



## I CONTRIBUTI

**del Centro Collaboratore italiano  
dell'Organizzazione Mondiale della Sanità  
per la Famiglia delle Classificazioni Internazionali**

**WHO-FIC Network Annual Meeting:  
Improving Quality and Implementation**

13 to 19 october 2012 / Brasília, Brazil



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In reply please  
refer to: WHO FIC 2012

Lucilla Frattura  
Head, WHO-FIC Collaborating Centre  
Regional Health Administration  
330 Via Pozzuolo  
33100 Udine  
Italy

Your reference: WHO-FIC 2012

06 June 2012

Dear Dr Frattura,

**WHO Family of International Classifications (WHO-FIC) Network Meeting  
Brasilia, Brazil 13-19 October 2012**

I take great pleasure in inviting you and your centre's delegation to the next annual meeting of World Health Organization Family of International Classifications Network, which will take place in Brasilia, Brazil, from Saturday 13 to Friday 19 October 2012.

The meeting will be co-hosted by the Brazilian Ministry of Health, the Brazilian WHO Collaborating Centre for the International Classifications based at the School of Public Health of the University of Sao Paulo and the Pan American Health Organization (PAHO/AMRO). The Secretariat function will be carried out by WHO HQ Classifications, Terminology and Standards unit.

"Improving Quality and Implementation" has been identified as the main theme for this year's meeting. This includes the following sub-topics: definition of quality and assessment framework; how to measure data quality; what are the actions for improving the data quality? road map for improving implementation.

Please find attached the draft provisional agenda and timetable and a tentative list of participants. These will be updated in line with comments from the Small Executive Group (SEG) and yourselves after review by the Secretariat. Updates will be posted on the WHO web site.

The meeting venue is the Convention Centre Ulysses Guimares in Brasilia.

The website for the coordination of meeting registrations and accommodation reservations developed by our hosts will be activated in due course. It will provide all the details regarding general orientation and meeting facilities, as well as accommodation and social program reservation forms and procedures. The website will be accessed via hyperlink from our WHO FIC website:  
<http://www.who.int/classifications/network/meeting2012/en/index.html>

Registrations to the meeting are mandatory and should be made through the meeting web site

Each WHO Collaborating Centre is to be represented by two main delegates and as many alternates as you deem appropriate. However, we would like you to restrict the size of each team to no more than 5 members, unless responsibilities for the work program warrant a higher number. Please send an updated list of your delegation with full individual details (including email address) to Eva Foust (fouste@who.int) by 3 August 2012, and complete their registration through the web site by 1 September 2012 at the latest.

As per established practice, we understand that all costs of your and your team's participation will have to be borne by yourself or your organization.

This invitation is sent to you by e-mail. Should you require a regular copy, please inform us and we will send one for you and your team members accordingly.

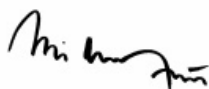
If you plan to submit a poster for the plenary poster session or for presentation in the committees or reference groups please use and follow the instructions in the attached poster profile and abstract form and the WHO web site at: <http://www.who.int/classifications/network/meeting2012/en/index.html>

The deadline for submitting the poster profile is 30 June 2012.

The deadline for submission of final posters is 1 September 2012.

If you require any further information regarding the meeting please do not hesitate to contact me and the members of the WHO-FIC Team. I am looking forward to meeting you in Brasilia.

Yours sincerely,



(Electronic signature)

Dr T. Bedirhan Üstün  
Coordinator  
Classifications, Terminologies and Standards  
Department of Health Statistics and Informatics

ENCLS.



## Composizione della delegazione 2012

### Lucilla Frattura

Italian WHO-FIC Collaborating Centre Head, Council (voting member), Update and Revision Committee (ICF voting member), Education and Implementation Committee (voting member), Family Development Committee (member)  
*Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine*

### Francesco Gongolo

Update and Revision Committee (co-chair and ICD voting member), Council (voting member), Functioning Topic Advisory Group (voting member)  
*Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine*

### Vincenzo Della Mea

Informatics and Terminology Committee (secretariat)  
*University of Udine, Dept Mathematics and Informatics*

### Andrea Martinuzzi

Functioning and Disability Reference Group (voting member)  
*"E. Medea" Scientific Institute, Conegliano Research Centre*

### Andrea Simoncello

Informatics and Terminology Committee (member)  
*Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine*

### Paula Tonel

Update and Revision Committee (ICF secretariat)  
*Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine*

I contributi sono scaricabili

- dal sito dell'Organizzazione Mondiale della Sanità  
(<http://www.who.int/classifications/network/meeting2012/en/index.html>)
- dal Portale Italiano delle Classificazioni previa registrazione  
(<http://www.reteclassificazioni.it>)



Building bridges for knowledge sharing:  
the performance monitoring plan of the Italian WHO-FIC  
Collaborating Centre

13 – 19 Oct 2012  
Brasilia, Brazil



C202

Lucilla Frattura & Francesco Gongolo on behalf of the WHO-FIC Italian collaborating centre’s network  
Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine

**Abstract** Moving from the 2011-2015 terms of reference of the Italian WHO-FIC Collaborating Centre, a performance monitoring plan (PMP) was defined in order to yearly assess the Centre’s performance. In the first year (21 July 2011-21 July 2012), the Italian WHO-FIC Collaborating Centre was active on five lines of work at international, national and regional level. A participative approach was chosen. Five main criteria were used. Few preliminary performance indicators were defined.

Introduction

Building solid knowledge bridges between workgroups and partners is crucial to distribute tasks, constructively review emerging issues, share results, and ultimately optimize the resources among different actors of a collaborative network. The aim of this work is to present the results of the monitoring of the Italian WHO-FIC Collaborating Centre’s activities, highlighting the bridges of knowledge among different activity areas.

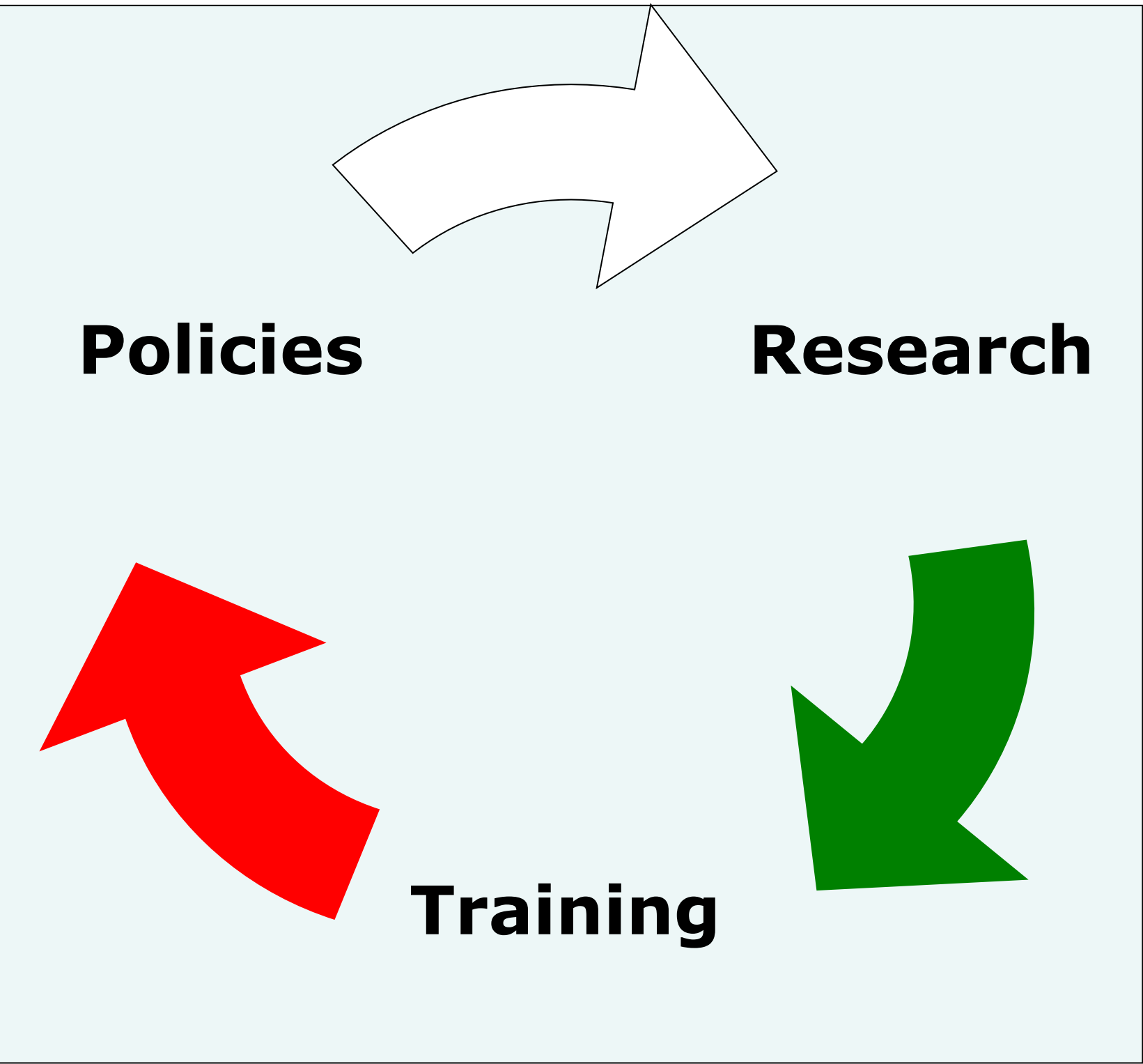
Methods & Materials

Moving from the 2011-2015 terms of reference of the Italian WHO-FIC Collaborating Centre (Table 1), a performance monitoring plan (PMP) was defined in order to yearly assess the Centre’s performance (Figure 1). An operating unit was established. A participative approach was chosen. Five main criteria were used: (1) adherence to the relevant lines of work of the WHO-FIC Strategic Work Plan (SWP); (ii) outcomes of the activities; (iii) new partnerships; (iv) communication power; and (v) resource consumption. Few preliminary performance indicators were defined.

Table 1 – The Italian WHO-FIC network

Institution designated as WHO-FIC CC:	Central Health Directorate, Classification Area, Friuli Venezia Giulia Region (Udine)
Research partners:	<ul style="list-style-type: none"><li>• ISTAT, Italian Institute of Statistics (Rome)</li><li>• Neurological Institute Carlo Besta Foundation (Milan)</li><li>• Eugenio Medea Clinical and Research Institute (Conegliano)</li><li>• University of Udine, Department of Mathematics and Computer Science</li><li>• University of Udine, Department of Economics and Statistics</li><li>• FISH, Italian Federation for overcoming handicap (Rome)</li></ul>

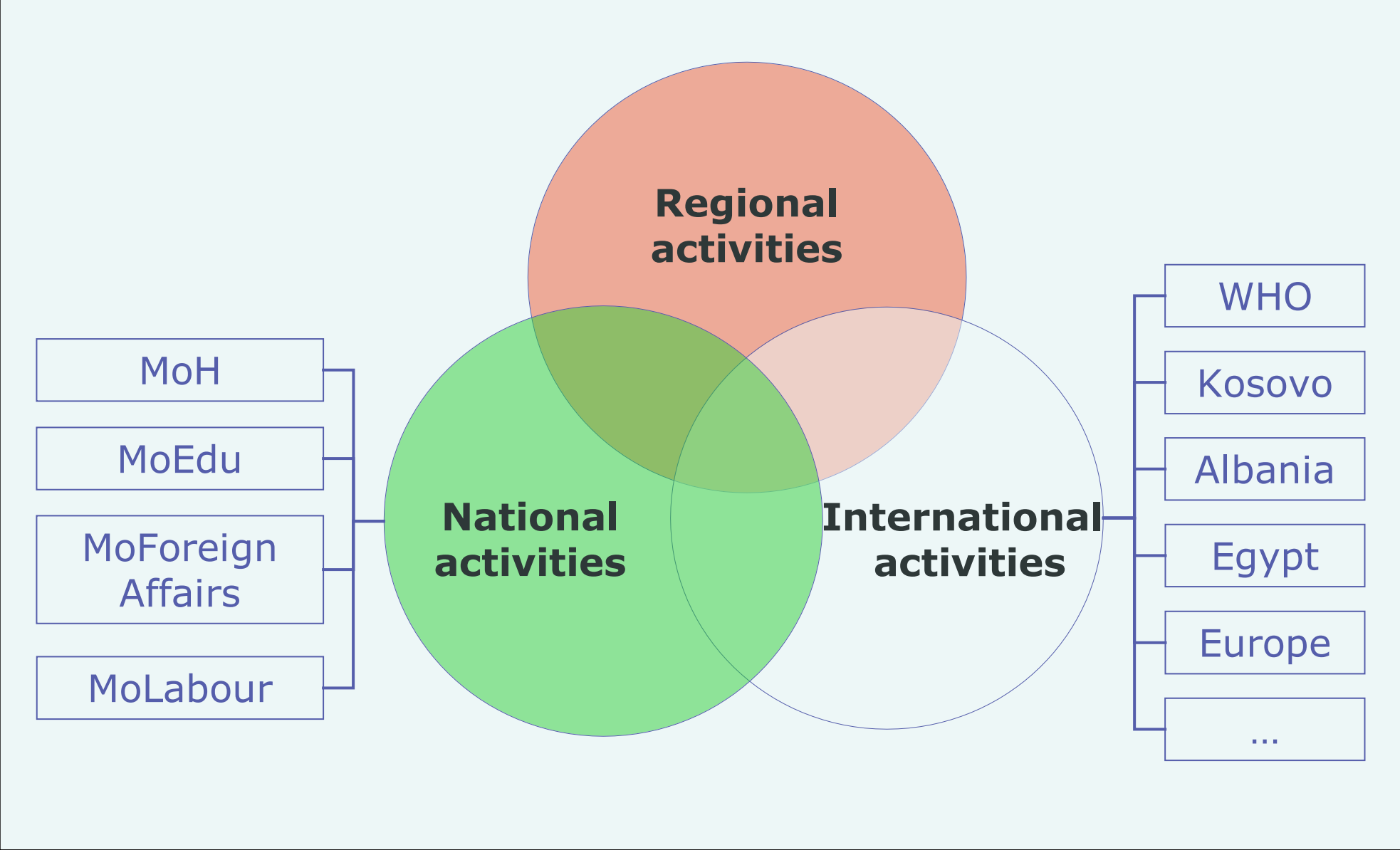
Figure 1 – The Italian CC’s approach to WHO-FIC



Results

In the first year (21 July 2011-21 July 2012), the Italian WHO-FIC Collaborating Centre was active on five lines of work at international, national and regional level: (i) revision of the International Classification of Diseases (ICD-11); (ii) IT and ontological development for WHO FIC; (iii) coordination and management of the ICD-10 and ICF update process; (iv) national work on WHO-FIC; (v) awareness building and implementation support of WHO-FIC in WHO regions (Figure 2).

Figure 2 – The Italian CC’s three levels of activities on WHO-FIC



All the activities were linked to the relevant lines of work of the SWP and to the related activity of the Collaborating Centre’s work plan. New partnerships were built between the Centre and Italian universities, scientific societies, and associations of persons with disabilities. The centre consolidated its role of knowledge broker in the WHO-FIC field, with particular regard to ICF implementation, at international, national and regional level (Figure 3). The communication power was evaluated considering papers, presentations, seminar and meeting organization, and active users of the Italian Portal of Classifications (Figures 4 and 5). The activities carried out at all levels by the Centre were possible thanks to the deep understanding by funders at local level.

Figure 3 – Some Italian CC «links» at the FDRG workshop in Udine, 27-29 June 2012



Conclusions

The adherence to the strategic work plan allows the identification of objectives, the definition of roles, and the sharing of results, under the scopes of the WHO and WHO-FIC network, thus realizing bridges of knowledge between institutions, enhancing the resources optimization, and reinforcing the role of the Centre itself as the interface between the international network on health classification and the implementation of regional, national, and international cooperation programs that the centre has the institutional mandate to coordinate.

Figure 4 – The Italian CC communication tool on WHO-FIC



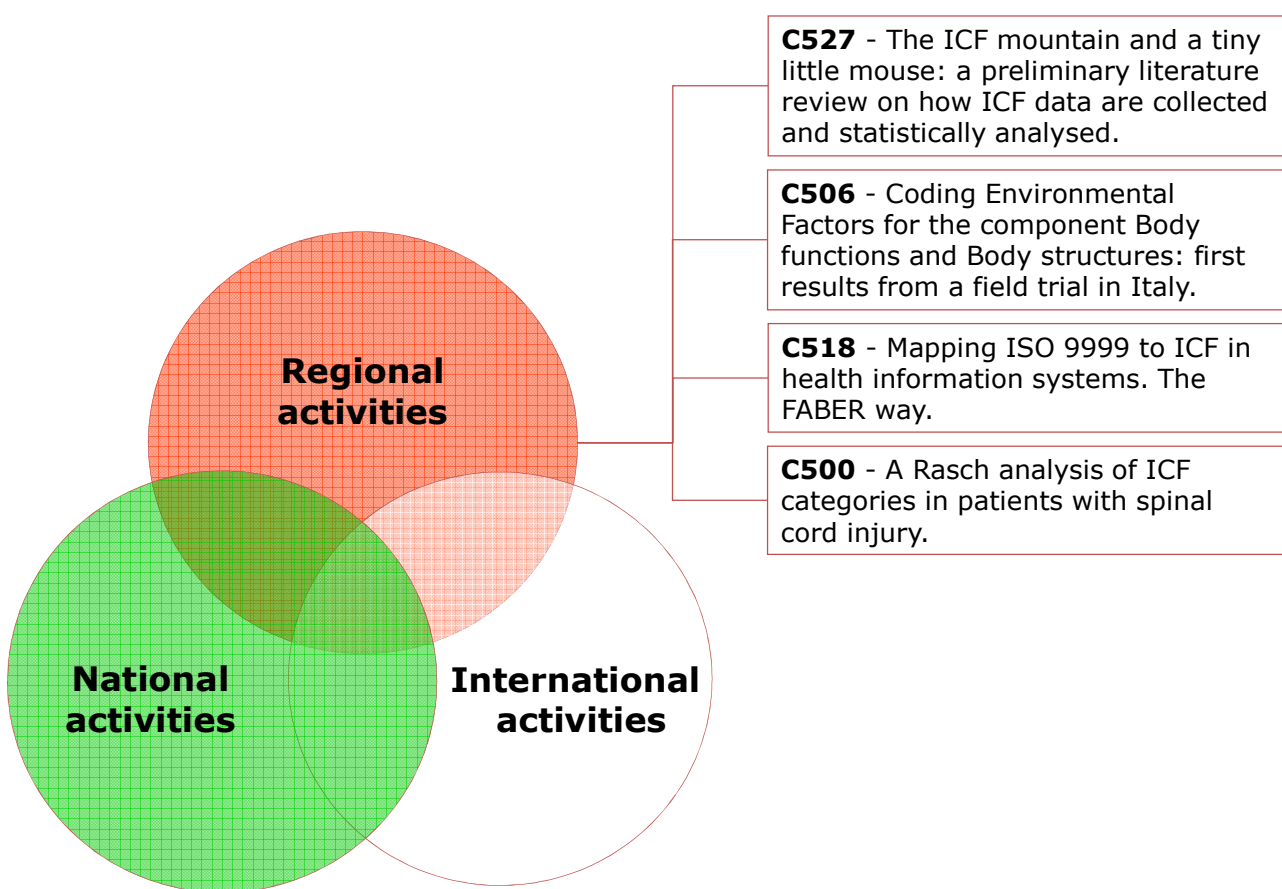
Figure 5 – The Italian flag published in the 2011 home page of the Italian Portal of Classifications - 150yrs Italian Unity celebration edition



Acknowledgements

Thanks are due to: Italian Ministry of Health for positive feedback and institutional support; Region Friuli Venezia Giulia for funding the Italian CC core of activities; Local Health Authority n. 5 Bassa Friulana for efficiently supporting management and administration; Insiel Spa for providing expertise in developing innovative tools using WHO-FIC.







Laura Rizzi (1), Lucilla Frattura (2), Sara Anzilutti (1), Michela Battauz (1)  
(1) University of Udine, Department of Economics and Statistics  
(2) Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine

**Abstract** In order to discuss how to analyze data aimed at describing functioning and disabilities using ICF, a preliminary study was carried out to review the statistical tools adopted in selected studies in relation to the results, design, and aims of the studies. Despite the great increase of contributions devoted to different ICF issues, the adoption of advanced statistical tools is not widespread.

Introduction

The number of articles relating to ICF is increasing since its release in 2001, both in journals and in books. A systematic literature review on the state of the art has been carried out by Jelsma (2009) [1], who considered 243 papers, and by Cerniauskaite et al. (2011) [2], who considered 672 papers. This analysis represents a selective literature review, not exhaustive, as it considers only contributions applying some statistical tool on ICF data, and devoted to give special emphasis to the quantitative approaches adopted. In order to discuss how to design epidemiological studies to describe functioning and disabilities using ICF, a preliminary study has been carried out to analyze the statistical tools adopted in selected studies in relation to the results, design, and aims of the studies.

Methods & Materials

Fifty-one papers were selected on the basis of the presence of some statistical data analysis applied to ICF data. The papers were from 21 different scientific journals but most of them (42%) were from Disability and Rehabilitation. Each paper was analyzed in order to describe the statistical methods adopted, considering separately descriptive tools and tests, correlation and heterogeneity measures, multivariate techniques, generalized and mixed models, and finally Rasch analysis.

Results

Most of the papers (33; 64.7%) presented mainly descriptive analyses, sometimes enhanced with parametric or non-parametric tests (12), correlation coefficients (6), or inter-rater agreement measures (2). They were published between 2003 and 2012 and generally considered cross sectional data (81%). Five papers (9.8%) introduced multivariate analysis techniques: confirmatory factor analysis to assess a theoretical model relating activities to domains of functions and ICF chapters; cluster analysis to define groups of people with common patterns of person-environment interaction or groups based on disability status to be compared with disease groups; and principal component analysis to derive a sub-component structure under the ICF broader context. Statistical models were used in 8 papers (15.7%), published from 2005 to 2012, displaying generalized linear models, sometimes extended to hierarchical or longitudinal data or to a non linear covariate effect (Table 1).

The choice of the statistical approach seems to be driven by the data structure ([3], [4], [5]) and not by the sample size (Table 1).

Table 1 - Statistical models applied with respect to the data structures

Statistical Tools Applied	Descriptive statistics - tests - correlation	Multi variate analysis	Statistical models	Rasch model
Min sample size	17	300	25	25
Max sample size	258.187	112.601	30.175	437
Median sample size	150,5	1.051	180,5	109

Finally, 5 papers (9.8%) were analyzed that considered Rasch analysis, together with other exploratory statistical methods, to assess the reliability of an ICF Core Set ([6] and [7]), to evaluate the metric of the qualifier scale, to test its possible use as a measuring tool ([8] and [9]), or to define groups of items according to the ICF framework [10]. The most adopted design study is characterized by cross-sectional datasets (Figure 1), which are generally analyzed through descriptive statistics and tests (65.1%), while longitudinal and panel data required mixed models in order to take account of the complex heterogeneity of observations (Figure 2 and Table 2).

