

Folder eCC_00007965 is in stage Annual_Report_Review

Name of the University, Hospital, Research Institute, Academy or Ministry

Regional Central Health Directorate

Name of the Division, Department, Unit, Section or Area

Classification Area, General Directorate

City Udine Reference Number ITA-85

Title WHO Collaborating Centre for Family of International Classifications

Report Year 07/2011 to 07/2012

1. Please briefly describe the progress made in the implementation of your agreed workplan as WHO collaborating centre during the past 12 months (or the reporting period listed above). Please report on how each workplan activity was implemented, if any outputs have been delivered, if any results have been achieved and if any difficulties have been encountered during this time. If an activity has previously been completed, has not started yet, or been placed on hold, please indicate this.

Activity 1

Title: Revision of International Classification of Diseases (ICD-11).

Description: Provision of technical expertise for the ICD-11 revision process until the end of the beta phase and particularly carrying out the following work:

1. To review added concepts, their definition and position in the classification for matching the criteria of a classification element.
2. To work on the transition from ICD-10 to ICD-11 identifying on iCAT the relevant issues raised by URC.
3. To work on the coding rules for morbidity.
4. To review imported definitions for categories for congruency with the meaning of the relevant category of ICD.
5. To work on the application of ICF to the content model of ICD, and propose solutions for alignment on either side, in collaboration with the relevant groups.
6. To review added concepts, and their position in the classification for matching the criteria of a classification element.
7. To review relevant parts of ICD-11 previous to their publication as an alpha draft, for content and structure.
8. To participate TAG Functioning, TAG Mortality and TAG Paediatrics.
9. To support the population of the ICD-11 content model and the development of IT tools.
10. To develop use cases and conduct field trials on ICD-10 to ICD-11 bridge coding and case mix groupings (DRGs, Primary Care, Territorial Groups).

The expertise will made available to WHO by the ItCC according to annual specific agreements.

The collaboration of Francesco Gongolo with WHO-HQ, based on specific TORs and entirely funded by the Italian CC, continued for the period July 2011 – June 2012, both remotely and at WHO-Geneva (30 working days). As per WHO-HQ request, the technical expertise for the ICD-11 revision process was mainly provided in the months before the end of the beta phase and the focus was on two main areas:

a. Transition from ICD-10 to ICD-11. Identification on iCAT and analysis of critical issues raised by URC, MbRG, MRG, and MbTA before and during the ICD revision process. A report was produced in which 118 critical issues (subdivided according to ICD chapters) were analysed, identifying the primarily involved TAG, the actions taken at the time the issue was first raised, the status of that item in the iCAT, and the actions to be taken by the different actors in the process.

b. Revision of the Infectious disease chapter of ICD. MbRG and other relevant groups had in several occasions pointed out the necessity to revise the first chapter of ICD. Together with WHO-HQ staff and other collaborating experts, chapter 1 was re-designed and a draft was produced in Excel format in order to be input into the collaborative platform.

Another area of collaboration in the ICD-11 revision process, mainly carried out by Francesco Gongolo remotely but also in a face-to face event organized at the WHO-FIC annual meeting, was the TAG functioning. The activities were mainly focused on the production of a methodological document on the population of the functional properties for ICD entities and on the production of a document on mirror coding between ICD and ICF.

Concrete outcomes

1. Report on the identification, in the iCAT, of issues related to the transition from ICD-10 to ICD-11 at level of relevant chapter (together with WHO-HQ).
2. Infectious diseases chapter list (together with WHO-HQ and collaborating experts).
3. Guidelines for populating the functioning properties (together with other fTAG members and WHO).
4. Draft document on ICD-ICF mirror coding.

Upon request of WHO-HQ, the CC provided an updated non-official Italian version of ICD-10 to be uploaded in the translation memory developed by WHO-HQ in order to allow simultaneous development of ICD-11 in multiple languages. The translation was made by the Italian CC.

Activity 2

Title: Development of a case mix application for ICD-11.

Description: The activity aims to develop and validate a case mix application of ICD-11, starting from the analysis of the current Italian ICD-9CM DRG system and its possible translation to other case mix systems, and load the corresponding groupings into iCAT also considering ICF for continuity of care applications. Those groupings should be then validated in suitable field trials. This activity not only leads to the development of a case mix use case of ICD-11 but potentially leads to the development of ICHI in case of a strong request coming from interested Countries.

