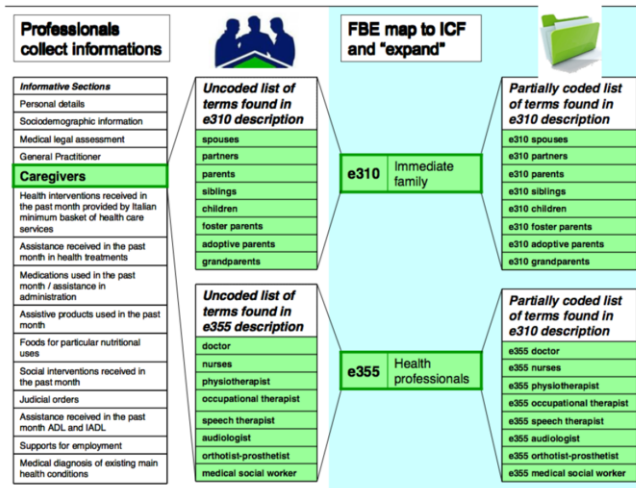

Figure 2. FBE content model: ONE to MANY Environmental Factors mapping.

2. Results

In 2011, a first field trial was carried out. 312 professionals from 6 regional Local Health Authorities recruited and evaluated 212 patients, who accepted to be enrolled [2]. A training programme for those professionals was carried out starting from March

to November. The FBE was filled in different steps and by different professionals. At the patient admission, information on personal and environmental factors was collected using natural language (no skill in ICF language was needed) by health or social professionals. In the multiprofessional assessment step, a multi-professional team inputed information to be coded, being facilitated by the web application in matching EFs to each category. For each patient, the web application released specific outputs useful to distinguish between functioning and disability in the same functioning profile and to highlight the EFs involved, and to plan reasonable adaptations to overcome disability. A printable version of each individual profile was provided. The statistical analysis of the enrolled cohort is ongoing (Figure 3).

3. Discussion

The major value of integrated clinical systems is that they enable us to capture clinical data as part of the overall workflow. By using the electronic ICF-based assessment tool box, it is possible to standardize data collection for evidence–based health and social planning and care and for statistical purposes using ICF as a standard language for the first time [9]. Since its publication in 2001, the ICF has been gradually implemented in a variety of settings and sectors [10] and FBE seems to be the first ICF application as a basis for an health information system.

The totally public FBE development process demonstrates the feasibility of public efforts in innovating informative infrastructures and professional culture. It was planned and realized by the staff of the regional health system.
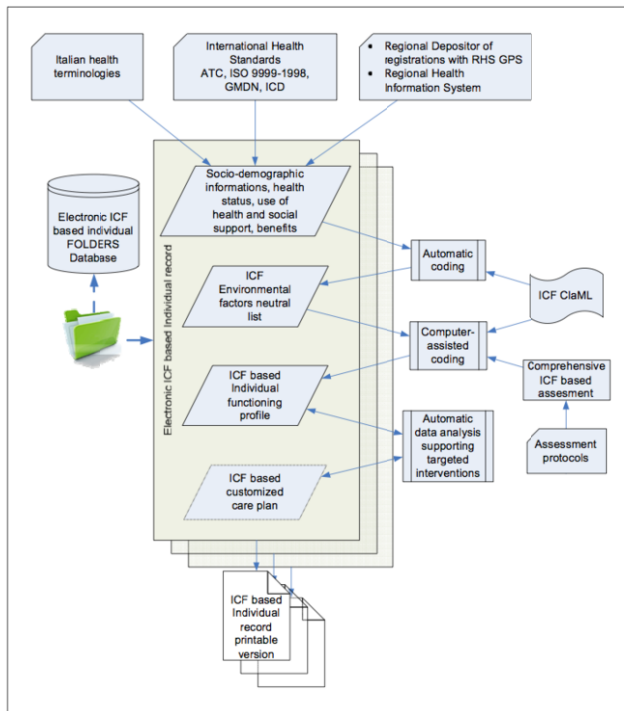

Figure 3. FBE Web application content model schema.

The practical lesson learned was that five main ingredients were needed: (i) "in house" experts to design, develop, train and test; (ii) health and social professionals to test FBE in the real-world care practice and provide feedback; (iii) patients who accepted to take part in the first field trials; (iv) methodological pillars in order to describe functioning and disability: and (v) one assessment protocol searching for "disabilities" as negative interactions or negative. The ICF provides a complete descriptive framework for all aspects of human functioning. Nonetheless, decisions about scope and coverage are essential, unavoidable, and have a profound effect on the usefulness of resulting data [11]. Thanks to the FBE development process, some proposals were submitted to WHO in order to operationalize the concepts of "disability" and "functioning" respectively as a "negative interaction" and a "positive interaction" between an individual and his/her environment [12]. Using the ICF in specialty settings may require to focus on a particular range and granularity of ICF codes. Main efforts were addressed in selecting subsets of categories [10] with low attention to the granularity of the ICF EFs component. According to the mapping to the ICF of many nomenclatures realized by FBE, a list of proposals was set up for updating the EFs component of ICF and ICF–CY [12]. Finally, data from national researches show that "although components of the ICF were identified across all data sources, the extent to which they were operationalised and the nature of their use differed greatly. Our aim is to compare data collected in different regions and countries in a standard way by using FBE. A new field trial was scheduled in 2012 in order to test and release a final product. The FBE alpha version works in Italian and was adapted to the Italian welfare system/services/policies, but an international version working in other languages/welfare systems can be designed.

References

[1]   National Institutes of Health National Center for Research Resources. Electronic Health Records Overview, 2006
[2]   Frattura L, Bassi G, Simoncello A, Bazzo G. ICF implementation in regional policies: the case of the Friuli Venezia Giulia Region, Italy , WHO-FIC Network annual meeting, Cape Town, 29 October-4 November 20112011
[3]   http://www2.ohchr.org/english/law/disabilities-convention.htm (2012-01-30)
[4]   http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf (2012-01-30)
[5]   Organizzazione Mondiale della Sanità. ICF. 2002. Edizioni Erickson
[6]   http://www.reteclassificazioni.it (2012-01-30)
[7]   Francescutti C, Frattura L, Troiano R, Gongolo F, Martinuzzi, A, Sala M, Meucci P, Raggi A, Russo E, Buffoni M, Gorini G, Conclave M, Petrangeli A, Solipaca A, Leonardi M. Towards a common disability assessment framework : theoretical and methodological issues for providing public services and benefits using ICF. Disability and Rehabilitation 2009; 31 (S1): S8-S15
[8]   Francescutti C, Gongolo F, Simoncello A, Frattura L. Description of the person-environment interaction: methodological issues and empirical results of an Italian large-scale disability assessment study using an ICF-based protocol. BMC, 2011
[9]   Frattura L, Simoncello A, Bassi G, Soranzio A, Terreni S. Information systems learn to speak ICF. WHO-FIC Network annual meeting, 2011
[10] Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. BMC Public Health 2011, 11(Suppl 4):S3
[11] WHO/ESCAP. Training Manual on Disability Statistics, 2008
[12] Frattura L, Griffo G. Updating Annex 5: ICF, people with disabilities and UN CRPD. Implications for statistics and policies monitoring. WHO-FIC Network annual meeting, Cape Town, 29 October-4 November 2011