Figure 1 - Distribution of the 51 papers by study design

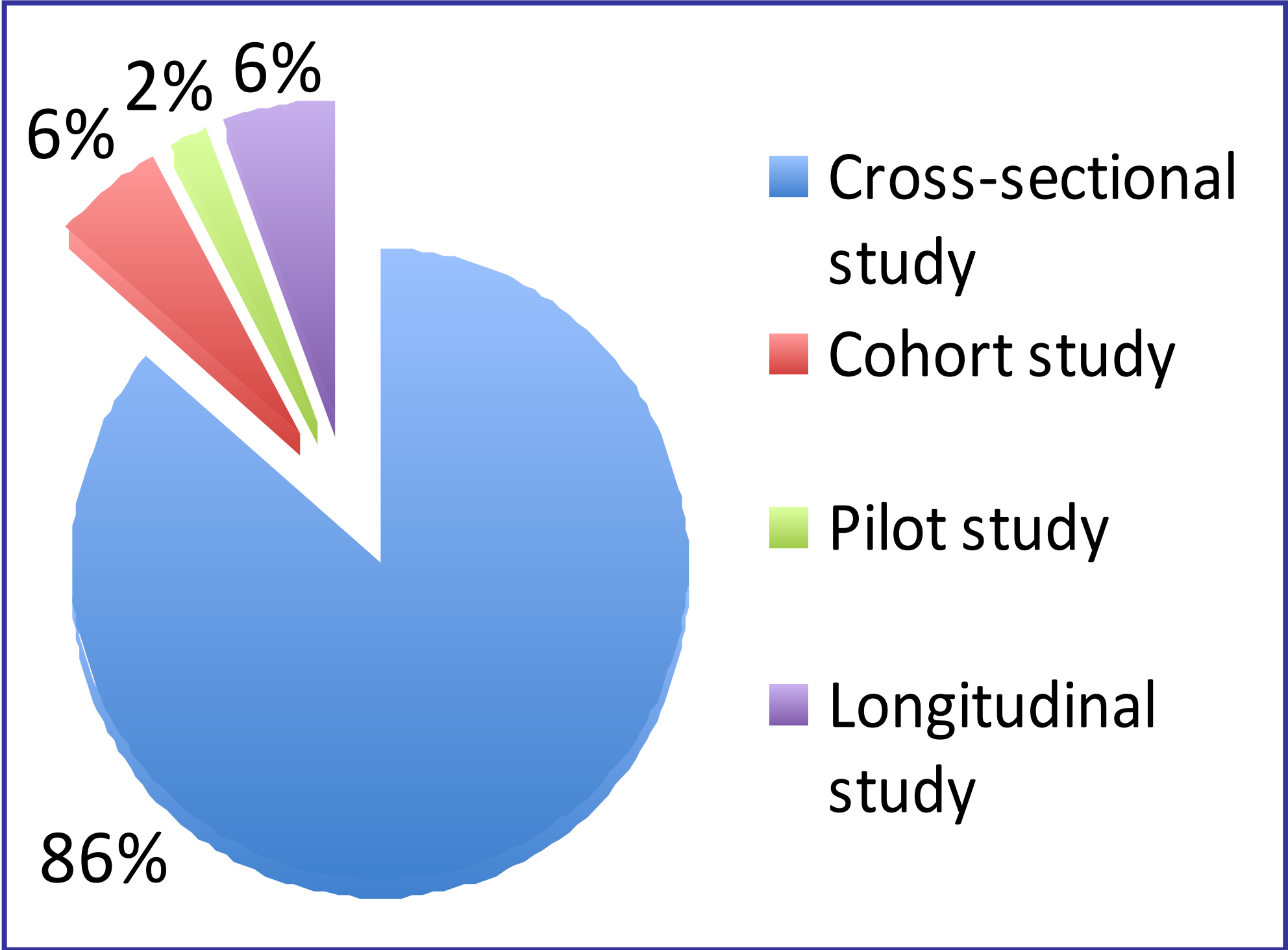
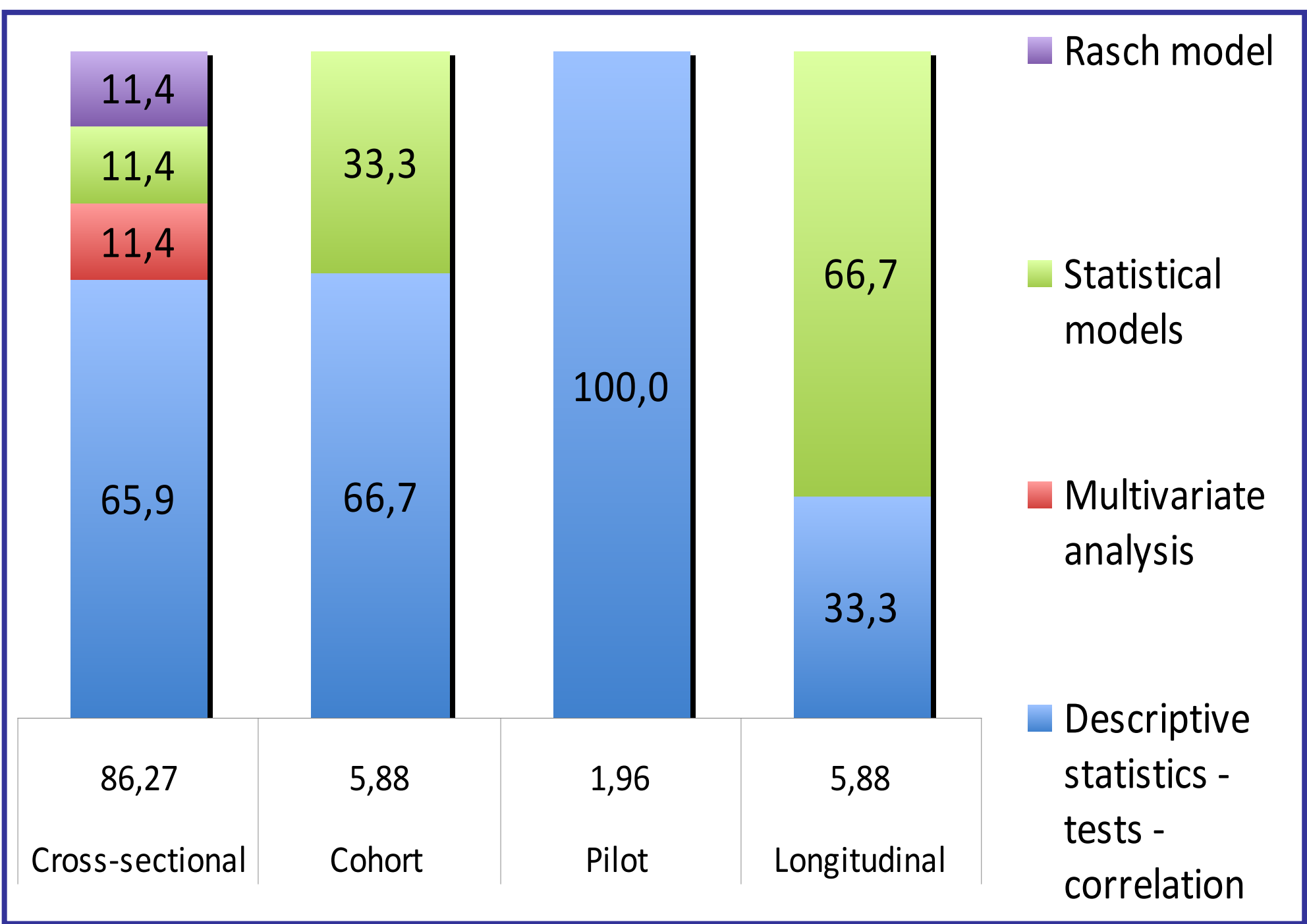


Figure 2 - Distribution of the 51 papers by study design and statistical tools



The five papers using Rasch analysis to explore reliability of the ICF as a tool to measure clinical conditions had a sample size ranging from 25 to 437 and performed also descriptive statistics and tests, sometimes together with PCA. Papers applying statistical models defined the approach on the basis of dataset structure as pointed out in Table 2.

Table 2 - Statistical models applied with respect to the data structure

Data structure		Statistical models applied
Simple	cross-sectional	logistic model
		multinomial logistic model
		linear regression with non linear coefficients
Complex	longitudinal	hierarchical linear and log-linear/multilevel regression models
	cohort	logistic model

All the contributions presenting advanced statistical approaches, displayed descriptive statistics and tests at an exploratory level.

Conclusions

Despite the great increase of contributions devoted to different ICF issues, the adoption of advanced statistical tools is not widespread. The lack of use of statistical models seems not to be due to a reduced sample dimension (the mean sample size results significantly smaller in studies displaying some advanced statistical model or Rasch analysis) but seems mainly related to the aims pursued and to the context of the analysis. When statistical models were used, the choice of the statistical approach was driven by the data structure.

References

1.Jelsma J. Use of the International classification of functioning, disability and health: a literature survey. J Rehabil Med, 2009; 41:1-12.  
2.Cerniauskaite M, Quintas R, Boldt C, Raggi A, et al. Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation. Disabil Rehabil., 2011; 33(4):281-309.  
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7.Kurtaiş Y. et al. Reliability, construct validity and measurement potential of the ICF comprehensive core set for osteoarthritis. BMC Musculoskeletal Disorders 2011, 12:255.  
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9.Cieza A. et al. The International Classification of Functioning, Disability and Health could be used to measure functioning. J Clin Epidemiol. 2009 Sep;62(9):899-911.  
10.Nilsson M.H. et al. Uncovering Indicators of the International Classification of Functioning, Disability, and Health from the 39-Item Parkinson's Disease Questionnaire. Parkinsons Dis. 2010.





Coding Environmental Factors for the component Body functions and Body structures:  
first results from a field trial in Italy.

13 – 19 Oct 2012  
Brasilia, Brazil

C506

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(1) Central Health Directorate, Classification Area, Friuli Venezia Giulia Region, IT WHO-FIC CC, Udine  
(2) University of Udine, Department of Economics and Statistics

**Abstract** This study provides a first exploratory analysis of a new EF coding approach, which allows to report EF also in relation to BF and BS categories in 213 subjects enrolled in the Friuli Venezia Giulia Region (Italy). The aim was to verify if this new coding opportunity is useful to describe “cared/treated” body versus “ill/impaired” body or “uncared/undercared/undertreated” body.

Introduction

According to the ICF, coding of Environmental Factors (EF) may be done following three coding conventions [1]. In this contribution the results of a novel approach is presented, i.e. coding EF for every item of Body Functions (BF) and Body Structures (BS). Being the first ICF qualifier a measure of the presence and extent (magnitude) of impairments, reporting EF in relation to BF and BS items allows to evaluate the interaction between a person with a health condition and the environment. The aim was to verify if this new coding opportunity is useful to describe “cared/treated” body versus “ill/impaired” body or “uncared/undercared/undertreated” body.

Methods & Materials

In 2011, a field trial was carried out in Friuli Venezia Giulia Region using a new ICF-based functioning/disability assessment protocol. The protocol included a paper form, a web application, an Informed Consensus form and a workflow [2]. The assessment protocol organized the collection of information useful to: analyse the interaction between the person and the environment in order to assess functioning and disability; evaluate the efficacy of the care plans using ICF-based data; make the tailored care planning more efficacious, thus overcoming the idea that the care plan is based on diagnosis. The protocol adopted the ICF and its version for children and youth (ICF-CY) both as a model of functioning/disability and as a descriptive language. The protocol was divided into two parts: the first part collected personal, socio-demographic, and treatment information; the second part organized ICF-based evaluation on all the three components. Environmental factors were coded in every BS, BF and Activity and Participation (AP) item [3]. After a preliminary description of the 213 sampled patients (see Table 1) and of measured impairments, the interest was devoted to the analysis of the most coded EF and their role in the impairment presence/extent.

Table 1 – Sociodemographic characteristics of the sample by group of patients

Groups of patients	Sample	% Female	% Occupied	% Living alone	% Married
GROUP 1 younger than 18 years	53	35,85	0	0	0
GROUP 2 in charge of MHS	51	43,13	11,76	41,18	9,8
GROUP 3 other patients	109	44.03	0	4,59	11
Total	213	78,98	11,76	45,77	20,8

In the analysis also 3 subsamples were considered separately: patients less than 18 years old (Group 1), patients in charge to mental health services (MHS) (Group 2) and the others (Group 3) (Table 1).

Results

Most of the patients were certified under Italian invalidity Laws, and in the everyday life activities they generally declared to need some help (patients requiring no help to dress up, to move, and to eat were 7%, 5.6%, and 9.8%, respectively). The coded BF categories were 354 in all the sample, 191 in group 1, and 156 in group 2. The most frequently coded BF category was b122 in the whole sample and in group 3, b140 in group 1, and b130 in group 2. The EF identified in relation to BF, BS, and A&P categories were 102. Some of the most frequently coded EF are reported in Table 2. While selecting the EF with counts over the 3<sup>rd</sup> quartile, 15, 6 and 25 EF were observed in relation to BF, BS and A&P categories, respectively.

Table 2 – Counts of the most coded EF

EF Chapters	BF Categories Counts	BS Categories Counts	A&P Categories Counts	Total
e310 immediate family	1054	27	3431	4512
e355 health care professionals	744	39	1477	2260
e110 products or substances for personal consumption	928	34	1083	2045
e575 general social support services, systems and policies	498	7	1609	2107
e580 health care services, systems and policies	479	66	1035	1580

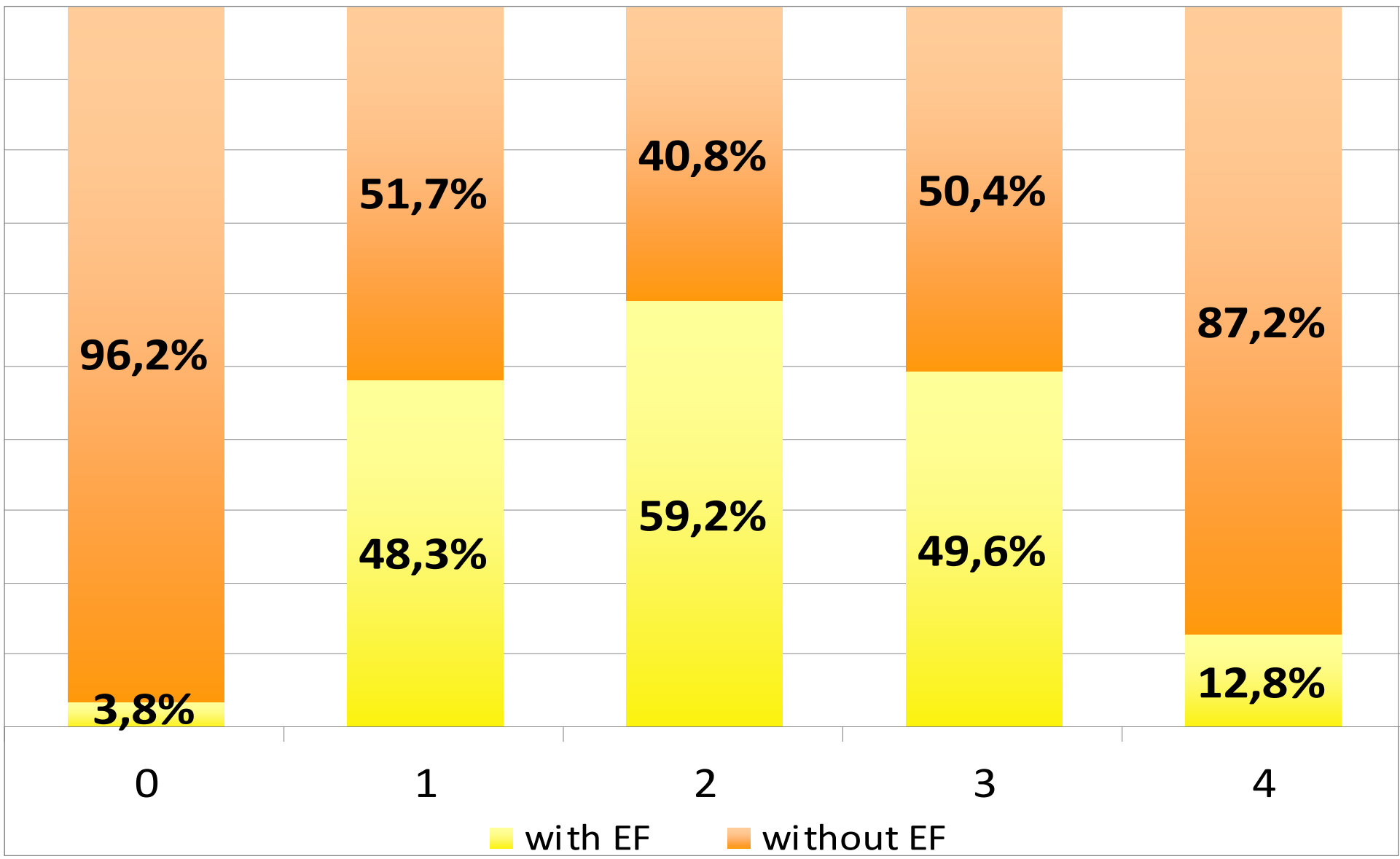
In Table 3 the EF counts as facilitators or barriers are shown.

Table 3 – EF Counts as facilitators or barriers, by EF chapter

EF chapters	Counts as facilitators	Counts as barriers	Total
e1	1327	105	1432
e2	5	7	12
e3	2694	152	2846
e4	56	53	109
e5	1172	9	1181
Total	5254	326	5580

The analysis of the role of the EF in the extent of the BF impairments was also deepened by comparing the distribution of the qualifier values (0, 1, 2, 3, 4) and the presence/absence of coded EF (Figure 1).

Figure 1 – Distribution of BF categories by qualifier value and EF presence



The same trend in the EF coding across qualifiers values was reproduced in all BF coded categories. The EF categories of e1 and e3 chapters were cited as barriers only in 7% and 5% of cases in the BF coded items, and in 2% and 3% of cases in the BS coded items. The e2 categories were coded as barriers in 58% of cases, while the e4 categories were coded as barriers in 49% and 100% of cases in BF and BS coded items, respectively. In Table 4, the percentage of times the EF chapters are coded as barriers in the BF categories is shown by group.

Table 4 - % of EF counts as barriers, by group of patients

EF chapters related to BF categories	% counts as barriers in group 1	% counts as barriers in group 2	% counts as barriers in group 3
e1	2	11	6
e2	50	100	0
e3	52	10	3
e4	45	55	33
e5	0	2	2

Conclusions

This study provides a first exploratory analysis of a new EF coding approach, which allows to report EF also in relation to BF and BS categories. This novelty allows a deep analysis of the role of environmental factors in the BF and BS items describing the individual’s health condition. The presence of some EF codes was heterogeneous across the qualifiers values describing the severity of impairment, with less EF registered where no BF/BS impairment (qualifier 0) was registered. The e1, e3, and e5 categories were generally facilitators in relation to BF and BS coded items, while e4 category more frequently represented a barrier. The BF and BF first qualifier construct (impairment) might be clarified, taking into account the role of EF, in order to describe “cared/treated” body or “uncared/undercared/untreated” body.

References

1. WHO, ICF International Classification of Functioning, Disability and Health. Geneva, 2001  
2. Frattura et al, Health information systems learn to speak ICF: Toward electronic ICF-based individual records, Who-FIC Network Annual Meeting, Cape Town 2011  
3. Frattura et al, ICF implementation in regional policies: the case of the Friuli Venezia Giulia Region, Italy, Who-FIC Network Annual Meeting, Cape Town 2011



Mapping ISO 9999 to ICF in health information systems.  
The FABER way.

13 – 19 Oct 2012  
Brasilia, Brazil



C518

**Abstract** The Italian WHO-FIC CC has developed a web application (FABER) using ICF and other medical terminology systems as a basis for a flexible standards-based electronic bio-psycho-social record. This poster presents the results of the one to many mapping of ISO 9999 to ICF as the solution used by FABER aimed at saving the double need to use the ICF as a standard language and to preserve the ISO 9999 granularity of information.

Introduction

The Italian WHO-FIC CC has developed a web application (FABER, previously named FBE) using ICF and other medical terminology systems as a basis for a flexible standards-based electronic bio-psycho-social record (1)(2). To create a suitable bio-psycho-social lexicon, information was aligned with a terminology collection containing ICF (3), ISO 9999 (4), national nomenclatures of medical products, and social and health intervention vocabulary. This poster presents the results of the one to many mapping of ISO9999 to ICF as the solution used by FABER aimed at saving the double need to use the ICF as a standard language and to preserve the ISO 9999 granularity of information.

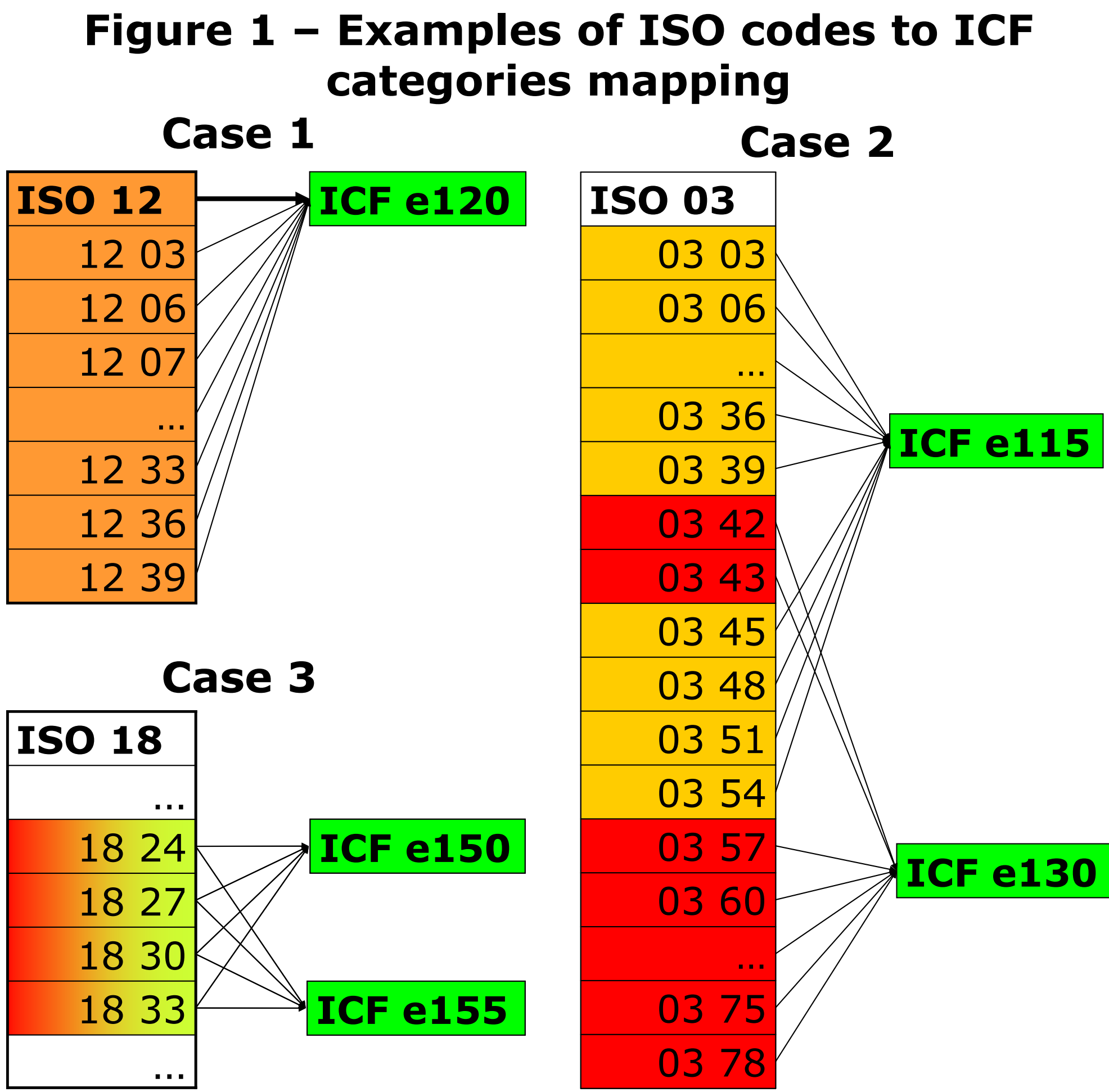
Methods & Materials

A one to many mapping was performed between the three digit categories of ICF Environmental Factors (EF) Chapter 1 and ISO9999 classes and subclasses. The work was based on the ISO9999-1998 Italian version, as adopted by law in our Country. The mapping of ISO 9999 classification to ICF categories from chapter e1 follows mainly semantic rules. ISO 9999 classification is based on the main function of the products being classified. The ISO 9999 classes were compared with the semantic content of the titles and definitions (including inclusions and exclusions) of ICF categories from chapter e1. In case of ambiguity of ISO 999 classes, the ISO 9999 subclasses and divisions were considered. Firstly, the ISO 9999 classes were analysed, starting from the name and, if necessary, from the definition or explanatory note and/or reference, following rule 5.4.1 of ISO 9999 classification, which states that “a class is equal to the sum of its subclasses and a subclass is equal to the sum of its divisions”. This means that if the mapping of a term was not clearly expressed, the mapping of the higher class or subclass has to be considered. When an ISO 9999 class was mapped to more than one ICF category, its subclasses were analysed; the same was done with the ISO 9999 divisions.