Vincenzo Della Mea, under the agreement with the Italian CC, started his cooperation at the Geneva HQ aiming at supporting stability analysis, which in turn was needed to help in the transition from ICD-10 and DRG to ICD-11. A number of prototype tools was developed to extract, merge, and compare data. The basic input of the process was the DIFF file automatically generated by the Alpha/Beta Browser, and the list of DRG-related ICD-10 codes. Most of the analysis could potentially be done using Microsoft Excel, but the amount of data to be manipulated was large and Excel has limitations in terms of table size and computational capabilities, in particular for older versions. In order to reduce these problems, some PHP scripts were implemented to pre-compile a cross table between DRG and ICD-10-CM codes to be used in Excel. However, these resources were insufficient, even only for counting stable and unstable codes. So another program was developed for coupling the DIFF file with the DRG/ICD-10 codes table, whose output could be (more) easily managed through Excel. This way, most of the least interesting work could be done automatically, leaving room for a better exploitation of the human expert intervention.

Further methods were investigated in order to i) better evaluate stability and ii) help in reaching stability when needed. As in previous attempts, this involved the development of small software pieces, either accessible through the web or producing CSV files to be opened in Excel. Some of the tools have the added value of providing a practical help in quality assurance of ICD-11, as described at the end.

More specifically, the following issues/techniques were investigated:

Which are the sibling codes that appear altogether in the same DRG groupings, but are not present in ICD-11? Among these, which ones have the parent in ICD-11?

A script was developed that produces a list of code clusters composed by a complete set of siblings (so that the whole family is in the same groupings), each of which is identified as having or not the parent in ICD-11. Those having the parent in ICD-11 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? Since postcoordination work individuated a number of postcoordination dimensions (laterality, temporality, etc), we tried to find indicators of such dimensions in sibling titles by applying natural language techniques. A prototype function for discovering postcoordination concepts was added to the above described script. In Mortality Stability, how many missing codes have the parent in ICD-11?

Starting from pure ICD-10, another script was developed to evaluate how many missing codes had the parent in ICD-11. Of about 1,300 codes, about 500 had the parent in ICD-11. Among the outputs, there was a CSV file where a link to iCat was provided for the codes to ease the work when trying to reinstate those codes.

How do duplicate codes impact on stability?

Stability evaluation is mainly based on the DIFF file, which labels each ICD-10 code as being present in both ICD-10 and ICD-11, or missing, or as being a new concept. However, codes were in both ICD-10 and ICD-11 only when it was modified. Moreover, some codes were created after having been removed, other codes were created even if already present, etc. All these issues decreased stability because codes are added that count as unstable codes.

A script was developed with two components. One component was aimed at extracting exact duplicates (same title): 126 exact duplicates were found. In addition to that, a small term comparison algorithm based on stemming was developed, stopwords elimination, and sorting. This was used to identify candidate duplicates when differences between titles were at most one meaningful word. About 330 duplicates were found, with some noise due to generically named concepts. 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. All programs and scripts developed should be considered as prototypes, whose functionalities might be embedded into a more stable tool, e.g., as a side component of the DIFF generation module on the Beta Browser or as a side component of iCat.

Disseminations of the results

Della Mea V, Minty E., Celik C., Ustun TU. Stability analysis support tools. WHO-FIC Annual Meeting, Brasilia, 2012, submitted

Activity 3

Title: IT and Ontological development for WHO-FIC.

Description: Provision of technical expertise, in presence as well as through teleworking, to support the IT and ontology-based developments of the WHO classifications, focused on the ontological redefinition of ICF, the building conceptual and operational linkages between ICD-11 and ICF through the modelling of functioning properties, the mapping of ICF to other terminologies or ontologies (SNOMED-CT, FMA, upper ontologies) and the mapping of measurement scales to ICF in OWL format (FIM, FAM, Barthels, and eventually others).

The activity consists in the following actions:

- (i) Updating of the analysis of the current status of ICF and discover underlying ontological principles on which is founded with reference to other basic ontologies;
 - (ii) Design of a ICF-based functioning properties model to be embedded in ICD11 content model;
 - (iii) Continuity of the Mapping of ICF to other knowledge bases and terminologies and represent mappings in formal languages like OWL;
 - (iv) Representation, by using formal languages, of the links between measurement scales and ICF;
 - (v) Exploration of new ways of ICF usage by means of knowledge based software;
 - (vi) Design of a collaborative project with other WHO-FIC network research centres and fund raising.
- The actions will be carried out in close cooperation with the Ontology Working Group of the WHO-FIC Informatics & Terminology Committee and the domain experts group provided by the WHO-FIC Functioning and Disability Reference Group.