Results

Four cases occurred (Figure 1):  
1. the semantic correspondences between ISO 9999 classes (subclasses and divisions) and ICF categories from chapter e1 are evident, so a ONE TO ONE mapping is explicit. For example, ISO 9999 class 12 “Assistive products for personal mobility” can be mapped to ICF category e120 “Products and technology for personal indoor and outdoor mobility and transportation”.

2. the ISO 9999 classes contain subclasses that can be semantically mapped to different ICF categories. For example, ISO 9999 class 03 “Ausili per terapia e addestramento”, which in general terms can be matched with ICF category e115 “Products and technology for personal use in daily life”, contains subclasses that can be mapped to ICF category e130 “Products and technology for education”.
3. one particular case is that of ISO 9999 class 18 “Furnishings and adaptations to homes and other premises”. This class has subclasses that do not exhibit a univocal correspondence with ICF. In fact, ICF makes a distinction between buildings for public use (e150) and buildings for private use (e155), thus it uses two categories. For this reason, we decided to map ISO 9999 terms with both ICF categories.



4. Not all ICF e1 categories were mapped to ISO 9999; furthermore, implantable medical devices, not present in the ISO 9999 but described by other reference terminologies (eg. GMDN - Global Medical Device Nomenclature; Italian CND – National Classification of medical Devices)(5) (6), had already been mapped to the e115 ICF category.

A total amount of 841 ISO 9999 classes were mapped to 8 ICF categories (Table 1). The final mapping is presented by FABER appending the ISO9999 label and code to the ICF code (Table 2).

Table 1 – Results of mapping ISO9999 to ICF

ICF category	ISO 9999 classes	Number (%) of overall ISO codes
e115	03, 06, 09, 15, 18, 21, 24, 27, 30	500 (59,5)
e120	12, 18	98 (11,7)
e125	21	125 (14,9)
e130	03	64 (7,6)
e135	24, 27	13 (1,5)
e140	30	21 (2,5)
e150	18	20 (2,4)
e155		
N=8	N=10	841 (100)

Table 2 – Examples of the Faber way of mapping

e115	Assistive products for administering medicines (ISO 03 18)
e120	Wheelchairs (ISO 12 21)
e125	Assistive products for seeing (ISO 21 03)
e130	Assistive products for training in the arts (ISO 03 69)
e135	Industrial transportation vehicles (ISO 24 39)
e140	Musical instruments (ISO 30 12)
e150	Assistive products for vertical accessibility (ISO 18 30)
e155	Construction elements in the home and other premises (ISO 18 24)

Conclusions

In order to describe functioning and disability of a person with a health condition, it is fundamental to collect detailed information about the environment in which he or she lives. Products and Technology listed in the chapter 1 of ICF EF do not assure a precise description of the specific products involved in functioning, due to their poor granularity compared to standard terminologies in use. These standards, adopted by laws and regulations, represent a highly inertial use case with the consequent risk of shadowing the descriptive potential of the ICF. The mapping of ISO 9999 to ICF has not been validated yet by domain experts. However, it has allowed to save the information generated by the use of well-known nomenclatures currently used by Italian health-care workers and to translate them into ICF language. This has been achieved by applying simple mapping rules into information systems. FABER expands the ICF chapter 1, combining redundancy (the same ICF category is replicated many times) and preciseness (the same ICF category is enriched by the specific ISO 9999 code). At the same time, two diverse standards are used jointly and synergically. There are aspects of the use of multiple terminologies and classifications in FABER that deserve further study. One possible development is to create the mapping using the ISO 9999-2011 version (7), given the its backward compatibility. There is also the necessity to describe the built environment, which at the moment is not described by standard nomenclatures or terminologies.

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7. ISO. 2011. ISO 9999 Assistive products for persons with disability – Classification and terminology. Geneva: International Organization for Standardization.



**Abstract** ICF data were analysed in order to obtain a measure of functioning for patients with chronic spinal cord injury. Analysis was performed through the Rasch partial credit model. Principal components analysis on residuals was used to assess the unidimensionality of the scale and the presence of differential item functioning was tested. Results show that ICF may be useful to measure the “ability to execute an action” considering the capacity qualifier.

Introduction

The ICF Core Sets represent condition-specific selections of categories from the whole classification, which can be used as a minimal standard for reporting functioning and health status [1]. A Core Set also exists for chronic spinal cord injury (SCI) [2]. The literature shows promising results on the construction of clinical measures of functioning by applying the Rasch model to ICF categories for various core sets, such as those for osteoarthritis [3], low back pain [4] and rheumatoid arthritis [5]. Nevertheless, the results are ambiguous about the qualifiers analysed. This study aims to investigate the applicability of the Rasch model to the analysis of data collected using the Brief ICF Core Set for SCI in order to obtain a measure of functioning for patients with Chronic SCI.

Methods & Materials

Data from 52 consecutive chronic SCI patients who regularly received care and rehabilitation therapy at an extensive rehabilitation centre of the regional Spinal Unit Department in Friuli Venezia Giulia were examined [6] . The sample was interviewed in 2011 using a subset of the ICF Core Set for SCI with some additional categories. The 32 A&P categories selected are shown in Table 2. The Rasch partial credit model [7] was applied only to the capacity qualifier in *Activity and Participation* domains, being the application to the performance qualifier not methodologically straightforward. Principal components analysis (PCA) on the residuals of the model was used to assess the unidimensionality of the scale, and presence of differential item functioning (DIF) was tested by sex, age, and types of paralysis (tetraplegia and paraplegia). Rasch analyses were conducted using the WinSteps Software [8]. The variables considered in the analysis were: sex, age, duration of SCI, type of injury (traumatic/non traumatic), ASIA score and type of paralysis (tetraplegia/paraplegia); the ICF categories were considered as *items* in the Rasch analysis. Table 1 shows the descriptive analysis of the sample.

Table 1 - Descriptive analysis of the sample			
	Total	F	M
N (%)	52 (100)	38 (73,08)	14 (23,92)
Mean age (sd)	54,27 (14,95)	54,11 (15,43)	57,71 (14,11)
Mean duration of SCI (sd)	17,96 (12,28)	18,26 (12,98)	17,14 (10,53)
Traumatic injury	41 (78,45)	33 (80,49)	8 (19,51)
Tetraplegia	23 (44,23)	20 (86,96)	3 (13,04)
Paraplegia	29 (55,77)	18 (62,07)	11 (37,93)
ASIA A	34 (65,39)	26 (76,47%)	8 (23,53)
ASIA B	4 (7,69)	1 (25)	3 (75)
ASIA C	14 (26,92)	11 (78,57)	3 (21,43)

Results

The categories related to walking and moving (d4500, d4501, d4502, d4503, d4600, d4601, d4602) were excluded from the analysis because almost all subjects presented the .4 capacity qualifier value, making these categories not informative for the Rasch analysis. The PCA were applied to the remaining 25 A&P categories. The PCA indicated the presence of two different constructs (first eigenvalue=5.3). The first construct represents Self-care (positive loading values in Table 2) and the second construct represents Relationships and the social and civil life (negative loading values in Table 2).

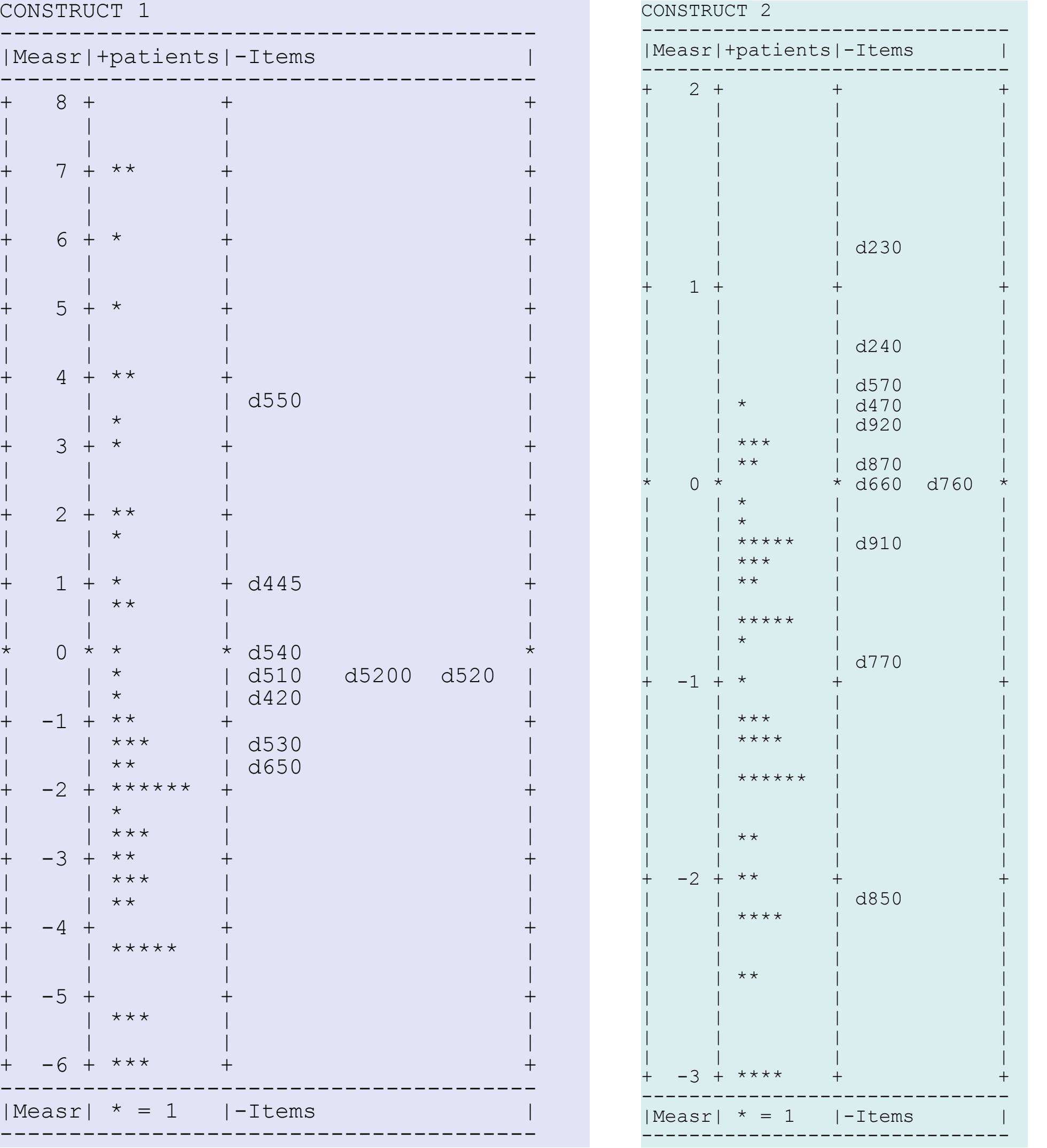
Table 2 – ICF A&P Categories used for the SCI sample and loadings of the first principal component

Group/Construct 1		Group/Construct 2	
Item	Loading	Item	Loading
d510	0.77	d570	-0.64
d540	0.75	d770	-0.58
d420	0.69	d910	-0.56
d520	0.58	d760	-0.53
d445	0.52	d660	-0.49
d5200	0.52	d240	-0.47
d550	0.46	d920	-0.40
d530	0.45	d230	-0.39
d410	0.23	d850	-0.34
d470	0.18	d870	-0.08
d9201	0.06	d475	-0.04
d650	0.04	d465	-0.02
d360	0.02		

All the A&P categories were divided into two groups according to the PCA and separate Rasch analyses were conducted (Table 2). The categories d360, d410 and d9201 did not fit the model and were excluded. Only 4 A&P categories showed DIF and then they were split into different items. The item d445 was split into two items according to the variable “type of paralysis”; the items d850, d770 and d570 were split respectively into two items for the variable “age”. The person reliability index was 0.95 for the first group and 0.77 for the second. These results allow to derive, for each individual, reliable and synthetic measures of “ability to execute an action”, representing a quantitative counterpart of the capacity dimension described by the qualified categories of the ICF Core Set. Figure 1 shows the distribution of the “ability to execute an action” and of the “difficulty to execute an action” for the two constructs, Self-care and Relationships and the social and civil life.

Each star represents a patient and is located in correspondence with his/her level of ability. The ICF categories are located in correspondence with their level of difficulty to execute an action. In the upper part of the Figure are located the easiest items and the less able subjects.

Figure 1. Distribution of the measures of “ability to execute an action” and of “difficulty to execute an action” for the two constructs.



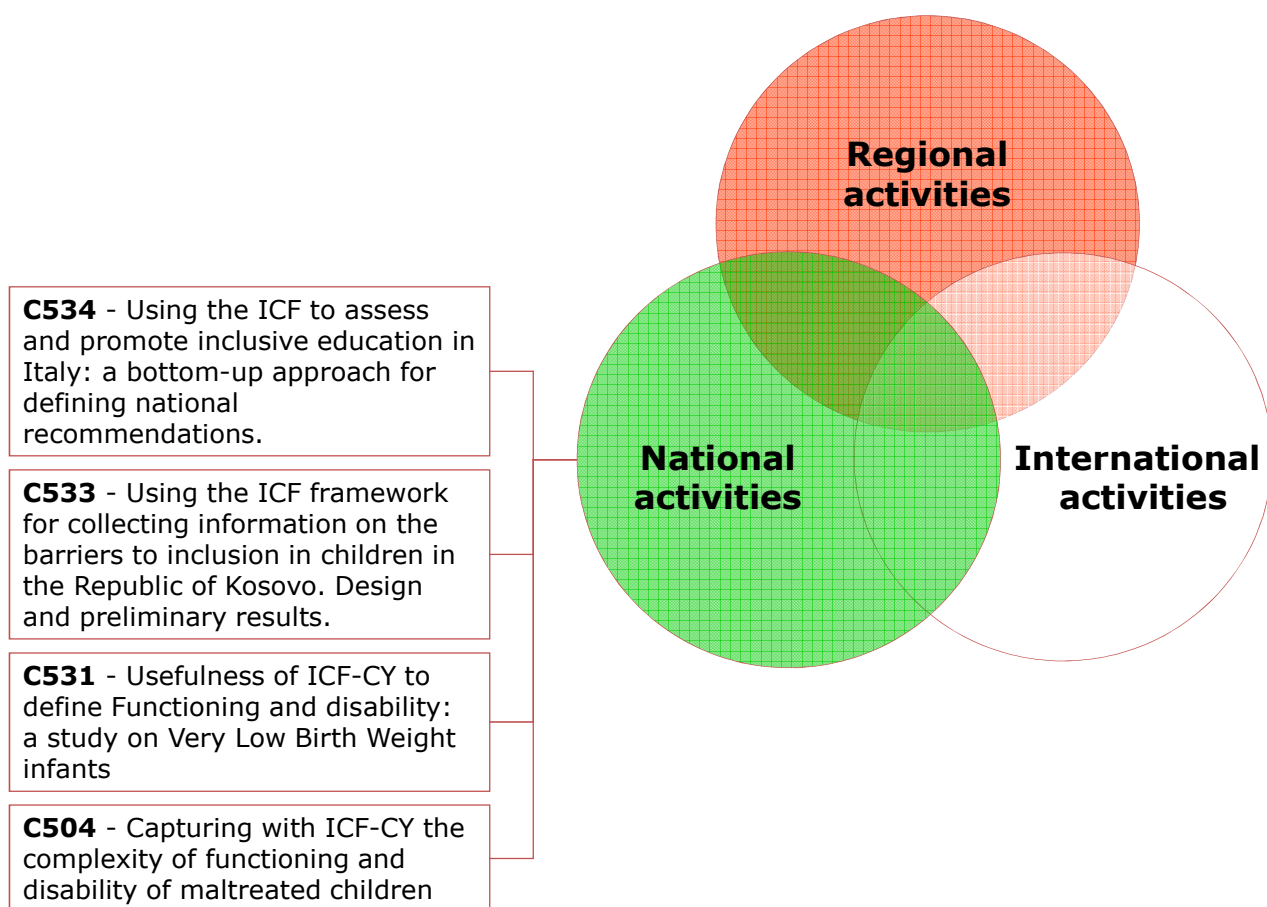
Conclusions

The Rasch analysis indicates that the ICF core set used may be useful to measure the “ability to execute an action” (quoting the ICF explanation of the capacity construct) in A&P domains of SCI patients and supports the usefulness of the ICF in clinical practice. The extension of the model to the performance qualifier represents at the moment a methodological challenge. The heterogeneity of item difficulties across persons is not considered in the Rasch model, whereas the ICF performance qualifier is influenced by different environmental factors, which may act either as barriers or as facilitators and vary across subjects.

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# Using the ICF to assess and promote inclusive education in Italy: a bottom-up approach for defining national recommendations.

13 – 19 Oct 2012  
Brasilia, Brazil

Lucilla Frattura (1), Raffaele Ciambrone (2), Giovanni Simoneschi (2),  
on behalf of the "ICF Technical Group" at Italian MEUR

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C534

**Abstract** The ICF Project is a national two-year programme financed by the Italian Ministry of Education, University and Research (MEUR) aimed at collecting inputs to recommend how to use ICF, especially in order to identify educational barriers and facilitators in participation. 91 projects were selected for funding. The mid-term monitoring results are presented.

## Introduction

The ICF Project is a national two-year programme that began in 2010 and is scheduled to end in December 2012. It is financed by the Italian Ministry of Education, University and Research (MEUR) with a budget of 1.7 million euro. It built on the ICARE initiative, piloted from 2007 to 2009. A national call was launched in 2010 by the MEUR for partnerships between schools/universities and other agencies, mainly local health authorities and social services.

The aim was to support the use of ICF in the assessment of educational environments for their ability to accommodate diverse student populations and facilitate participation for all children.

The goal was to collect inputs to recommend how to use ICF, especially in order to identify educational barriers and facilitators in participation.

This paper presents some results of the project mid-term evaluation (1).

## Methods & Materials

544 projects were submitted, coming from all the twenty Italian administrative regions; of these 95 were selected and funded. In May 2012, monitoring was carried out to verify the state of the art of each project and the usefulness of ICF in assessing the goodness of fit between environment and diverse students.

Information was collected using an ad-hoc self-reported questionnaire divided into three parts: Part 1 comprised general information about the partnership; Part 2 collected information about the assessment of the educational environment using ICF; and Part 3 explored the relationships between ICF-based assessment and individual educational plan. A database was created and a descriptive analysis was performed in order to manage the schools' answers.

## Results

Data of Parts 1 and 2 of the questionnaire were considered from 91 projects. 4,430 personnel were involved (75% were teachers).

The great majority of the project networks comprised local health authorities too. In 75% of the projects, "contexts" other than the educational one were analyzed, mainly the health services context and the social services context.

70% of the schools believed that the ICF terms were sufficient and suitable to describe the educational setting. 65% of the schools utilized third level ICF categories. Existing ICF checklists were used in one third of the projects, while ad-hoc checklists were created in another third (Figure 1).

Figure 1 – Usage of ICF checklists

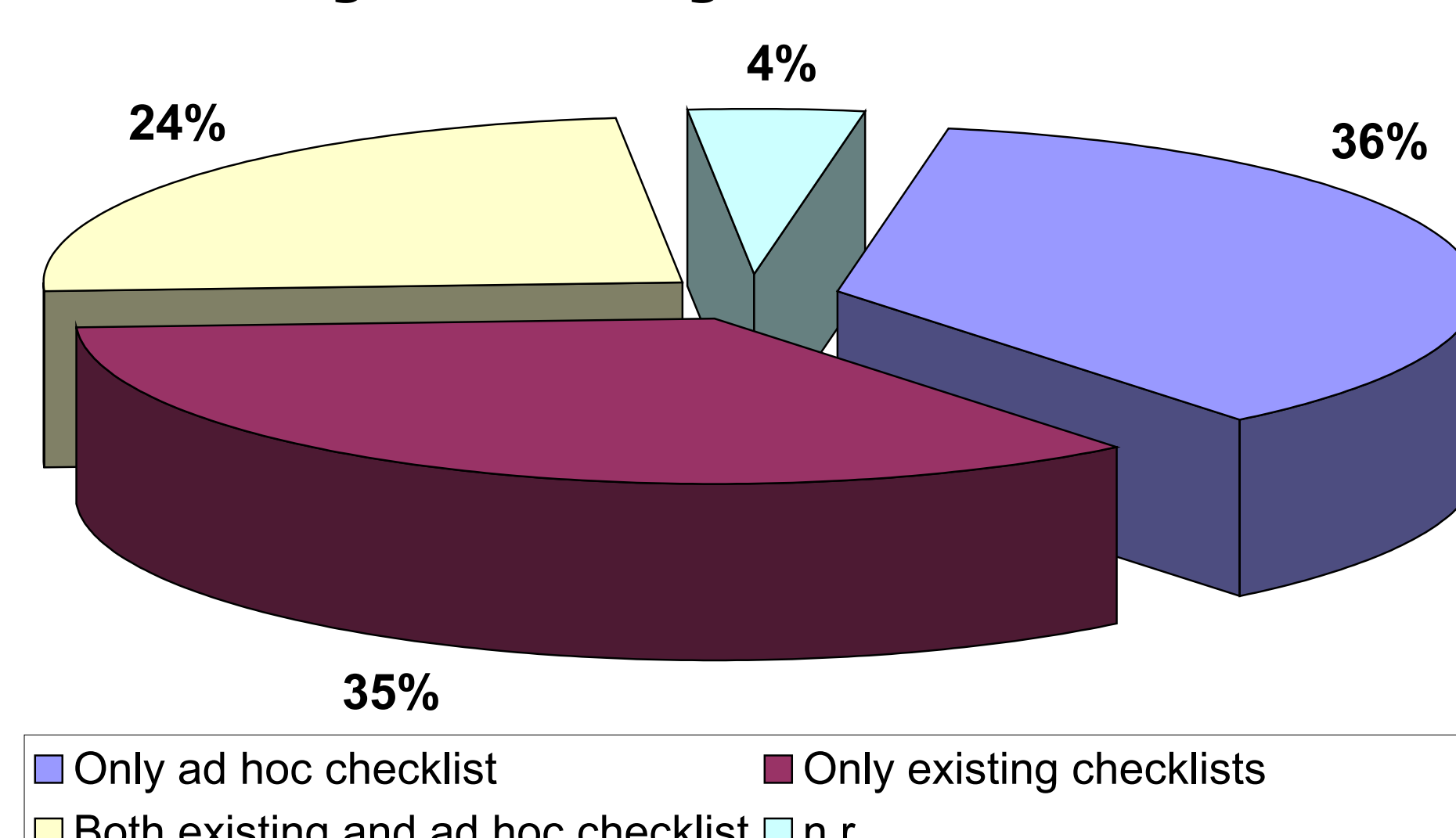
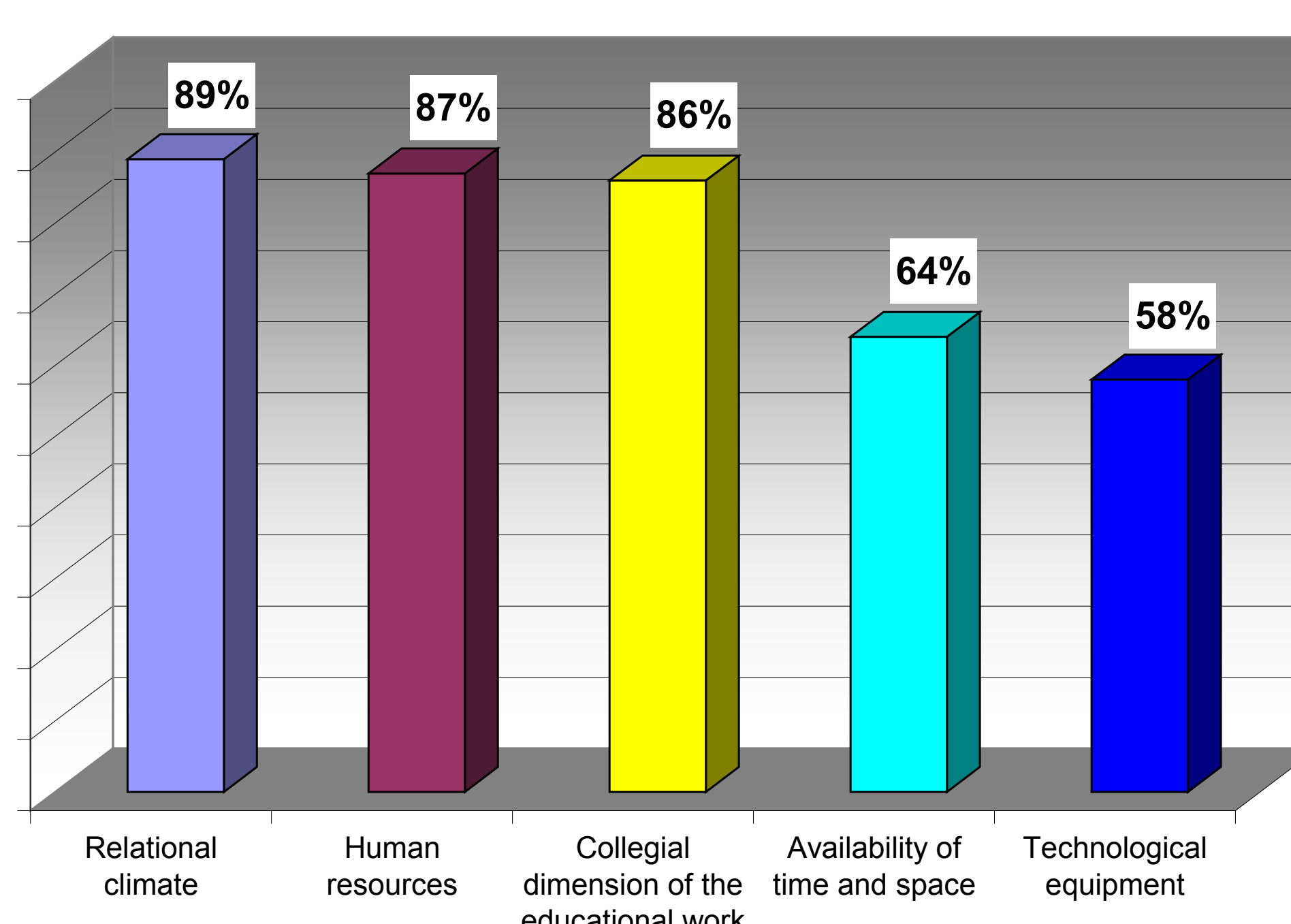


Figure 2 – Environmental factors considered for describing educational settings



*Qualifiers were used very frequently:* the first qualifier for body functions and body structure was used in 73% of the cases; performance and capacity, as well as facilitator and barrier qualifiers, were used in 93% and 96% of the projects, respectively. The great majority of the schools stated that *environmental factors* were evaluated jointly to the performance qualifier.

Figure 3– Pupils/Students' point of view in detecting barriers and facilitators

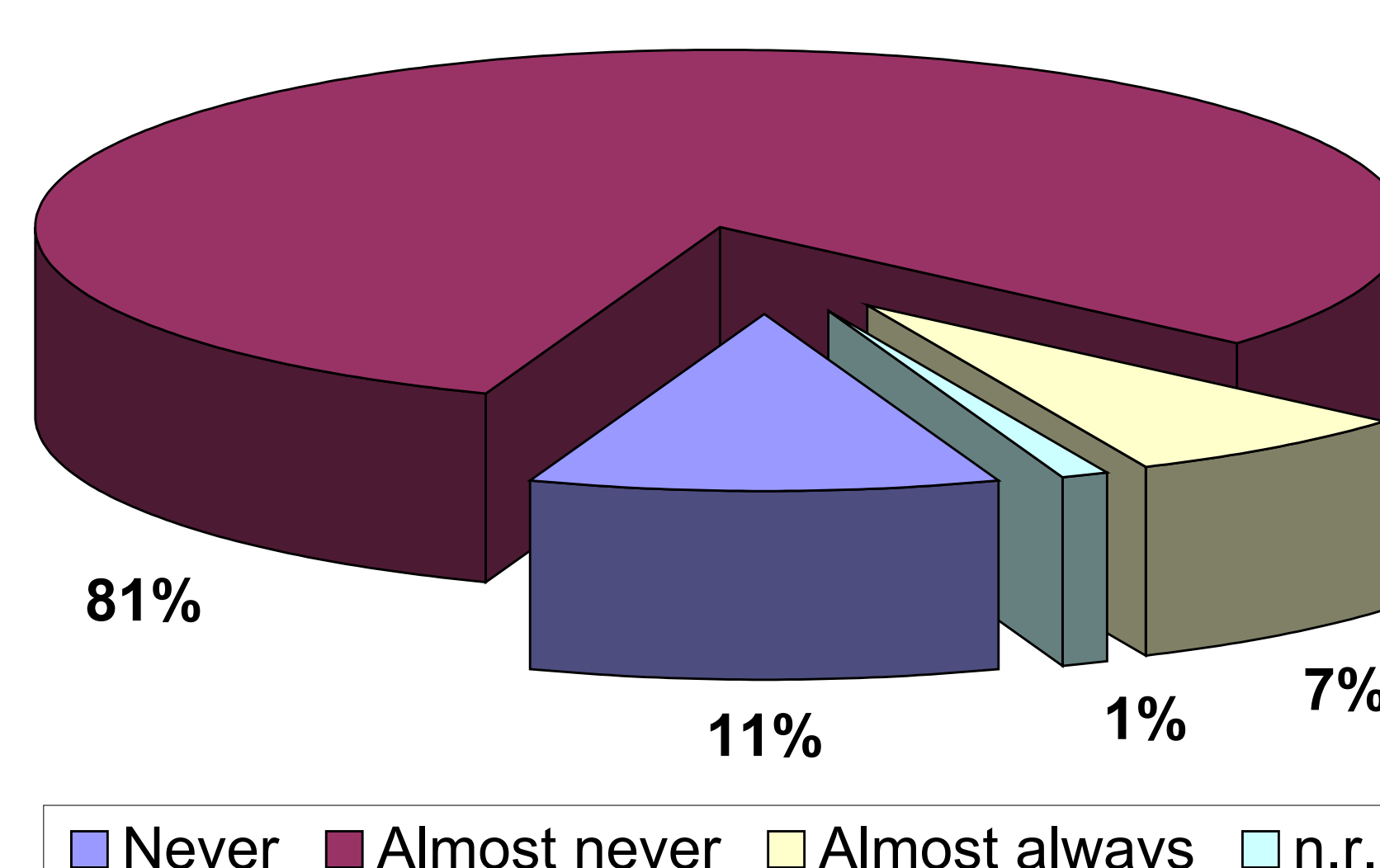
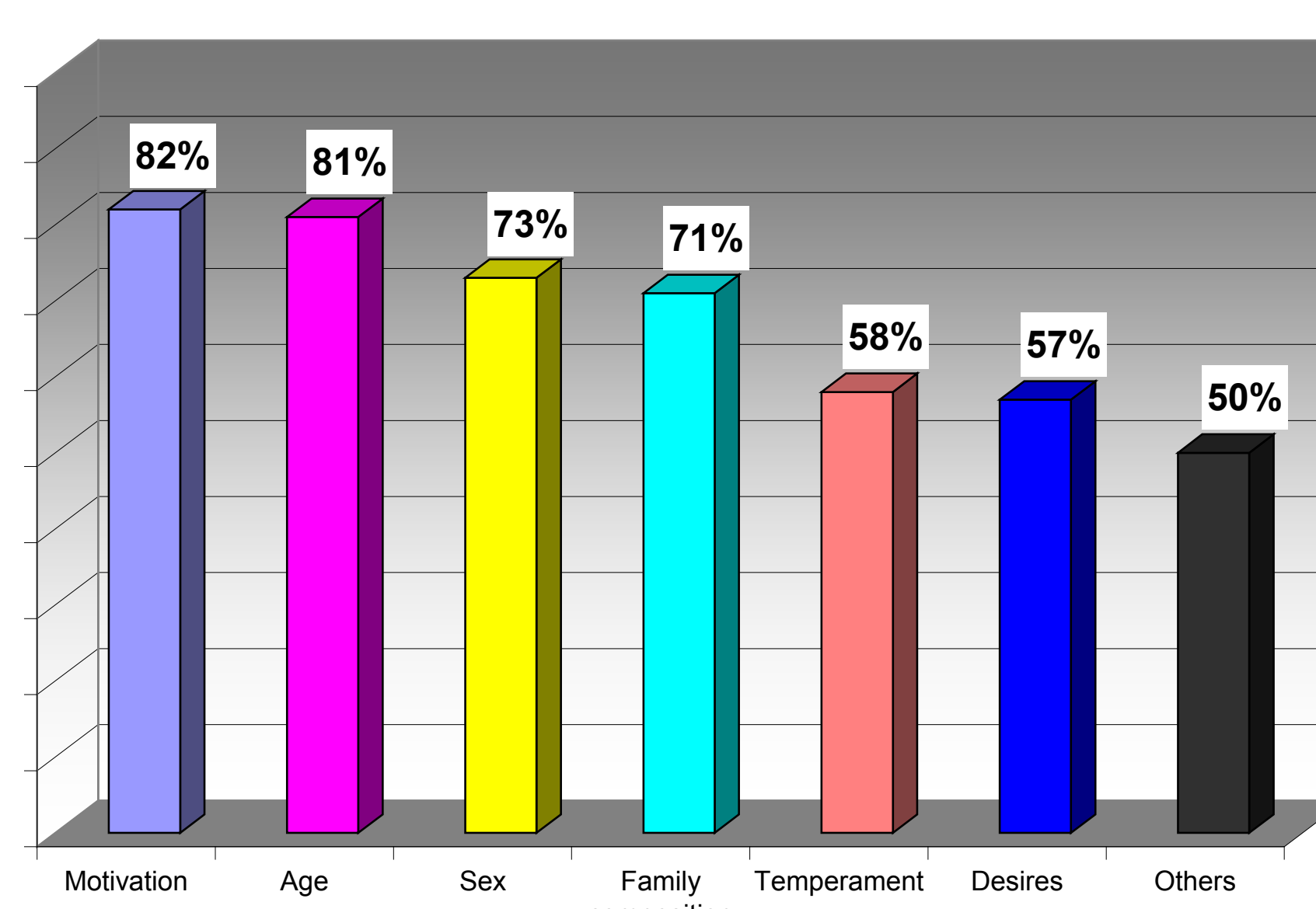


Figure 4 – Personal factors considered for describing students (N=91 projects)



The *child point of view* was used to assess the environmental factors effect in half of the projects, while the family point of view was considered in 81% of them (Figure 3). The *personal factors* were recorded in natural language. Sex (73%), age (81%), family composition (71%), personal attitude (58%), motivation (82%), and desires (57%) were the most common personal factors considered (Figure 4).

## Conclusions

The goal of inclusive education has been part of the Italian agenda in the field of equity in education for several years. According to a study by OECD, 99.5% of students with disabilities are fully included in mainstream education in Italy (OECD, 2004). Since its publication, ICF has been used in Italy as an excellent conceptual framework helpful in promoting the quality of inclusive educational environments for diverse students. The national project aims at supporting the use of ICF in order to meliorate the inclusive capacity of the Italian school system. Some suggestions arising from the mid-term evaluation are useful to delineate national recommendations for using ICF profitably. These recommendations will be published in December 2012.

In the meanwhile, in July 2012, MEUR signed an agreement with the Italian Ministry of Health in order to adopt the ICF framework for eligibility purposes (2).

## ICF Technical Group at MEUR

**MEUR staff**, Unit VII, DG Student, integration, participation and communication: **Raffaele Ciambrone** (Chair, Director Unit VII,), **Mirella Della Concordia Basso**, **Guido Dell'Acqua** (high school Mathematics teacher), **Maria Rita Lolli**, **Antonella Mancaniello** (Gymnastics teacher), **Giovanni Simoneschi** (high school Philosophy teacher). **External staff**: **Serenella Besio** (Chief, Education Dept, Valle d'Aosta University, Aosta), **Sabrina Boarelli** (Chief, Umbria Regional MEUR Department, Perugia) **Lucia Cajola Chiappetta** (Professor, Roma Tre University, Rome), **Italo Fiorin** (Professor, LUMSA University, Rome), **Lucilla Frattura** (Head, Italian WHO-FIC CC, Udine), **Pasquale Pardi** (Co-Chair, Past Director Unit VII, DG Student, integration, participation and communication, MEUR, Rome), **Mario Rusconi** (Director, Newton Scientific High School, Rome; Vice President, Italian School Directors' Association)

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## Acknowledgements

Thanks are due to Giovanni Bassi and Andrea Simoncello at the Italian WHO-FIC Collaborating Centre for realizing the midterm evaluation database and supporting the descriptive analysis.



# Using the ICF framework for collecting information on the barriers to inclusion in children in the Republic of Kosovo.

13 – 19 Oct 2012  
Brasilia, Brazil

## Design and preliminary results.

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(1) Italian Ministry of Foreign Affairs, Italian Development Cooperation (2) Republic of Kosovo, National Disability Action Plan Project (3) Friuli Venezia Giulia Region, Central Health Directorate, Classification Area, IT WHO-FIC CC, Udine (4) Republic of Kosovo, Directorate of Health and Social Welfare (5) Republic of Kosovo, Directorate of Education (6) HandiKOS Gjilan (7) University of Udine, Department of Statistics



C533

**Abstract** The Italian Development Cooperation has been intervening in Kosovo in the area of inclusion of persons with disability since 2008, supporting the Development of the first National Action Plan. In 2010, a new initiative was launched in partnership with the Office of Good Governance and the Municipality of Gjilan, where pilot activities were undertaken in order to promote an integrated approach to inclusion. The paper presents the preliminary results about the effort made in cooperation with the Italian WHO-FIC collaborating center to collect data on children with disabilities in the Municipality of Gjilan (around 100,000 inhabitants).

### Introduction

The Italian Development Cooperation has been intervening in Kosovo in the area of inclusion of persons with disability since 2008, supporting the Development of the first National Action Plan (1).

In 2010, a new initiative was launched in partnership with the Office of Good Governance and the Municipality of Gjilan, where pilot activities were undertaken in order to promote an integrated approach to inclusion. Awareness of the 2006 UN Convention on Persons with Disability and the WHO Classification on Functioning, Disability and Health (ICF) was built in cooperation with the Italian WHO-FIC collaborating center (2).

The main obstacle for rational planning is the lack of information on persons with disability.

At Municipality level, information is scanty and fragmented, partially gathered by local chapters of the NGO HandiKOS (2011). According to the European Commission 2011 Progress Report, in 2008 Kosovo had a population of 2,153,000 (3): 346,000 were students, more than 1,000 of whom identified as children with special needs and attending regular schools (in so called attached classes) or special schools. In the same year, according to Unicef, an estimated 10,000 children did not attend school: 7,000 of them were children with special needs (4).

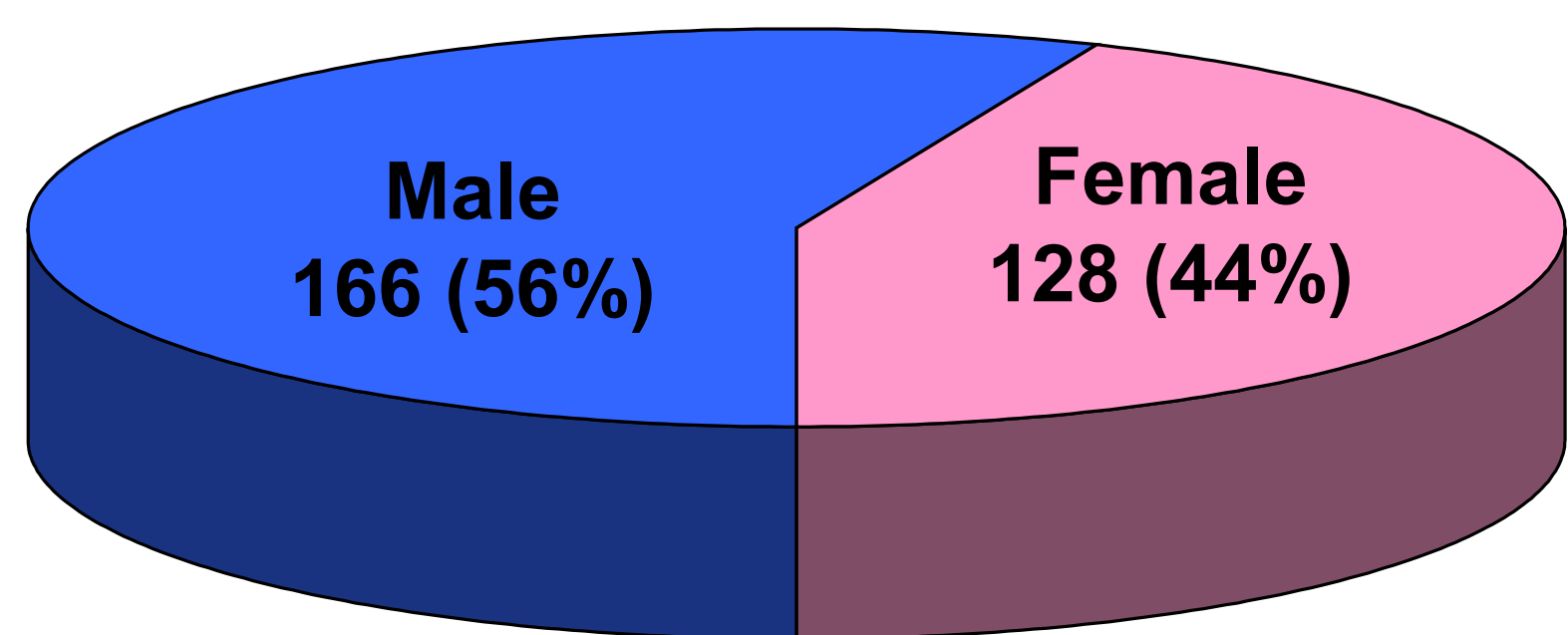
The high proportion of school-age children in the population and the characteristics of the education system as far as inclusion is concerned, have driven the attention of the study group on this particular age group. This paper presents the preliminary results of the effort to collect data on children with disabilities in the Municipality of Gjilan (around 100,000 inhabitants).

### Methods & Materials

A descriptive study was designed in order to provide a profile of children with disability, barriers faced in accessing education, health and social services, existing support network, and economic impact of the disease on their families.

A questionnaire was set up to collect information on different areas using the ICF framework. The interviewers were selected. The data collection started on 7 August 2012.