In this year, efforts were directed mainly to IT support for ICD11 revision and implementation, with some strategic involvement in activities related to the ontological development of ICF, as detailed below.

a) 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, replicating online the features of social networks, we started some experiments to bridge the gap between classification revision and social networking. In the case of ICD11, we started from the available ICD11 Browser. In particular, during the first half of 2012, Vincenzo Della Mea spent two months in total in Geneva to explore the feasibility of this approach, in direct collaboration with WHO-FIC headquarters and with the support of Omar Vuattolo at University of Udine (developer of the software solutions). Two research lines were set up:

- development of a prototype application called SocialICD, which is able to show new comments on categories selected by the user directly inside Facebook;
- development of the Open Graph infrastructure, which is needed to add automatic Facebook connection to actions occurring in the ICD11 Browser (i.e., commenting, reviewing, answering questions).

In June 2012, Vincenzo Della Mea was also nominated in the WHO-IHSTDO Joint Advisory Group, whose aim is harmonization between WHO-FIC and SNOMED-CT, and was in turn involved in the ICD11-SNOMED Joint Working Group, which up to now has met once in presence and twice by teleconference.

b) Regarding ICF, the ontology-based exploration of the concepts and relationships in the Activities and Participation component (including mapping to SUMO) was completed and published in the Journal of Biomedical Informatics. At the WHO-IHSTDO JAG meeting, it was decided to form a new joint working group that will work on SNOMED-ICF harmonization; one of the initial inputs could be the preliminary mapping presented at the Cape Town WHO-FIC Network Meeting.

c) Collateral activities:

Vincenzo Della Mea also participated in ICHI development through the development of software aimed at translating current ICHI Excel files into a format more suitable for electronic representation and usage. Developments were discussed at the ICHI Meeting in Freiburg, January 2012. Furthermore, he provided support to the International Council of Nurses in the development of the ClaML implementation profile for ICNP (International Classification of Nursing Practice).

Andrea Martinuzzi participated in the WHO-FIC Family Development Committee mid-year meeting which was held in Beijing (China) on 2-4 July 2012. The meeting focused on ICHI development, with a complementary focus on ICD, Casemix and DRG development. Within this framework Andrea Martinuzzi leads the line of work on functioning interventions (FI), which is based on a list that he had

drafted during a dedicated workshop in Manly (Australia) in 2011, discussed and enriched in Conegliano (Italy) in 2011, and presented to the WHO-FIC meeting 2011. The list of FI, which initially took its start from the interventions listed in chapter 16 of ICD-9-CM, was refined, enriched, and revised with the help of professionals from various rehabilitative and "functional" areas (PT, OT, mental health, neurophysiology). Furthermore a revision/enrichment of the "Means" list was performed by considering some items previously in "Actions" as "Means" (e.g. psychotherapy becomes therapeutic communication, manual therapy is considered as action but different techniques will be listed as means, etc.). A revision of all the "F" targets was carried out starting from the ICF b1 codes in order to populate interventions matching with them (assessments, testing, therapeutic interventions). Considerations on future work were also made starting from overlapping targets between functions and actions (e.g. functions of language and communication). Outputs: (i) draft ICHI chapter on functioning interventions from ICD-9-CM enriched with a list of neurophysiology interventions; (ii) definition of the use of qualifier to signal the use of devices or equipment and the number of recipients (one to one, one to small group, one to family, one to large group); (iii) systematic addition of targets from the A&P list; and (iv) ICHI plan of actions for 2013.

Dissemination of the results

Della Mea V, Simoncello A. An ontology-based exploration of the concepts and relationships in the activities and participation component of the international classification of functioning, disability and health. *J Biomed Semantics*. 2012;3(1):1.

Andronache A, Simoncello A, Della Mea V, Daffara C, Francescutti C. Semantic aspects of ICF: towards sharing knowledge and unifying information. *Am J Phys Med Rehabil*. 2012 Feb; 91(13 Suppl 1):S124-8.

Della Mea V. Lo sviluppo e manutenzione di terminologie e classificazioni e la loro applicazione nei sistemi informativi. In: Congresso Nazionale SIAPEC-IAP, Palermo, ottobre 2011.

Martinuzzi A., Meyer T. Functioning interventions in ICHI: populating a crowded desert. WHO-FIC Network Annual Meeting, Cape Town 2011, D018

Della Mea V., Vuattolo O., Celik C., Ustun BT. Experiments in social networking for classification revision and update. WHO-FIC Annual Meeting, Brasilia, 2012, submitted

Activity 4

Title: Coordination and management of the ICD-10 and ICF update process.