**Table 1 – Sample Gender**

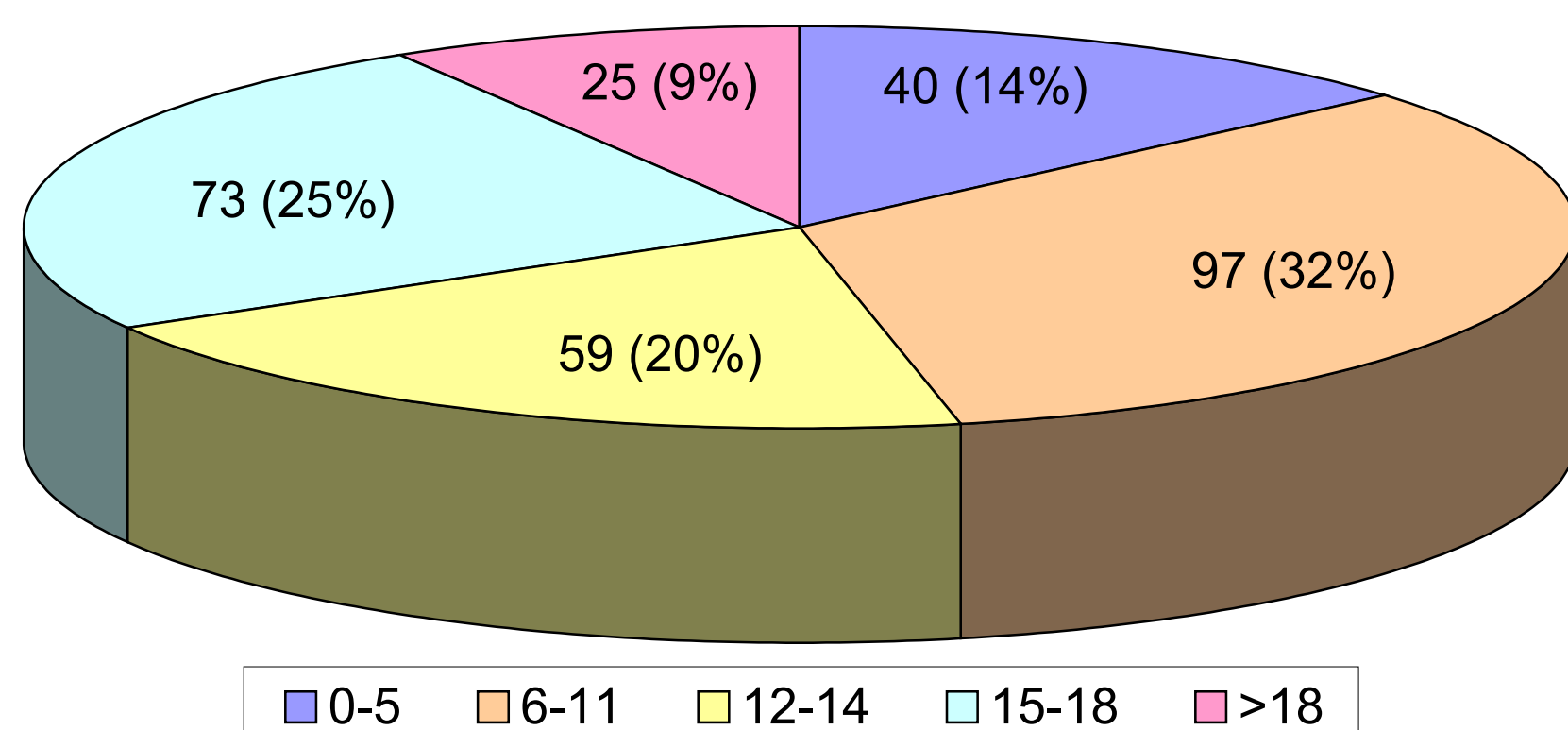


### Results

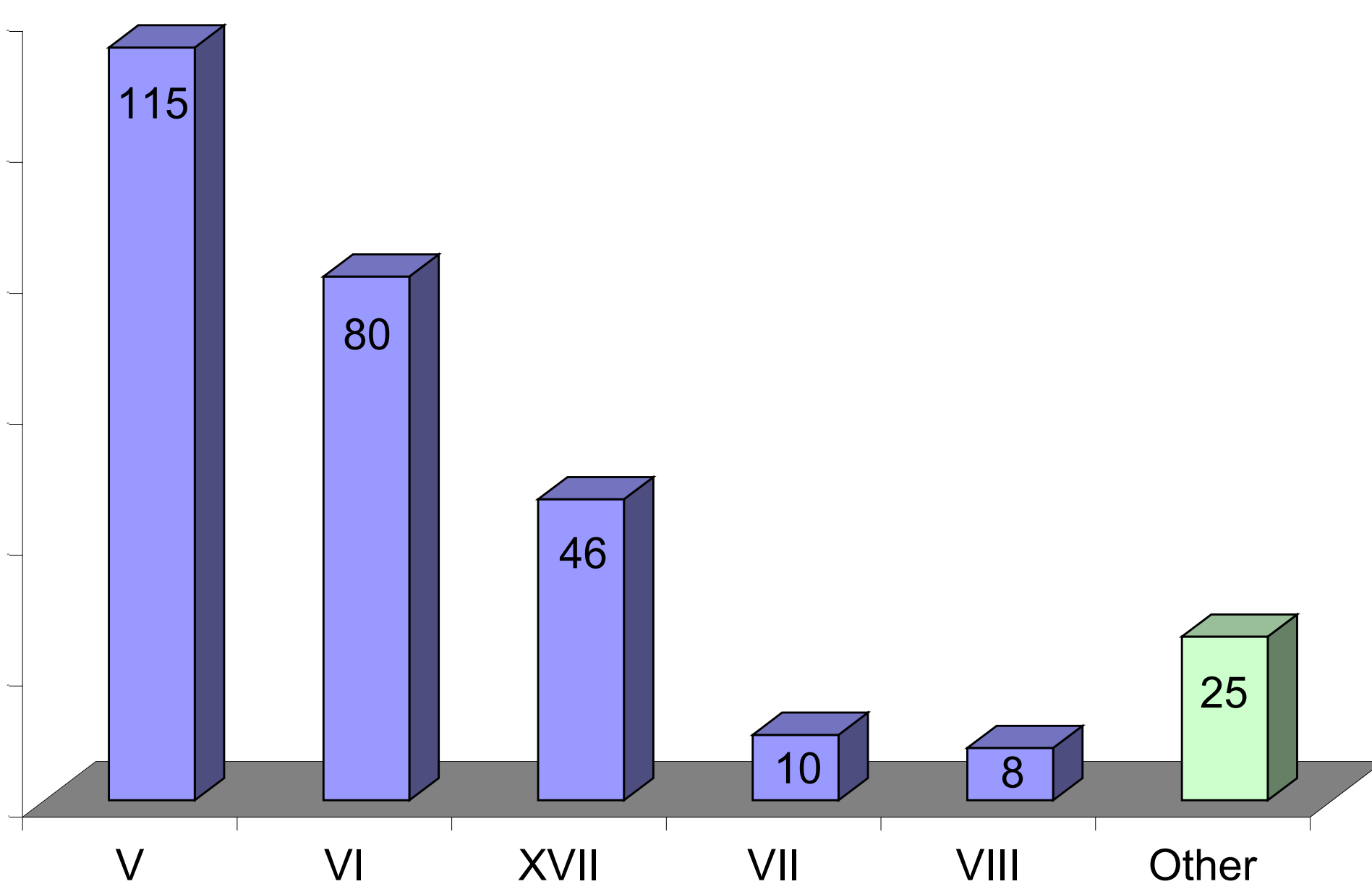
The sample was selected with the support of local institutions. It included 322 children whose families had applied, from July 2009 to March 2012, to the Commission for benefits granted by the Material Support Law (100 Euros a month).

56% of the children were males (Table 1). One third was 6-12 years old. 59 children with disability were attending local schools; of these, 40 are still on material benefits, whereas some have already been moved to an other category, which means a lower benefit (45 Euros). As per Table 4, information on the diagnosis was collected from the final reports of the Commission for disability assessment: the diagnosis was defined only in 59% of the sample (CC), 28% had no diagnosis at all (ND), and 14% had an unreadable or incorrect diagnosis (TBS). Diagnoses were coded ex post by the Authors using ICD-10. The most frequent diagnoses pertained to ICD chapter V (39.4%), chapter VI (27.4%) and XVII (15.8%). This is consistent with the results of the Broad Survey of Persons with Disabilities in Kosovo (2011), which reported, among persons with disabilities aged 0-18 years, "Intellectual or learning disability" in 55% of the sample, and "Psychological or Emotional disorders" in 49% of the cases.

**Table 2 – Sample Age**

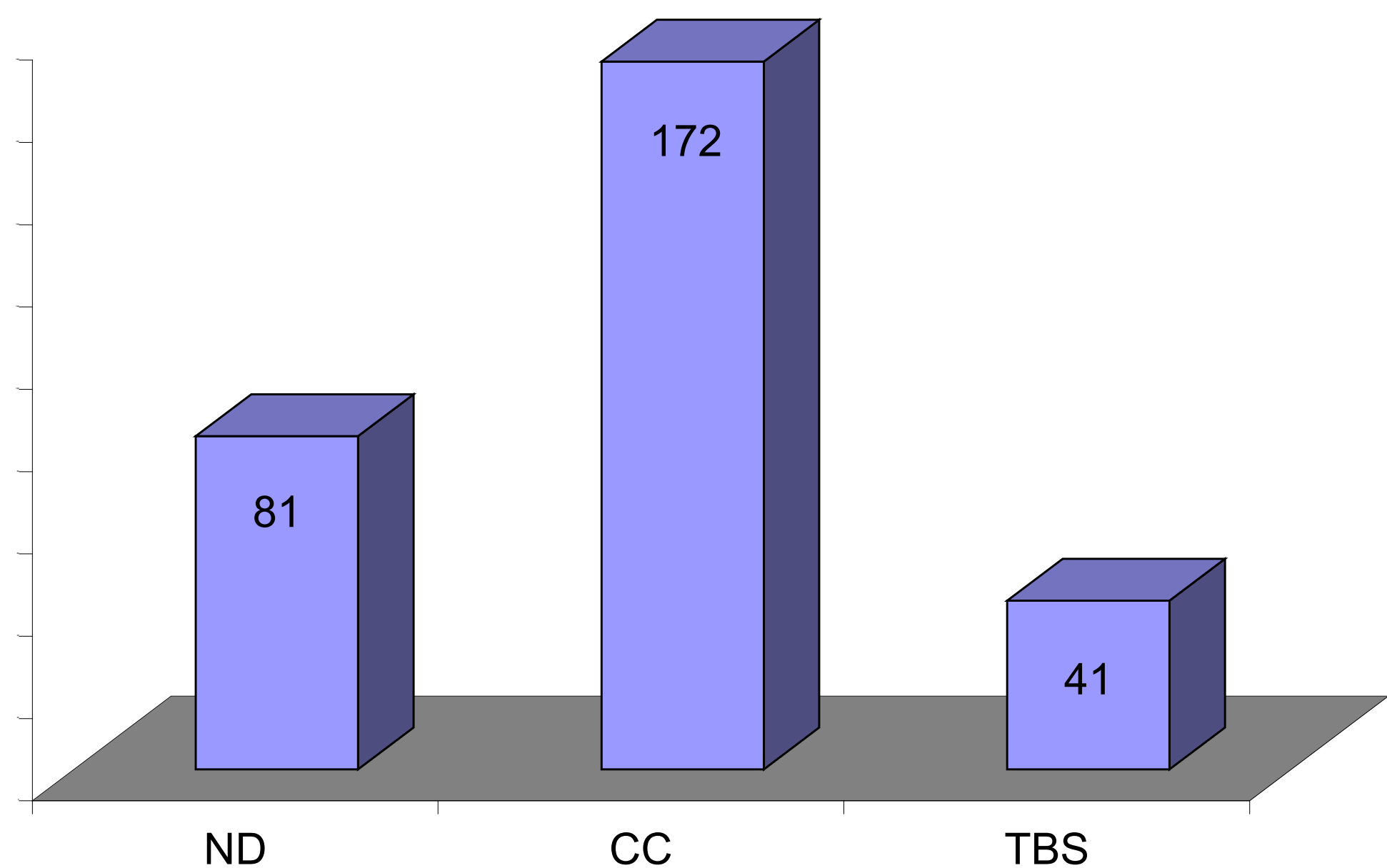


**Table 3 – Diagnoses in the sample**



Chapter	Female	Male	Total
V	51	64	115
VI	30	50	80
XVII	22	24	46
VII	3	7	10
VIII	4	4	8
Other	14	11	25
Total	124	160	284

**Table 4 – Diagnoses per child**



	F	M	TOT	F %	M %	TOT %
ND	32	49	81	25%	30%	28%
CC	71	101	172	55%	61%	59%
TBS	25	16	41	20%	10%	14%
	128	166	294	100%	100%	100%

### Conclusions

Kosovo is a country in transition, in the process of refining and redefining its institutions; between 2008 and 2012, a key element has been the acceleration in the decentralization process at Municipality level. Education and accessibility have been considered as the most dynamic areas of inclusion and the optimal entry point to challenge a silted situation. Inclusive education requires attention and actions, notably to enhance the situation of marginalised groups such as children with disabilities. Data will be collected during the summer. A better understanding of the living conditions of children with disability will allow identification of gaps in the provision of services in the health, education, and social sectors. Moreover, it will provide critical information for the formulation of local policies, hopefully enhancing commitments and resources allocation from the government, both at central and municipal levels, and de facto implementing the existing legislation on the matter.

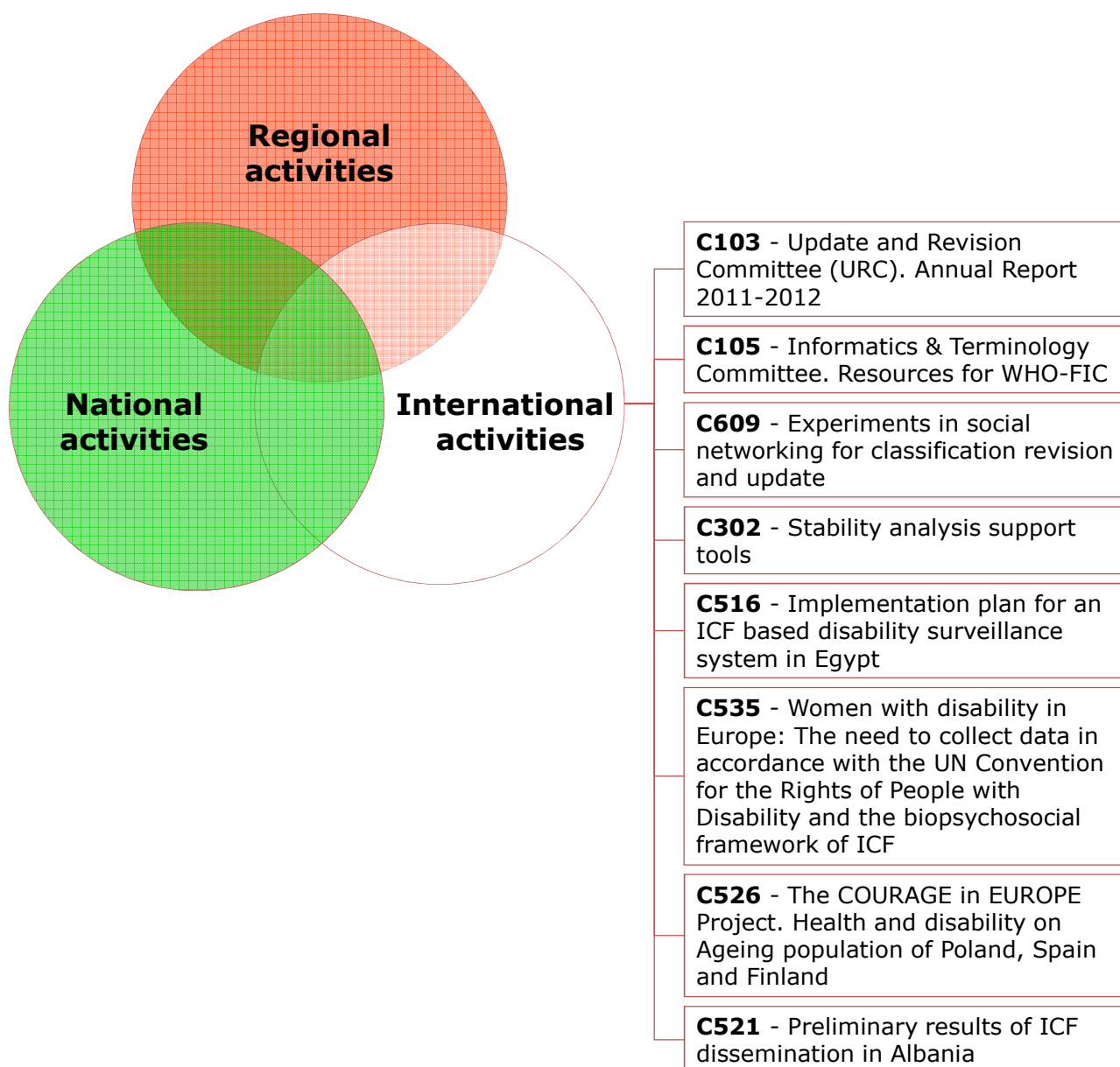
### Acknowledgements

Thanks are due to the Friuli Venezia Giulia Region that supported the sharing of technical expertise on disability in order to support the Disability Action Plan implementation.

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# Update and Revision Committee (URC) Annual Report 2011-2012

13 – 19 October 2012  
Brasilia, Brazil

C103

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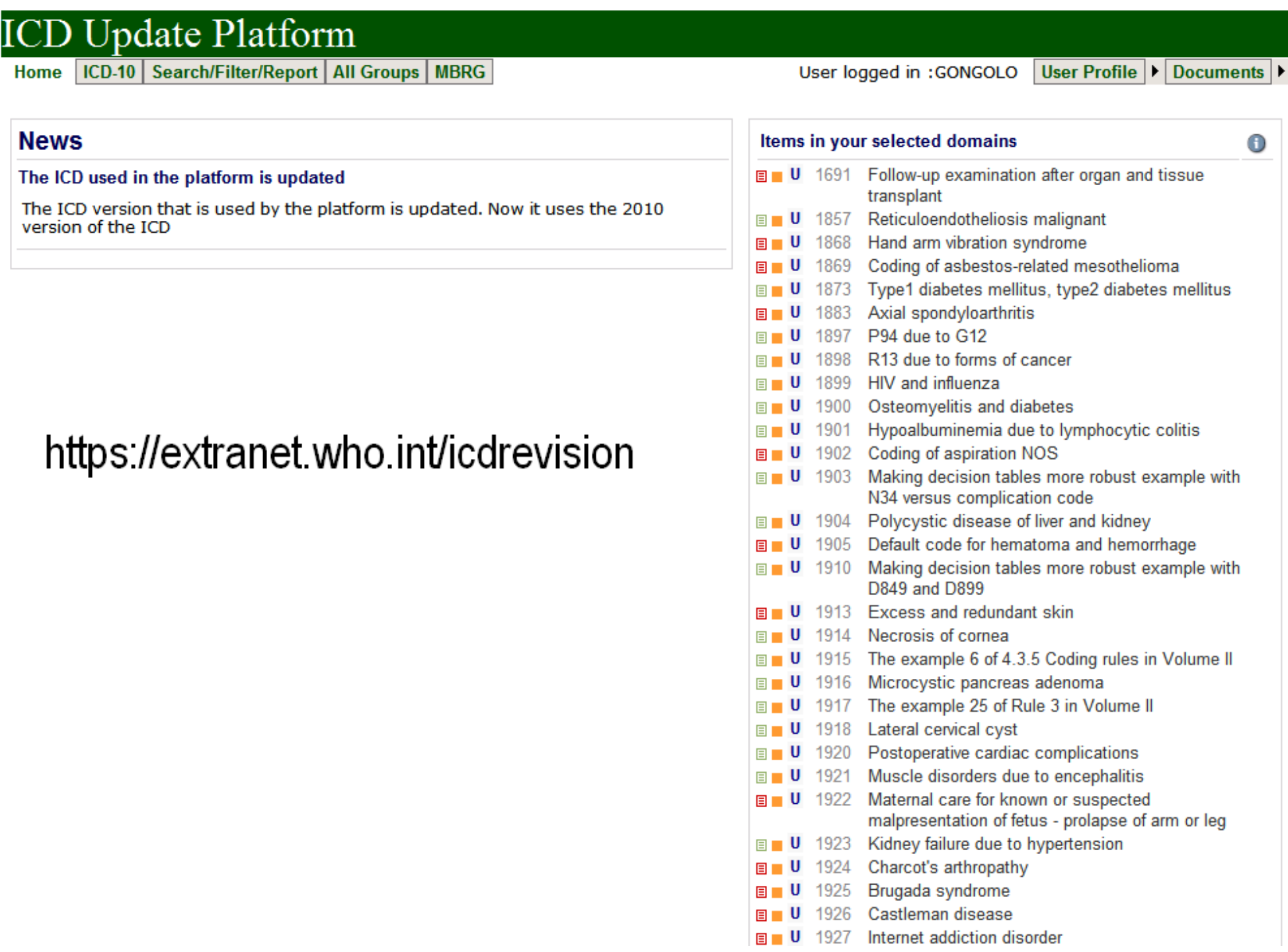
**Abstract** The following are highlights of decisions made at the Annual Meeting held in Cape Town, South Africa 29 October - 4 November 2011 and in November 2011 URC special Teleconference on ICF Updates: 45 of 101 proposals for updating ICD-10 were approved; 24 proposals for updating ICF were approved. The committee reviewed 22 proposals from ICD-11 TAGs and determined that categories with mandatory 5th characters were outside the scope of ICD-10. The committee discussed the updating and utility of the ICD-10 cumulative update document in Word format and determined it should continue. Currently there are 47 proposals on the 2012 ICD-10 update platform. There are 15 proposals from the Dermatology TAG previously submitted in 2011 that may be added if they can be completed in time for review by URC members. Currently (August 22) there are 184 proposals on the ICF update platform: 10 newly added into the Initial Review Group Layer, 137 awaiting review input in the Open Discussion Layer and 37 under decision in the URC Closed Discussion Layer.

## Introduction

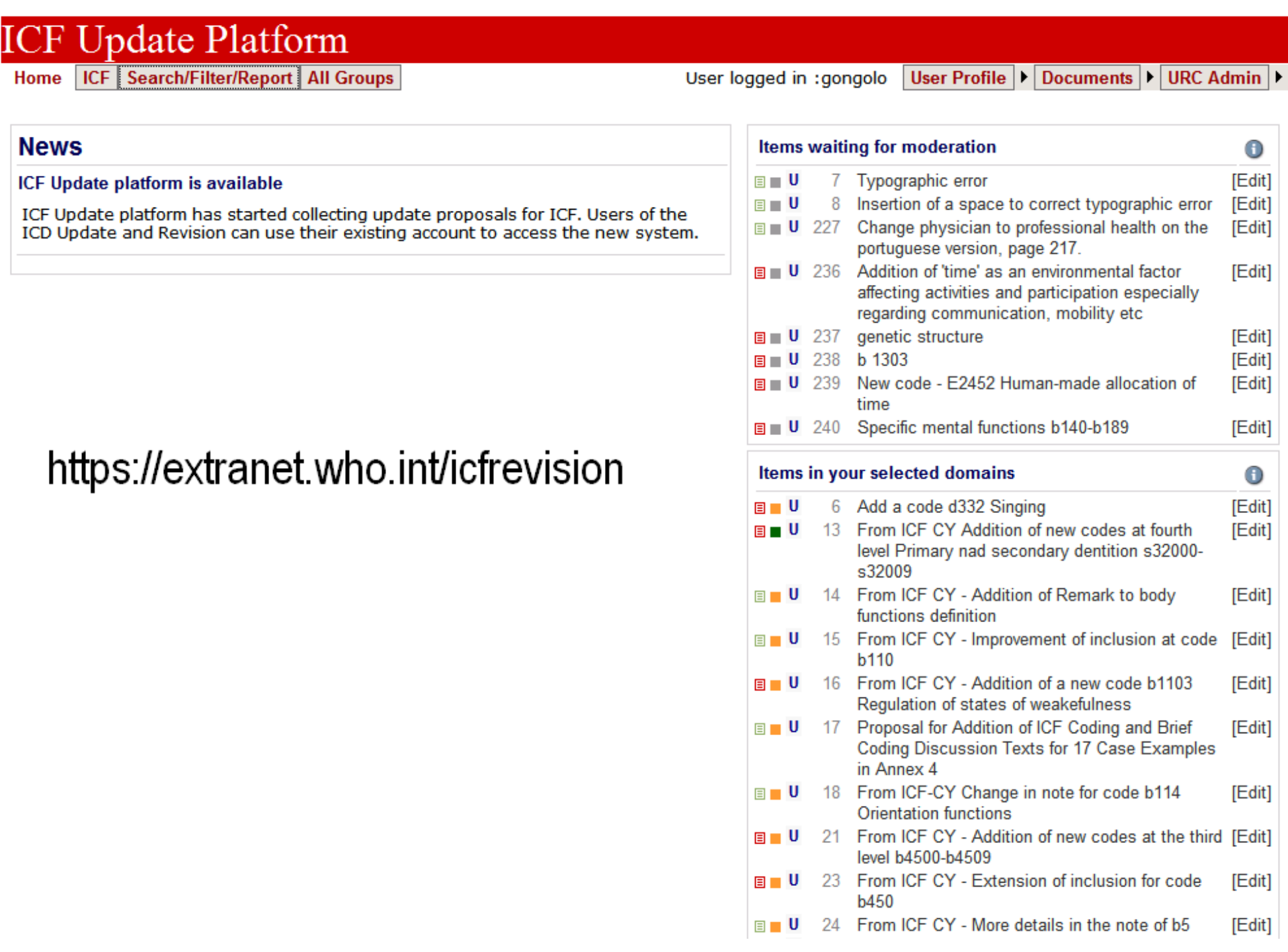
The Update and Revision Committee supports the WHO-FIC Network in the update of the WHO Classifications: it coordinates the whole classification update process, from submission of update proposals by reference groups and other sources, to final approval of proposed updates by the WHO-FIC Council.  
The present work is to highlight the status of the 2012 Committee’s work-plan for ICD-10 and for ICF.

## Methods & Materials

The entire update process is managed through web-based platforms thus ensuring standardization of submission, review, decision and implementation of update proposals. These web-based tools allow contributors from around the world to work collaboratively and ensures transparency as each contribution is visible to all users. The platform is accessible to any person who can register and become a user.



<https://extranet.who.int/icdrevision>



<https://extranet.who.int/icfrevision>

## Results

**Highlights of Major Decisions and Recommendations for updating ICD:**  
101 recommendations for updating ICD were considered in 2011  
Final outcome: 45 supported, 16 rejected or withdrawn, 20 held over.  
•New code for dependence on artificial heart; Classification of Kimura disease; proposals that included mandatory 5th characters were outside the scope for addition into ICD-10  
•Updates for ICD-O-3 were determined to be outside the scope of the URC  
•Annual and cumulative updates will continue in Word format  
At the time of the second round of voting (July 20 –September 6, 2012) there are 47 proposals on the ICD-10 platform for review.  
•10 proposals from the MRG that are posted for information only.  
•URC#1673) was withdrawn.  
•Thirteen proposals from the ICD-11 Dermatology TAG with potential for fit in the ICD-10 structure have been moved off the platform for further work by the TAG.

## Highlights of major ICD-10 issues for 2012

- classification of asbestos-related mesothelioma
- classification of ankylosing spondylitis to spondyloarthritis
- new code titles for diabetes
- new code for excessive and redundant skin
- new inclusion and index entry for Brugada syndrome
- new inclusions for NSTEMI and STEMI

**Highlights of Major Decisions and Recommendations for updating ICF:**  
There are two major focuses of activity in updating ICF: the realization of a Foundation ICF by merging the derived classification ICF-CY into a unique classification, and the provision of annual updates of ICF.

In 2011, the URC received 45 reviewed proposals from the FDRG. 24 proposals were approved: 13 at the annual meeting held in Cape Town, South Africa and 11 in November 2011 URC special teleconference on ICF updates. 2 update proposals have been rejected by the URC: #112(Cape Town annual meeting) and #138 (URC November 2011 teleconference).  
  
19 proposals needed to go back to the Open discussion layer:  
• 6 proposals at Cape Town 2011 URC and WHO-FIC Annual Meeting  
• 7 proposals after the Cape Town 2011 meeting dealing with the issue of “play”  
• 6 proposals during the November 2011 URC Teleconference).

A document called “Reporting form ICF Updates 2010\_12 English version” was produced and circulated together with the table of all the approved update proposals compared to the original ICF version.  
The ICF database was updated together with WHO and made available to the Collaborating Centres who required it, in order to update the ICF based information systems.

At present, 184 proposals are on the platform:  
• 137 from ICF-CY in the open layer  
• 37 newly reviewed by FDRG and under decision by URC  
• 10 newly submitted for Initial Review Group and FDRG for 2013.

## Conclusions

- The work of the URC has been successful in its goal of updating the ICD and ICF.
- Collaborating centres are encouraged to continue support of this work.
- Input from additional collaborating centres is sought.
- The evolution of this committee to provide ongoing support in transitioning to ICD-11 and thereafter maintenance of ICD-11 is under discussion.





# Informatics & Terminology Committee

## Resources for WHO-FIC

13 – 19 October 2012  
Brasilia, Brazil

C105

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**Abstract** The Informatics & Terminology Committee supports the WHO and the WHO Family of International Classifications in the development of electronic tools and standards for classifications and their dissemination. The present poster illustrates the informatic and conceptual resources made available by, and/or discussed, in the ITC committee.

### Revision Platform

#### ICD11 Browser

Web access to and support to revision and update for ICD11

#### iCAT

Knowledge-based support to authoring of ICD11

#### Update platform

Support to revision and update for ICD10 and ICF

#### Multi-language support

Multilingual platform  
Translational memory

#### Open data platform

API and services for third party application development (REST, XML, ClaML, etc)

### WHO Family of International Classifications

*ICD, ICF, ICHI, ...*

### SNOMED-CT

**Common Ontology**  
Harmonization between WHO-FIC and SNOMED-CT

#### Mapping experiences

ICD and SNOMED-CT  
ICF and SNOMED-CT  
ICF and other resources

#### Social Networking

Browser integration with common social platforms (Facebook, Twitter, ...)

#### ClaML

Classification Markup Language and implementation profiles

#### Classification Browsers

Web access to ICD10 and ICF

#### CTK – Classification Tool Kit

editor of classifications with multiple outputs: printable, Web, computable (ClaML)

#### Automated Coding tools

IRIS, MMDS

Third-party applications





# Experiments in social networking for classification revision and update

13 – 19 October 2012  
Brasilia, Brazil

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**Abstract** The collaborative work behind classification revision and update can be truly defined as a social experience. Since in the last years novel web-based tools started to appear to support the features of social networks, aim of the present poster is to present some experiments in bridging the gap between classification revision and social networking, by linking together the ICD Browser and Facebook.

## Introduction

The collaborative work behind classification revision and update can be truly defined as a social experience, with the participating community of experts behaving like a social network in the traditional sense. Since in the last years novel web-based tools started to appear, directly replicating, online, the features of social networks, aim of the present poster is to present some experiments in bridging the gap between classification revision and social networking, in the case of ICD11, and starting from the available ICD11 Browser.

## Methods & Materials

At first, we reviewed the main social networking platforms currently available (Facebook, LinkedIn, Twitter), to understand their capabilities in terms of personalization and adaptation to the specific needs of the revision work. Personalization may occur at different levels:

- by embedding into a web site the code for adding some social aspect (e.g., “like” or “Tweet” buttons);
- by developing platform-hosted specific applications (e.g., Facebook apps);
- in the case of Facebook, by translating actions occurring into the originating web site (e.g., the ICD11 Browser) in elements of the Facebook Open Graph. Since Facebook seems to be the most used social network, and also the one with most personalization features, we initially concentrated our efforts on it. However, a preliminary implementation of part of the system has been experimented on Twitter.

## Results

Two research lines have been set: development of a prototype app called SocialICD, able to show new comments on categories selected by the user directly inside Facebook; development of the Open Graph infrastructure needed for adding automatic Facebook connection to actions occurring into the ICD11 Browser (i.e., commenting, reviewing, answering questions). The former application needed the development of an experimental REST API on the ICD11 Browser to make comments available and searchable by category. The app itself has been developed in PHP. When a user starts the app, he/she can select his/her preferred categories, and have a quick list of recent comments, linked to appropriate areas of the ICD11 Browser. The latter Open Graph approach has been experimentally prototyped and needed adaptation of the current ICD11 Browser. An experimental version of the ICD11 browser has been thus set up to embed the Facebook features needed.

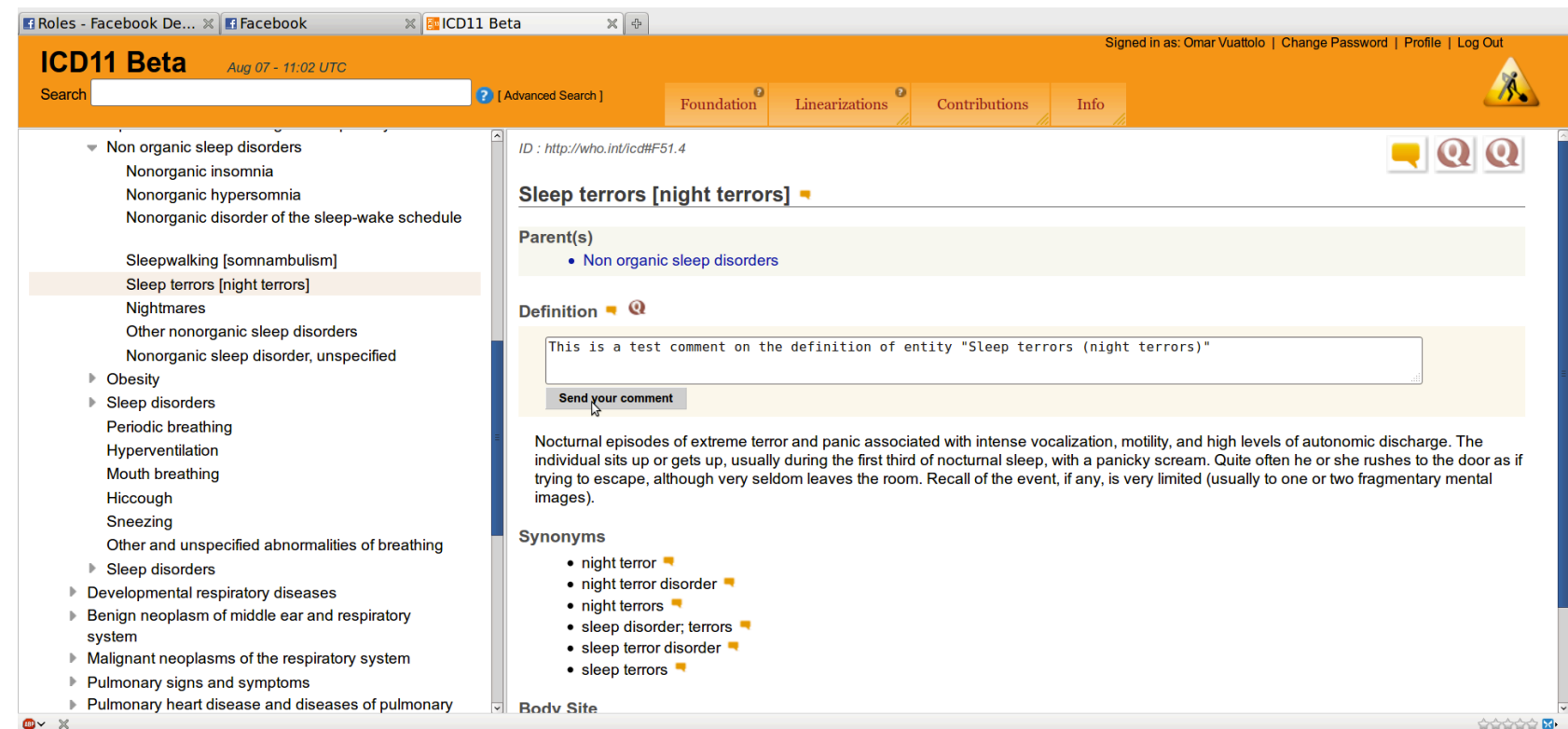
With this approach, the user working inside the ICD11 Browser may have his/her own actions recorded and summarized on his/her Timeline, and published on the wall. This might serve as a basis for developing automatic rewarding systems like those seen in Foursquare, Klout and some online games.

## Conclusions

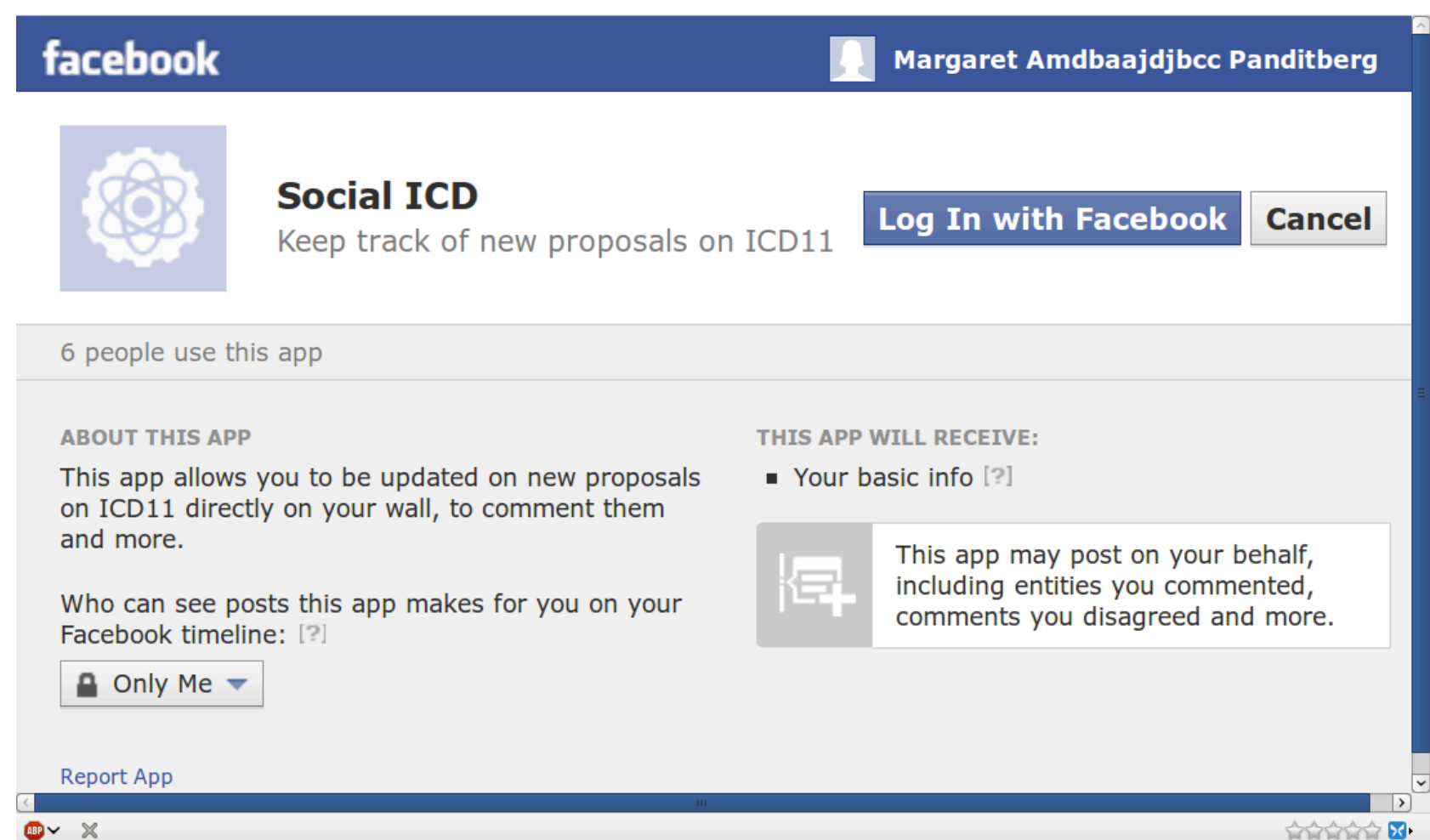
The system has been implemented as a prototype in an experimental version of the ICD Browser, and linking on Facebook applications not yet available to the general public. Further developments include:

- a survey on the possibly involved subjects to understand the diffusion of social networking, and the willingness in using them for professional work like that needed for classification revision and update;
- a better integration with the ICD11 Browser;
- as soon as official classification URIs and API become available, a seamless integration with them;
- experiments with other social platform, i.e. Twitter and LinkedIn.

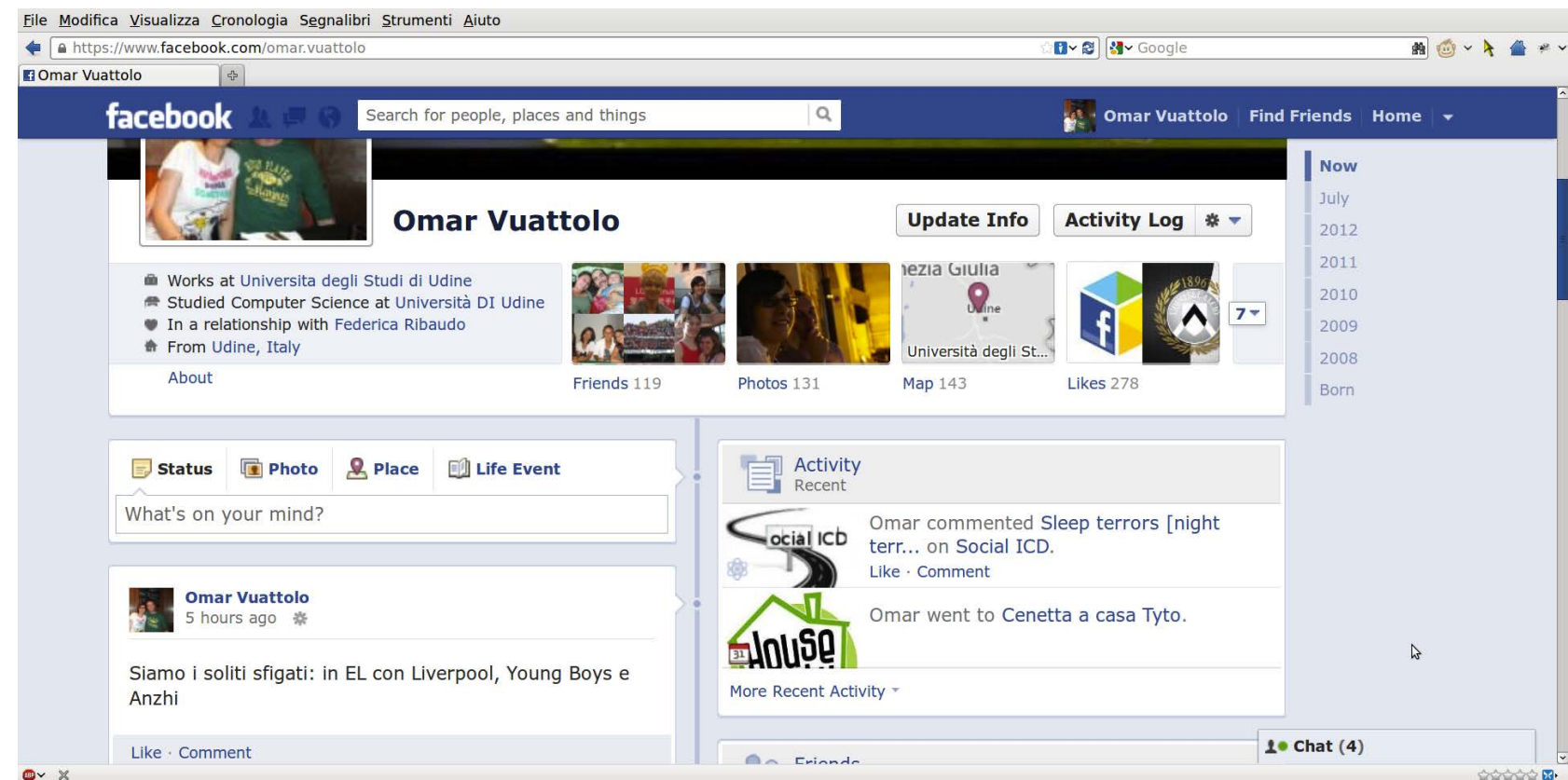
## BROWSER - FACEBOOK INTEGRATION



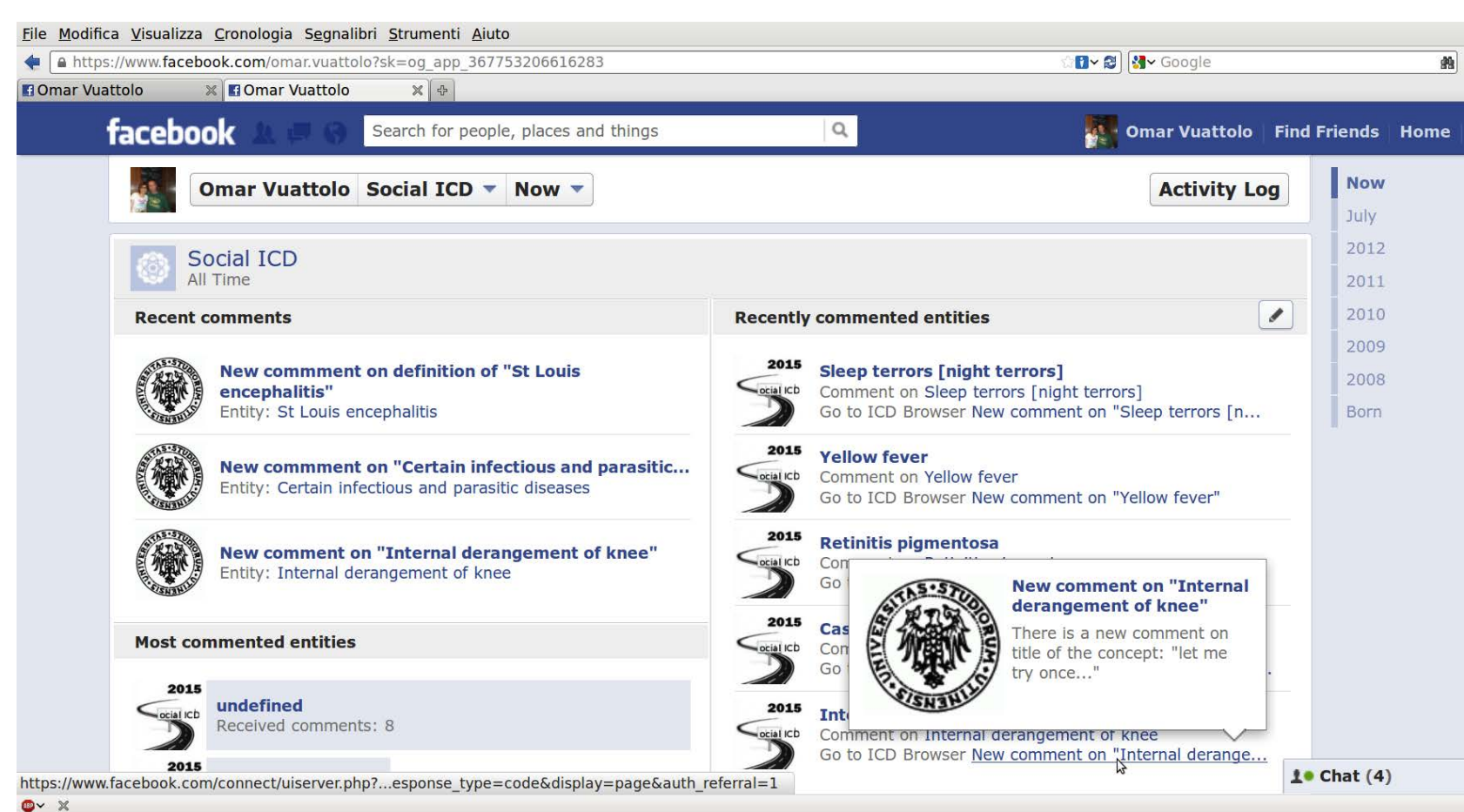
When commenting any category in the browser, FB users are suggested to authorize the application to publish actions on FB:



Then, comments will appear in user own timeline, and on friends wall, depending on permissions given.



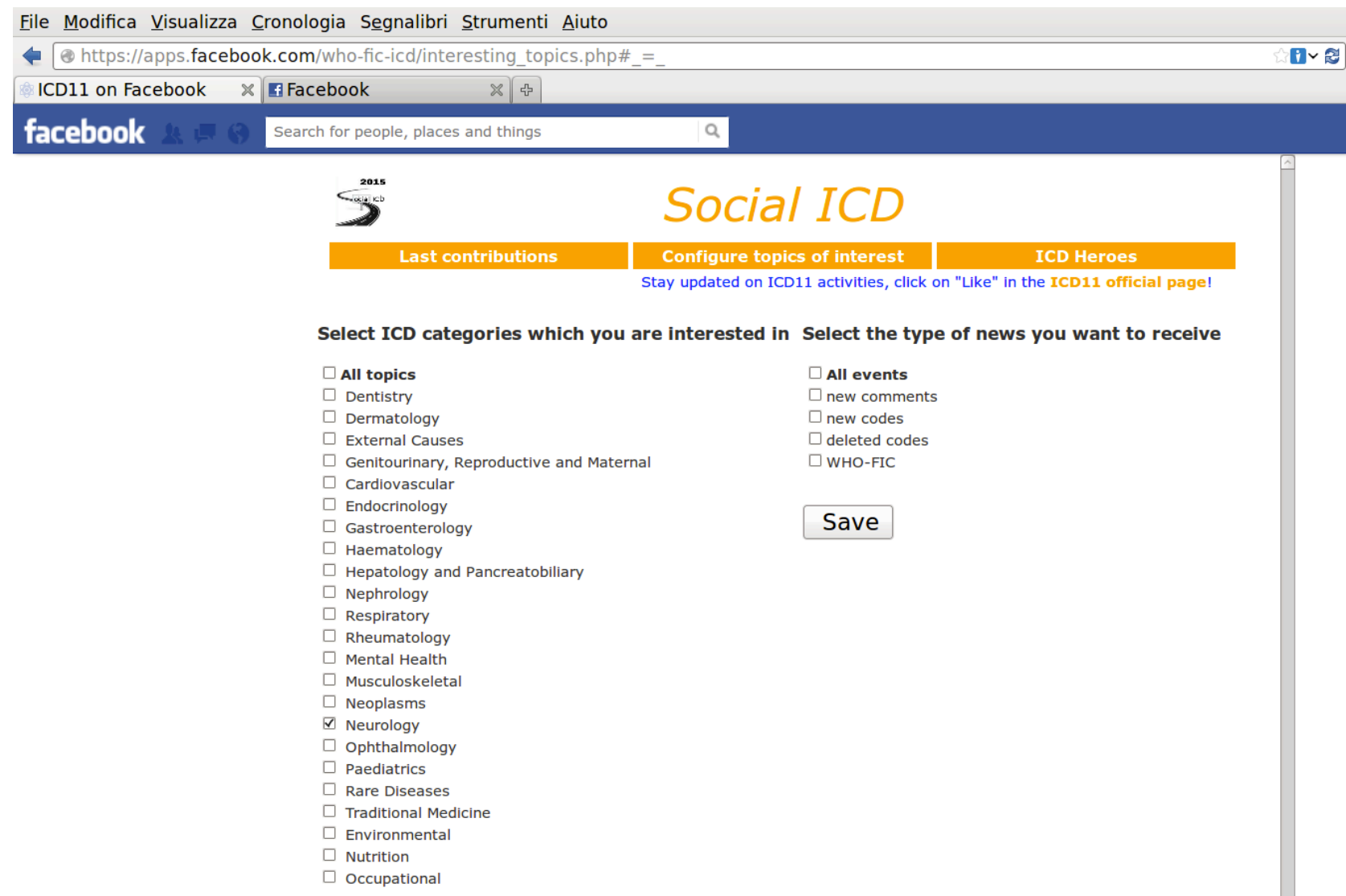
In the timeline is possible also to find some aggregated report on activities:



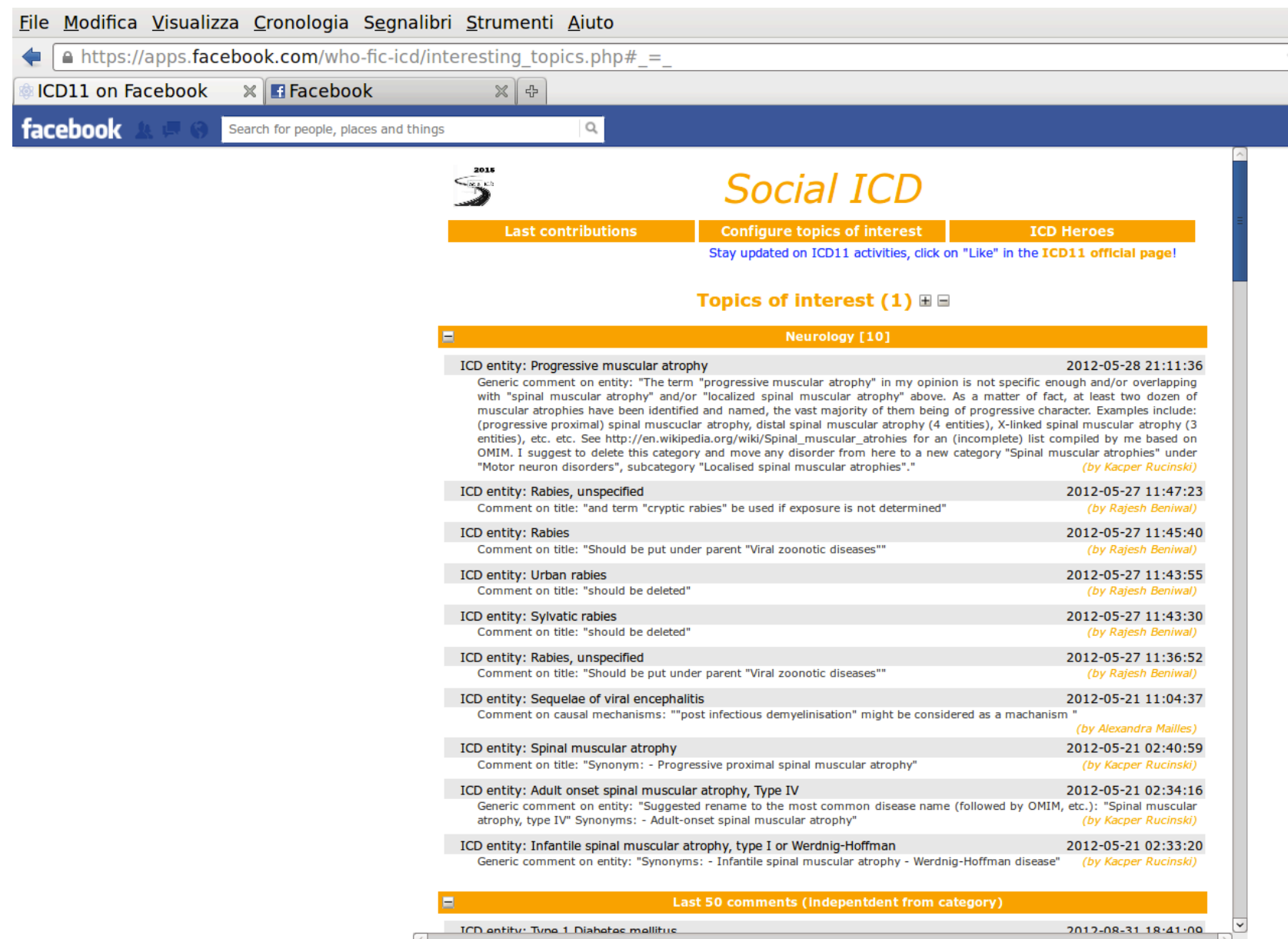
## BROWSER COMMENTS ON FACEBOOK

Thanks to a FB app, it is possible to quickly access the last comments appeared on the ICD browser in the areas of interest, or even on any category.

At first the user should choose areas of interest:



And then he/she can see last comments:







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C302

**Abstract** Stability analysis is needed to ensure smooth transition between current and next version of classifications, and in particular is needed for ICD11 easier deployment. The amount of data on which to work is large, so not always it can be done efficiently. With the aim of supporting stability analysis, a number of prototype tools have been developed to extract data, merge it, compare, based on some open data made available by the ICD browser.

Introduction

With the aim of supporting stability analysis, in turn needed to help in transition from ICD10 and DRG to ICD11, a number of prototype tools have been developed to extract data, merge it, compare, etc., accessible through the web or producing CSV files to be opened in Excel. Stability analysis is also aimed at a specific use case: here we focused on DRG and on Mortality. The basic input of the process is constituted by the DIFF file automatically generated by the ICD Browser, and a list of DRG-related ICD10 codes. In fact, most of the analysis can be potentially done using Microsoft Excel, but the large number of data to be manipulated makes the work too cumbersome due to Excel limitations in terms of table size and computational capabilities, in particular for older versions, where the number of rows and columns is insufficient. For this reason, a set of web-based prototype tools have been developed to pre-process data for further spreadsheet analysis.

ICD11 and DRG

At first, we concentrated on ICD stability from the point of view of DRG usage. For this reason a crosstable between DRG and ICD10CM codes, to be then used on Excel, but again resources were insufficient even only for counting stable and unstable codes. So another program has been developed for coupling DIFF file with DRG/ICDcode table, which output can be (more) easily managed through Excel. This way, most of the least interesting work is done automatically, leaving room for a better exploitation of the human expert intervention.

ICD11 Stability Preprocessor

v0.2 - 20120410

Please submit the ZIP compressed DIFF file (as coming from ICD11 browser, [here](#)):

Sfoglia...

Select the number of code characters on which to compare (you may iterate if you need all three versions):

☒ 3 ☐ 4 ☐ 5

Start Stability Preprocessing

You will obtain a .csv file to be opened in Excel or other tool, with a matrix relating ICD10CM codes to the DRGs where they are used. In the crossing cell you will find: B if the code is present in ICD11, R if it has been retired, N if is not present.

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Support in reaching stability

After these first programs, further methods have been investigated for i) better evaluate stability and ii) help in reaching stability when needed. Some of the tools have the added value of providing a practical help in quality assurance of ICD11.

More specifically, the following issues/techniques have been investigated:  
*Which are the sibling codes that appear altogether in the same DRG groupings, but are not in ICD11? Among those, which ones have the parent in ICD11?*  
A script has been developed that produces a list of code clusters composed by complete set of siblings (so that the whole family is in the same groupings), each of which identified as having or not the parent in ICD11. Those having the parent in ICD11 may be “salvaged” for DRG stability aims by using the father instead. About 20% of missing codes might be salvaged this way.  
*Which are the differences among those missing siblings? Could be reduced to some concept taken into account for postcoordination?*

Since there are a number of postcoordination dimensions (laterality, temporality, etc), we tried to find indicators of such dimensions in sibling titles by applying natural language techniques.  
*In Mortality Stability, how many missing codes have the parent in ICD11?*  
Starting from pure ICD10, another script has been developed to evaluate how many retired codes have the parent in ICD11. On about 1300 codes, about 500 have the parent in there. This has as output also a CSV file where a link to iCat is provided for the code, to ease the work when looking for reinstating those codes.

ICD10 - ICD11 Mortality Stability

Experiments in Mortality Stability evaluation

The following list shows retired ICD10 codes. Those in bold have also the parent retired; others' parent is instead still in ICD11.

Duplicate codes are new concepts in ICD11 with title equal to the retired one; possible duplicates have title only similar, which may be or not equivalent to the retired code or also to some possible parent.

Number of retired: 1350

A020 (Salmonella enteritis) : A02 (Other salmonella infections)

- Possible Duplicates or parents: Bacterial enteritis due to salmonella, Other salmonella enteritis,

A079 (Protozoal intestinal disease, unspecified) : A07 (Other protozoal intestinal diseases)

A310 (Pulmonary mycobacterial infection) : A31 (Non-tuberculous mycobacterial infections)

- Duplicate: Pulmonary mycobacterial infection

- Possible Duplicates or parents: Pulmonary mycobacterial infection,

A91 (Dengue haemorrhagic fever)

B002 (Herpesviral gingivostomatitis and pharyngotonsillitis) : B00 (Herpes simplex infection)

B150 (Hepatitis A with hepatic coma) : B15 (Acute hepatitis A)

B159 (Hepatitis A without hepatic coma) : B15 (Acute hepatitis A)

Duplicate codes analysis

The last question we tried to answer is:  
*How duplicate codes impact on stability?*  
A code is in both ICD10 and ICD11 only when it has not been modified, while some code has been created after having being retired, some code has been created even if already present, etc. All these issues decrease stability because add codes that count as unstable.  
A script has been developed with two components, one aimed at extracting exact duplicates (same title): at development time, 126 have been found. The other was a term comparison algorithm based on stemming and stopwords elimination. This is used to identify candidate duplicates, when differences between titles are at max one meaningful word. About 330 have been found, however with some misidentification. While giving an idea on numbers to be considered when evaluating stability, this script also provides a practical tool for taking care of at least the easiest quality issues.

ICD10-ICD11 Duplicate Finder

A couple of attempts at identifying duplicates.

B: present in both ICD10 and ICD11; R: retired in ICD11; N: new concept in ICD11

You may click on codes and go straight to iCat.

Wait patiently...

Preparing... 10:45:17

Test approximate matching on R vs N types

Titles of retired codes are approximately compared to titles of new concepts. When differences are few, the retired code is shown, followed by one or more matching candidates. Since matching is approximate, some unmeaningful candidates are always present and need to be checked manually.

Wait patiently...

Preparing... 10:45:23

1) A02.0: Salmonella enteritis

- 2172 2780462e\_2372\_4ebc\_a671\_bf8ffd1008f6: Bacterial enteritis due to salmonella

- 2244 2780462e\_2372\_4ebc\_a671\_bf8ffd1008f6: Other salmonella enteritis

3) A31.0: Pulmonary mycobacterial infection

- 15730 b047675b\_e7d6\_403d\_8ca9\_f59ab5570ff4: Pulmonary mycobacterial infection

Conclusions

All programs and scripts developed should be considered as prototypes, whose functionalities might be embedded into some more stable tool. They are based on open data coming from the ICD browser and other sources, and represent also a case use for them. Some of the issues dealt with might be better treated in advance, e.g., by avoiding mistakes when introducing new codes. As soon as an ICD API becomes available, those tools might be consolidated into a sort of ICD workbench for checking duplicates, missing codes, etc.



Implementation plan for an ICF based disability surveillance system in Egypt

Oct – 6 Oct 2012  
Brasilia, Brazil

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C516

**Abstract** A shift in attention from acute communicable diseases to consequences of chronic conditions is seen as important both in high and low resource countries. The use of the ICF to provide a reliable standardized picture of the functional profile of persons with disability would provide the solid basis to build any Nationwide disability surveillance system from which to move towards meaningful epidemiological data and on which to base any action aimed at responding and minimizing disability. Egypt has taken the first steps towards this goal by launching with the leadership of WHO-Egypt and the assistance of the Italian WHO-FIC CC an ambitious plan to build a Nationwide Disability surveillance system presently undergoing the first extensive field testing

Introduction

Disability conceptualization has changed since the signing of the UN convention for the rights of the persons with disability (Egypt, 2009). The ICF is the internationally agreed, WHA endorsed standard language that describes human functioning and is the best tool to represent disability in all aspects. Use of ICF in national and international documents and data sets describing disability is a pre-requisite to fulfill the commitments mandated by the UN convention. Egypt is in a special position to review the national perception of disability and the policies and programs addressing it and to do so starting from sound and scientifically based data on which all stakeholders (governmental and non governmental organizations, state offices, health provision systems, advocacy groups) may rely and agree. To this end WHO Egypt, the Egyptian Ministry of Health, with the support of the Research Branch of the Italian WHO-FIC Collaborative Center launched a scaling up plan to test and introduce in Egypt an ICF-based disability surveillance system.

Objectives of the plan are:

- To identify information needs and technical requirements for a disability surveillance system in Egypt
- To set the stage for a locally based ICF training dissemination
- To draft a plan outline for the development of an ICF based disability surveillance system. This goal is preceded by a pilot implementation test articulated as follows:
  - O test the coding ability and feasibility at selected test sites
  - O frame a commonly agreed ICF based form to report functioning and disability data to the MoH
  - O test the form over a 6-8 months
  - O define the information load and the analytical methodology to handle the information produced
- report to MoH on the results of the pilot phases for further action

Methods & Materials

**Phase 1: training, pilot testing.** November 2011-March 2012  
The program started with a training *workshop* involving 19 professionals of different background and from various Institutions.  
Aim: to introduce the ICF and train the participants in its use for describing and reporting functioning and disability information at the clinical level.  
*Pilot testing*, in which each participant tested the ICF in his clinical setting.  
Aim: test feasibility and provide information needed to frame the definitive common ICF based form to be used in the following phase.  
**Phase 2: development and testing of the common ICF form; training dissemination.** June-September 2012.

- Review of the results of phase 1 pilot and the discussion in order to define a commonly agreed ICF-form;
- Definition of the ICF report form;
- “Lab-test” of the form on real cases to confirm in its validity and applicability. B
- test-training of participants to the workshops in view of their activity as on-site trainers for their Institution and initiators of ICF training dissemination.

All prospective trainers are expected to held at least 1 training course involving all needed participants at the local level by February 2013. Training efficacy will be objectively tested with pre/post test questionnaires.

Egypt ICF working Group

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Results

**Phase 1**  
ICF profiles were completed in 6 sites in for 240 cases, mostly children and adolescents with mainly neurodevelopmental and psychiatric disorders. Coding was mainly completed from available medical records. Different methodologies were followed (from free coding to the ICF checklist).  
*Main problem* was identified in the lack of non-medical but functionally relevant information.  
*Main benefit* was seen in the change in perspective brought by the need to describe the person in all his functioning aspects in interaction with the context.  
**Phase 2:** *The ICF form* displays expandable fields for body functions and structures (up to 5 categories per chapter), a fixed menu of 42 codes for A&P, and free coding of up to 3 environmental factors attached to the function or the A&P category being affected. The final electronic format of the document, which should take into consideration the type of data analysis to be conducted both locally and centrally, will be defined with the Health Information Center of the MoH. The e-form should also allow check for double encounters.

The form will be field tested for 6 months at 9 sites in 4 Provinces.

Conclusions

- Deliverables (March 2013):
- 1) Fully defined, electronically supported and field-tested ICF based form for Disability and Functioning description in facilities providing services for the persons with disability;
  - 2) Complete ICF record describing functioning and disability for 500 new encounters consecutively seen at the participating sites;
  - 3) ICF Training material in Arabic tested at different sites
  - 4) Defined paradigms for data entry, transmission, storage, analysis
  - 5) Plan for nationwide extension of the process.



**Abstract** In recent years, various European Institutions have highlighted the lack of data on people with disabilities; the difficulty to compare data collected between different institutions and countries due to the absence of a common definition of disability and methodology of data collection; the lack of information in many areas related to disability (e.g., access to social and health services, independent living, rehabilitation, assistance and support); and finally the lack of gender perspective regarding women with disabilities. The aim of our research is to present available and updated data on women with disabilities in Europe linking these data to ICF and highlighting gaps and needs in order to encourage new ICF-based data collection that can support the development and implementation of evidence based policies which promote rights, so as to respect the mandate of UN Convention on the rights of people with disability.

Introduction

Results

Conclusions

Up to date, worldwide **comparable data** about functioning and disability are not available, including data about women and girls with disabilities. At international level, it has been recognised by the **Article 31** about Statistics and data collection of the **United Nations ‘Convention of the Rights of Persons with Disabilities’** that the codification, collection and analysis of consistent information about health and disability is important in order to construct and implement policies which promote the rights of persons with disabilities [1].

Across Europe there is an evident need towards improved measurement methods in the health and disability sector, because of the current existence of **various definitions of disability**. The **International Classification of Functioning, Disability and Health** (ICF) of the World Health Organization (WHO) is based on the biopsychosocial model and defines disability as an interaction between features of the individual’s health status and features of his or her physical, social and attitudinal environment giving life to a multidimensional phenomenon.

Methods & Materials

In order to identify available data and statistics at European level on women with disabilities, our search was restricted to European Official web sites of the European Union’s Bodies and Institutions specifically European Parliament, Council of Europe, European Commission and Eurostat web sites ([http://europa.eu/abouteu/institutions-bodies/index\\_en.htm](http://europa.eu/abouteu/institutions-bodies/index_en.htm))

The research was realized using the words “women/girls/disability/statistics” on the English version of web sites consulted. Inclusion criteria were:

- a) European official documents from Official web sites specified above.
- b) Documents containing data and statistics on women and girls with disabilities.
- c) Documents published in the last 10 years.

We consulted about 700 documents. Although there are several European documents on women with disabilities, just few of them indicate updated data and statistics on the number of women with disabilities in Europe [2, 3].

Richest data (tables 1 and 2) came from the study supported by the European Community Programme for Employment and Social Solidarity (EC, 2007), collected data on European person with disabilities from 33 different countries [2].

Table 1. Prevalence of women with disability in Europe

	Gender distribution; population* with disabilities (N=)	Gender distribution; total population*
Women	16,145,792	3.76%
Men	21,415,098	4.98%

*\*referring to the population of the countries included in the source study (EC, 2007)*  
Source: data modified, based on p.22, EC, 2007.

Table 2. Proportion of women with disability by age in Europe

	Women with disability: distribution by age*	Men with disability: distribution by age*
16 - 24	3.1%	3.6%
25 - 54	8.4%	8.3%
55 - 64	18.8%	22.0%
Tot. 16-64	15.6%	16.2%

*\* referring to the population of the countries included in the source study (EC, 2007)*  
Source: data modified, based on p.17, 18, EC, 2007

In general data found in our research vary considerably between countries, though they were collected through pan-European surveys and were based on self-reports rather than on objective measurements such as definitions and classifications used by Member States.

This may have occurred due to the fact that the concept and **the definition of disability used by different countries in different surveys varies among European countries.**

The strongest aspect that emerges from our study is the **need for more systematic data collection on disability and on disability seen from a gender perspective**, since this is an object of study in itself.

In the available EU documents, there is **a lack of official statistics** considering the importance and need for political inclusion and social promotion for people with disabilities and women with disabilities in particular. Everywhere is underlining the difficulty of comparison due to the **absence of a common definition of disability**. A clear sign of harmonization is needed at the level of Member States, as recognized in Article 31 of the UN Convention on the Rights of persons with Disabilities.

This study clearly shows that for the collection of data on people with disabilities, and on women in specific, there is an urgent need in all European Member States for **a common conceptual and methodological framework at European level, ideally based on the biopsychosocial paradigm of the ICF**. The ICF provides the framework for documenting the interaction between a person’s health condition and the contextual factors surrounding him/her and uses an internationally comparable language; thus, difficulties in functioning and disability can be conceptualized and operationalized [4].

In order to ensure the preservation of the rights of women with disabilities, in this time of crisis in which the European governments’ responses may exacerbate the social exclusion and poverty among women with disabilities policies should be even more necessary.

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# The COURAGE in EUROPE Project

## Health and disability on Ageing population of Poland, Spain and Finland

13 – 19 October 2012  
Brasilia, Brazil

C526

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**Abstract** **COURAGE in EUROPE Project** developed and validated an original survey protocol for European studies on ageing and disability with specific tools to evaluate the role of the built environment and social networks as determinants of health and disability on an ageing population. The main survey to evaluate the determinants has been conducted by the partners in Finland, Poland and Spain where the survey has been administered to a final sample of 10800 persons.

### Introduction

There is a need to measure health, environment and social networks and their impact on quality of life and well-being of ageing population to produce comparable data in European ageing population.

**COURAGE in EUROPE Project (Collaborative Research on Ageing in Europe)** propose the background of the ICF and based on a theoretical framework that defines disability as the interaction of a health condition with contextual factors, will try to produce these comparable data on determinants of health and disability in ageing (WHO, 2001; Leonardi et al., 2006).

**COURAGE in EUROPE** is a three-year project, coordinated by Neurological Institute 'Carlo Besta' (Milan, Italy) involving 12 partners from four countries (Italy, Spain, Poland and Finland) and the World Health Organization. It has been funded to answer the pressing need of the European Commission to have valid and reliable measures to describe health and disability in ageing population.

**COURAGE in EUROPE Project** developed and validated ICF-based tools to measure health outcomes (both physical and mental), quality of life, and well-being in ageing populations and, thereby, to find and empirically substantiate determinants of ageing across populations, looking also at the role of the built environment and social networks as health and disability determinants.

### Methods & Materials

The survey was administered to 10800 persons divided into two age groups: 18-49 and 50+ years in Finland, Poland and Spain.

Data was collected using the **COURAGE in EUROPE Protocol for Ageing Studies** that helped to implement the project in the three countries assuring the quality of the interview's process. Information on different aspects of health, well-being, quality of life, built environment and social networks was collected.

Some preliminary results on socio-demographic characteristics mobility functioning, built environment and social networks profiles are presented below.

### Results

For the three countries almost half of population was married (Finland: 49%; Poland: 55%; Spain: 50%) and more than half lived in urban areas (Finland: 79%; Poland: 62%; Spain: 90%).

Main Chronic Conditions of population of the three countries were back pain (F:37%; P:43%; S:38%), arthritis (F:28%; P:18%; S:15%) and depression (F:13%; P:9%; S:17%).

According to our results self-reported Mobility problems in the three countries increases with ageing and in particular in women, in activities such as walking long distances or climbing stairs.

Preliminary analysis of Social Networks patterns suggested correlations between the number of people composing the networks and the frequency of contacts and the closeness of the contacts. In this sense, higher the layer, higher the frequency of contacts and the closeness of them.

Finally, regarding Built Environment self-evaluation, the results show prevalently the presence of positive characteristics both in open-to-public buildings, facilities and places, and in living places (Finland: 74%/80%; Poland: 64%/70%; Spain: 83%/82, respectively) which suggests the facilitating role of the environments of interviewees.

### Conclusions

**COURAGE in EUROPE Project** collected data on disability, quality of life and well-being, in ageing population and evaluated social cohesion and built environment as factors influencing non-fatal health outcomes in ageing population. Furthermore, COURAGE in EUROPE Consortium produced the **COURAGE in EUROPE Protocol for Ageing Studies** to measure health outcomes and associated factors comparably across Europe.

For further information: [info@courageineurope.eu](mailto:info@courageineurope.eu)

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Please visit the COURAGE website: [www.courageineurope.eu](http://www.courageineurope.eu)

**COURAGE in EUROPE Project: A European Commission project funded within the  
Seventh Framework Program Number HEALTH-F2-2009-223071**





# Preliminary results of ICF dissemination in Albania

13 – 19 October 2012  
Brasilia, Brazil

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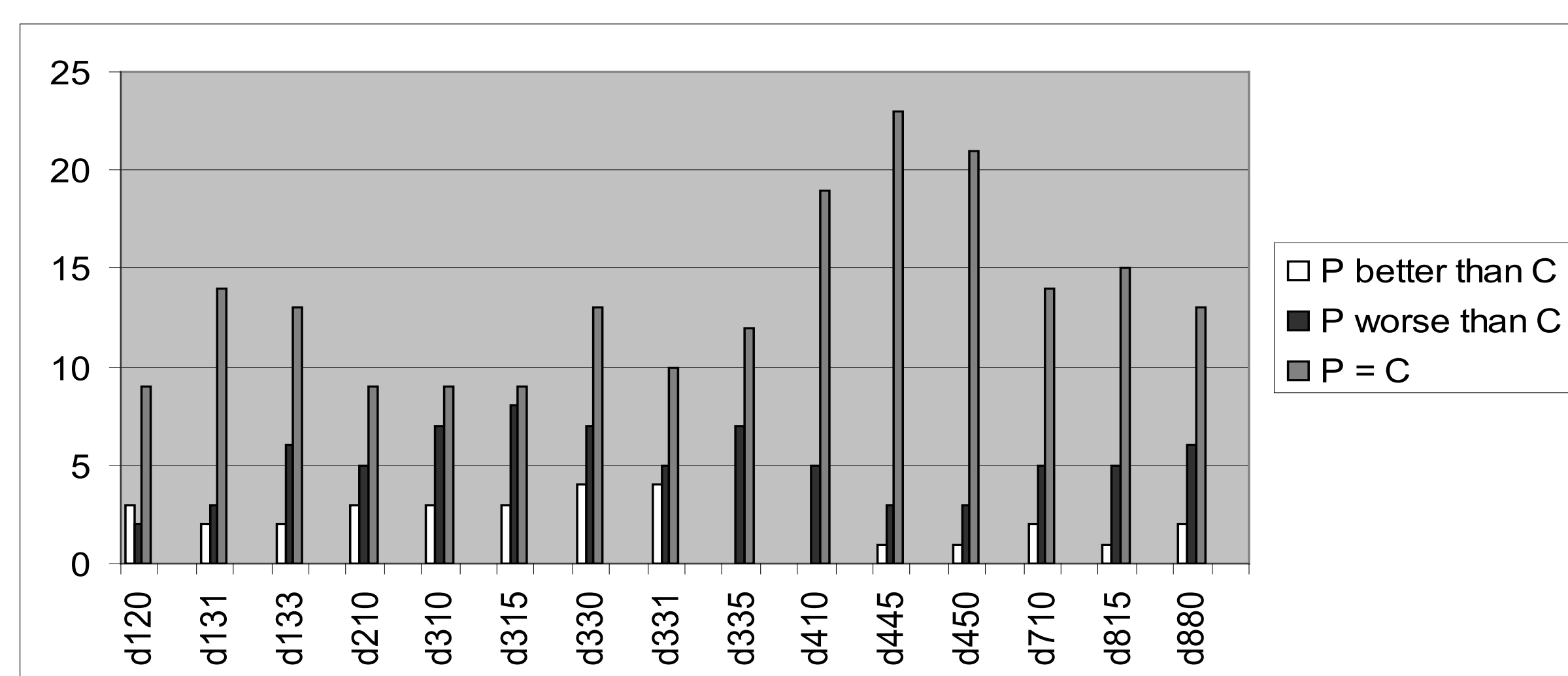
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**Abstract** This project aims to bring to the use the International Classification of Functioning, Disability and Health (ICF) from World Health Organization (WHO) and its nosological fundaments in Albania. After the material adaptation and modification of DIN training tools, two courses were performed. The preliminary results allow the consideration that the Classification could represent a tool to improve outcomes permitting the development of improved rehabilitation projects also reinforcing multidisciplinary approach.

## Introduction

In June 2007, 94,804 people with disabilities (3% of the population), were officially reported in Albania: they receive disability pensions and are registered as recipients through the social welfare system. A survey conducted in 2000 showed that 50% of citizens from rural areas referred to a general practitioner and 45% were registered in a health centre, supporting the idea that limited access to medical evaluation commissions may explain limited disability prevalence in Albania. The rate of institutionalisation is high, even among children, that represent 17% of those in LTC institutions. The disability rights movement in Albania is giving emphasis on community-based services and inclusion but, despite this, people with disabilities in Albania still have difficulties in participation in the labour market, the health and education systems, and are more prone to falling into poverty. The Foundation Besta has been participated in a ICF project in Albania whose aims to assess participation, inclusion and discrimination of PWD in the health centre of Tirana area.

Fig. 3 Comparison (number of cases) of Capacity and performance in Activities and Participation component (on 52 children)



## Methods & Materials

The agenda of the project identified 2 methodological or logistical phases:

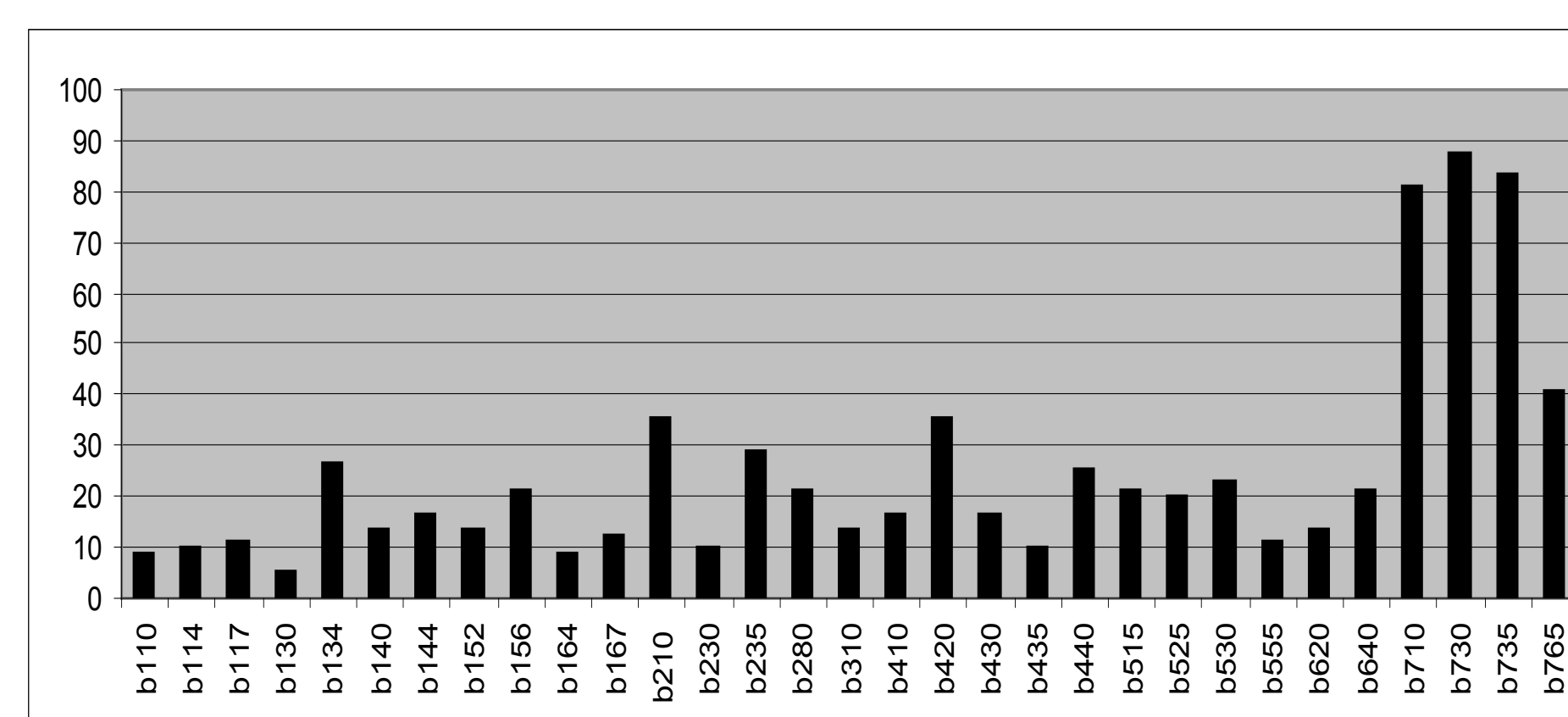
1. Adaptation and modification of training course material to increase the applicability of the protocol (based on ICF and ICF-CY checklist). The training on the International Classification of Functioning, Disability and Health (ICF) was prepared according to the Disability Italian Network (DIN) rules.
2. The training course was organized in a two-step process: the first ICF course was done in April 2010 to the health and social professionals in Tirana area. This course was done having as a framework the theoretical principles of UN Convention on rights of person with disability, and the ICF biopsychosocial model. The second ICF course was done in January 2011 to the health and social professionals in a Rehabilitation Center in Tirana in collaboration with the National Center for Persons with Limited Capacity (an Albanian National entity founded in 2001 with the support of Dokita). This course involved 3 Social Workers, 2 Forensic Scientists, 6 physiotherapists and 5 members of the National Center for Persons with Limited Capacity. The training was done having as a framework the ICF biopsychosocial model and the ICF-Checklist.

## Results

During the collection faze, 142 cases were collected. The pilot study sample was composed of 52 children (26 male and 26 female with an age range from 1 year to 18 year) and 90 adults (36 male and 64 female with an age range from 25 year to 82 year).

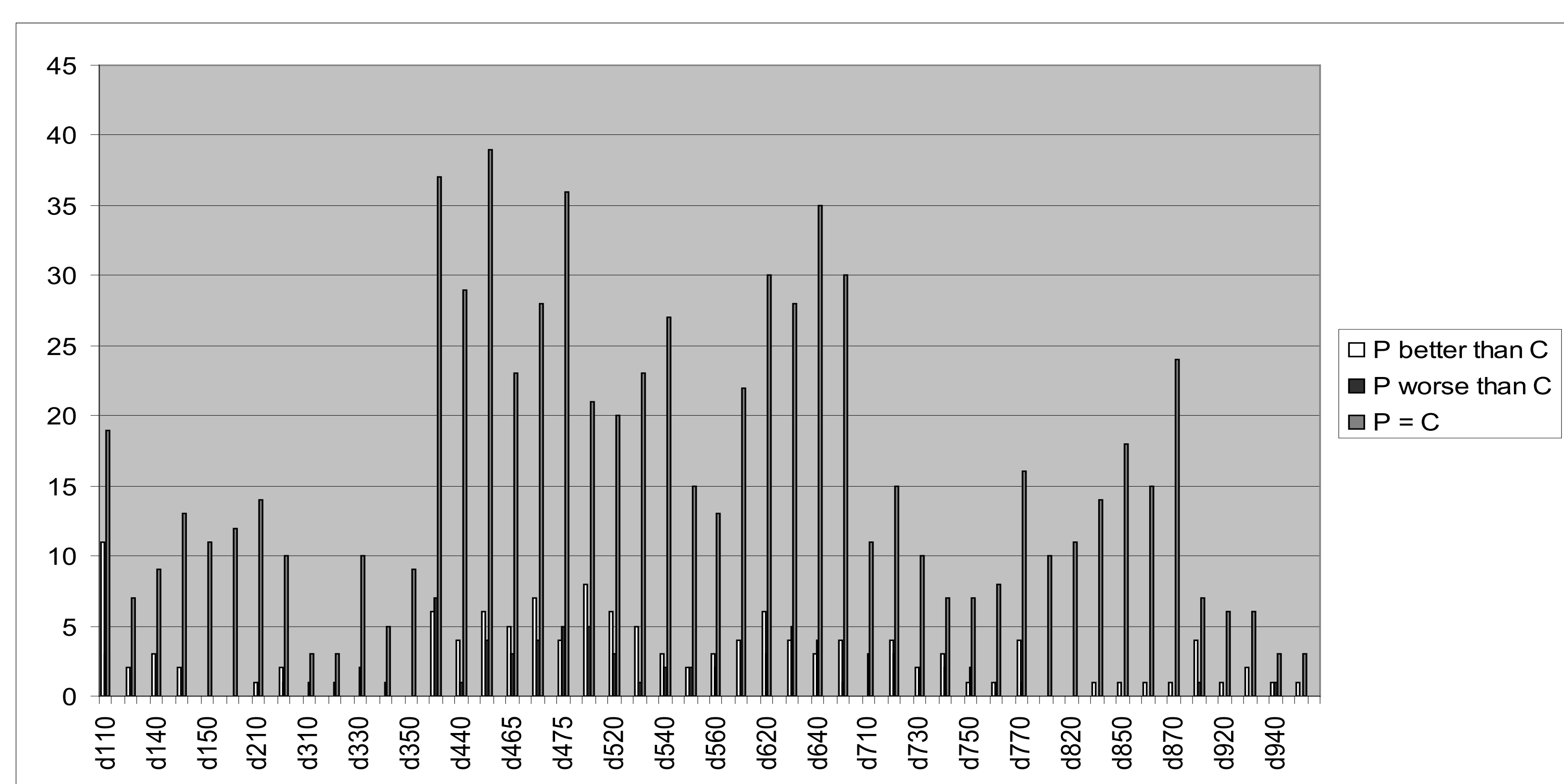
Analysing the ICF data on children, in the Body Function component problem concerned the Chapter 1 – Mental Functions and the Chapter 7 - Neuromusculoskeletal and movement-related functions. The results are presented following the order of the items reported in Figure 1.

Fig. 2 Percentage of ICF items in the body funtions component (on 90 adults)



Regarding A&P, for both children and adults (Figures 3 and 4) P=C was the most common situation, and Performance was worse than capacity more frequently among children than among adults.

Fig. 4 Comparison (number of cases) of Capacity and performance in Activities and Participation component (on 90 adults)



Regarding Environmental Factors the results show the prevalence of Barrier in all Chapters. However, among facilitators, categories regarding Support and relationship (Chapter 3) and Attitudes (Chapter 4) were reported for both children and adults.

## Conclusions

This ICF-based approach enabled a description of the domains of functioning and disability, showing the low impact of EF in determining the actual lived experience of disability in Albanian citizens enrolled in the study. To our knowledge this is the first ICF implementation experience in Albania and it indicates a possible effective approach to its diffusion and future implementation. Opportunities in using ICF tool were generally well appreciated by training participants especially because they considered that the Classification could represent a tool to improve outcome description, enabling the development of rehabilitation projects, reinforcing multidisciplinary approach and community support.



**Abstract** This study aims to describe functioning and disability profile of Very Low Birth Weight (VLBW) infants with the ICF-CY, linking this to traditional psychomotor and cognitive evaluations, namely NFA and GMDS 0-2. ICF profile and correlation between ICF domains and NFA and GMDS 0-2 scores were presented. 56 children completed the assessment. A total of 37 ICF-CY categories were defined as problems, and 18 Environmental factors (EF) act as substantial facilitators. ICF domains correlate with NFA and GMDS 0-2 scores, with a weaker value for EF. In conclusion, the use of ICF-CY checklist significantly enhance the utility of infant’s profile with a biopsychosocial prospective.

**Introduction**

Prevalence of preterm births significantly increased in Western countries in recent years. Approximately 7% of newborns are preterm, and 0.8%-0.9% of them are very low birth weight (VLBW) infants, weighting less than 1500g. Factors such as older age of mother, assisted medical procreation, advances in neonatology and perinatal care, contribute to this increase. Preterm birth is significantly associated with developmental difficulties and disability: it is estimated that around 14-17% of VLBW infants has a disability. They have more risk to develop neurological disorders (such as cerebral palsy, sensory impairments), eating problems, sleep-wake disorders, abnormal postural-motor development, language delay, cognitive difficulties, emotional instability, attention deficit disorder and hyperactivity. Hence, it becomes of primarily interest to understand VLBW infants functioning to improve treatments and interventions. Aim of this study is to describe functioning and disability profile of VLBW infants with ICF-CY Classification [1], linking this to traditional psychomotor and cognitive evaluations.

**Methods & Materials**

A cross sectional study was conducted at Intensive Neonatology Care of Mangiagalli Clinic in collaboration with Neurological Institute Besta. VLBW infants were consecutively enrolled and an assessment protocol composed of Neurofunctional Assessment of

premature baby (NFA) [2], Griffiths Mental Development Scales-Revised-Birth to two years (GMDS 0-2) [3] and ICF-CY questionnaire for age 0-3 [4], between November 2011 and March 2012. Descriptive statistics were performed on sociodemographic and clinical data. ICF-CY categories reported as problem, in at least 20% of the sample, were selected as relevant. The relationship between children assessments and ICF-CY profile domains’ scores, created with a count-based methodology, was evaluated using Spearman’s correlation coefficient.

**Results**

Sixty VBLW infants were enrolled, aged from 12 to 24 months. For 56, mainly female (58,9%) the assessment was completed. Sociodemographic and clinical characteristics are reported in Table 1 and 2. A total of 37 ICF-CY categories reached the relevance criteria, 8 categories from Body Functions, 3 categories from Body Structures, 8 categories from Activity and Participation were defined as problems. Considering the EF only one was a problem and 18 act as substantial facilitators. NFA and GMDS 0-2 total scores

<b>Sibling Pregnancy - n (%)</b>	
One child pregnancy	37 (66.1)
Twins	19 (33.9)
<b>Country of origin - n (%)</b>	
Italy	49 (87.4)
Foreign countries	7 (12.6)
<b>Gestational age - mean (SD)</b>	28,3 (2,9)
<b>Birth weight - mean (SD)</b>	1052,1 (280,3)
<b>Age in months - mean (SD)</b>	20,5 (4,9)

Table 1 Sociodemographic characteristics of the sample

significantly correlated with the ICF-CY domains, but this correlation was lower for EF (Table 3).

<b>NFA - mean (SD)</b>	1,5 (1,0)
<b>GMDS 0-2 - mean (SD)</b>	86,0 (17.3)
<b>ICF domains - mean (SD)</b>	
Body Functions extension	13.9 (14.2)
Body Functions severity	2.3 (5.8)
Body Structures extension	10.0 (14.3)
Body Structures severity	2.9 (7.1)
Performance extension	19.6 (19.0)
Performance severity	2.0 (7.5)
Capacity extension	16.8 (20.3)
Capacity severity	4.2 (12.4)
Facilitators extension	2.6 (6.2)
Facilitators severity	3.5 (5.5)
Barriers extension	3.5 (5.5)
Barriers severity	0.1 (0.5)

Table 2 Clinical characteristics of the sample

<b>ICF domains</b>	<b>NFA</b>	<b>GMDS 0-2</b>
Body Functions	0.813**	-0.775**
Body Structures	0.628**	-0.506*
A&P – Performance	0.594*	-0.665**
A&P – Capacity	0.597**	-0.639**
Facilitators	0.558**	-0.336*
Barriers	0.197	-0.280*

Table 3 Spearman’s correlation (\*P<.05; \*\*P<.01)

**Conclusions**

The low correlation between NFA, GMDS 0-2 and ICF EF domains, shows that NFA and GMDS 0-2 pay few attention to the role of environment in the infants development. The high number of EF codes opened suggests the importance of taking into consideration this aspect. In conclusion the use of an ICF-CY questionnaire together with the traditional assessment instruments can be useful to better describe infants’ functioning and disability profiles, and to define specific and tailored interventions at personal and environmental level, being the last often not considered as a key therapeutical intervention with infants.

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Abstract

Records of 45 maltreated children hosted in Italian Center - Centro Accoglienza Minori della Nostra Famiglia di Ostuni – were linked to ICF-CY and analyzed with the aim to identify the most common problems. This study showed the utility of ICF for structuring information and also identifying information gaps to be filled in in the future.

Introduction

Maltreatment of children is a very complex phenomenon. Literature shows that usually more than one form of maltreatment is present. Short or long term consequences of maltreatment can be detected at different levels: emotional, cognitive, behavioural, etc. It is important to evaluate health and disability and identify personal and environmental factors for effective actions to be taken.

The aim of this study was to define functioning and disability of maltreated children hosted in Italian Center (Centro Accoglienza Minori della Nostra Famiglia di Ostuni), using the International Classification of Functioning, Disability and Health Children and Youth version.

Materials and Methods

ICF-CY questionnaire (for age 7-12) was used to create a data coding protocol for organisation of records of children. Records of children of ages 6-10 from 2003 to 2011, including detailed medical and social information were analysed. All information was read and linked to the ICF-CY second level categories.

Most common problematic areas in Body Functions, Body Structures, Activities and Participation, and Environmental Factors were identified.

Results

Records of 45 children (17 boys, 28 girls, mean age 7.5 years) were analysed.

Sociodemographic and family information was in line with previous findings, showing that maltreated children very often come from fragile social contexts.

The majority of children had parents with various health problems, 12 had parents with previous criminal history, 80% of siblings stayed in the center before.

All children had at least one ICD-10 diagnosis. Twelve children before coming to the Center lived with their family of origin and only one child came back to his family after he/she left the Center.

Identified problems of maltreated children involved different domains of ICF-CY. All components except Body Structures were affected. The most common (reported in 50% of cases) problematic areas were global psychosocial, emotional functions, mental functions of language, temperament and personality in **Body Functions**. The most of them fell into the first chapter of mental functions. Difficulties in Body functions reported more than in 20% of cases are reported in Table1.

Table 1. Problems in Body Functions present in more than 20% of 45 children

ICF code	Description
b117	Intellectual functions
b122	Global psychosocial functions
b126	Temperament and personality functions
b140	Attention functions
b144	Memory functions
b147	Psychomotor functions
b152	Emotional functions
b156	Perceptual functions
b164	Higher level cognitive functions
b167	Mental functions of language
b172	Calculation functions
b210	Seeing functions

Language acquisition, learning (to read, write, calculate), managing tension and stress, talking, interactions with others, participation in play were the most common problems (reported in at least 50% of children) in **Activities and Participation**. Table 2. shows difficulties present in 20% of children either in Capacity or in Performance. Many difficulties are also age-specific, keeping in mind that our group of children were attending primary school where such activities as learning to read, write, count are of great importance.

Table 2. Problems in Activities and Participation present in more than 20% of 45 children

ICF code	Description	ICF code	Description
d133	Language acquisition	d310	Receiving spoken messages
d137	Acquisition of concepts	d315	Receiving nonverbal messages
d140	Learning to read	d330	Speaking
d145	Learning to write	d335	Producing nonverbal messages
d150	Learning to calculate	d350	Conversation
d155	Acquiring skills	d510	Washing oneself
d160	Focusing attention	d530	Toileting
d166	Reading	d540	Dressing
d170	Writing	d710	Basic interpersonal interactions
d172	Calculating	d720	Complex interpersonal interactions
d175	Solving problems	d750	Informal social relationships
d210	Undertaking a single task	d760	Family relationships
d230	Carrying out daily routine	d820	School education
d240	Handling stress and other psychological demands	d880	Involvement in play
d250	Control one’s behaviour	d920	Recreation and leisure

With regard to **Environmental Factors** health professionals and other professionals and their attitudes were reported as main facilitators. Family and their attitudes were the most often reported barriers. This was not surprising taking into account difficult situation of these children and their setting in time of evaluation that is the Center. Although very often families of maltreated children are very complicated, it is very important to identify their strengths that might be lost using the second level ICF categories.

However, a lot of information was considered as possible Personal Factors that are not classified in ICF.

Conclusions

This study showed the potential and utility of biopsychosocial model of International Classification of Functioning, Disability and Health to structure and present information on functioning and disability of maltreated children. Our results suggest that for an effective action it is crucial to have more specific data on environment (that appeared a weaker part of data registration) to act also on environmental factors.