Description: Provision of URC co-chair and secretariat functions, together with the other URC co-chair and secretariat, for 2011-2012 and offer availability for 2013- 2014 to ensure, with cross sectional competence both in ICD and ICF, an integrated approach to the update of the WHO-FIC members. More in detail this activity consists of the overall coordination of the update process done by the co-chair together with the secretariat and in other activities such as refinement of the workflow, clarification of membership and further elaboration of the user guide for the update platform, production of documentation such as desiderata and practical guidance for submission of updated proposal, and in the development and maintenance of policies of update in the perspective of the transformation from ICD-10 to ICD-11.

The Italian CC provided for the Update and Revision Committee co-chair and secretariat functions, together with the other URC co-chair and secretariat. In the timeframe July 2011- July 2012, the Italian CC continued to support the ongoing process of ICF update on the items coming from the ICF-CY. As final outcome, 46 update proposals were put forward by the FDRG and processed by the URC during the face-to-face annual meeting and a dedicated extraordinary teleconference organized by the URC in order to process as many updates as possible. To better streamline the update process, the Italian co-chair of the URC, together with Paula Tonel as secretarial support for the Committee, joined the works of the Initial Review Group, participating in the monthly teleconferences of the group in order to define work steps and to ensure meeting of deadlines. The update platform was monitored in order to report on the advancement of the work and to send reports on the status of the proposals to the Initial Review Group, the FDRG, and the URC. The platform was managed accordingly and every step of the process was recorded for transparency.

A series of documents were produced:

- 2010-2012 Update list (Reporting form ICF Updates 2010_12 English version), with the usual strike-through underline convention to highlight changes between the approved version and the original ICF text
- ICF database in Microsoft Excel format, which was updated accordingly in order to be made available by WHO-HQ in due time (together with WHO-HQ)
- Status of the update platform's Closed Group Layer: working document for URC members at the beginning of the Open Discussion Layer review period
- Comments on ICF proposals: working document for the co-chairs and secretariat of FDRG and for the Moderators of the Initial Review Group in order to summarize and draw recommendation on the Update Proposals at the end of the Open Discussion Layer review period
- ICF updates – new items for URC decision – 1st voting round: working document for URC members at the beginning of the Closed Discussion Layer period
- URC draft minutes from the Cape Town Annual meeting
- URC draft minutes from the November 2011 Update Teleconference.

Dissemination of the results

Gongolo F. Updating the ICF in WHO Family of International Classifications (FIC) Newsletter, RIVM, Volume 10, Number 1, 2012

Gongolo F. Synchronization between update and revision processes in the transition from ICD-10 to ICD-11 (remotely at Las Vegas beta preparation meeting, March 2012)

Renahan M., Gongolo F., Moskal L., Update and Revision Committee (URC) Annual Report 2010-2011 WHO-FIC Network Annual Meeting, Cape Town 2011

Renahan M., Gongolo F., Moskal L., Tonel P., Update and Revision Committee (URC) Annual Report 2011-2012 WHO-FIC Network Annual Meeting, Brasilia 2012, submitted

Activity 5

Title: National work on WHO-FIC.

Description: Translation of WHO-FIC materials into Italian. The Italian Centre serves as a focal point for translation and publication of WHO classifications and related documents in Italy. It promotes the adoption, on the basis of the work plan agreed with the Italian Ministry of Health, of the translated versions of the WHO-FIC materials of national relevance.

Design and diffusion of WHO-FIC training tools and guidelines to describe functioning/disability profiles. The Italian Centre serves as a focal point for translation, publication and training of WHO-FIC training tools. The Italian Centre is also specifically committed to WHO and national and local institutions for the development of training tools and guidelines on how to use ICF in disability assessment and eligibility according to ICF disability/functioning definition. It acts as a national reference point for training on WHO-FIC use.

Software applications for using WHO-FIC in national data collection and analysis. Design and develop software that implement new ways of interacting with FIC-based data, including collection, usage, visualization, decision support. This includes software to: - Support social networking-based update of WHO classifications (e.g. ICD-11); - Collect coded data in health and social information systems; - Deliver codes from local information systems to general repositories; - Provide software modules for other WHO -compliant software. In the design process, exploitation of current standards might be involved, as well as development of specifications for communication standards.

ICF implementation in national disability policies and development and deployment of national ICF implementation knowledge database.. This line of work is a national priority. The Italian CC officially supports four national Ministries to introduce ICF in disability evaluation at different levels and in different policies. The Centre ensures adherence and coherence to ICF conceptual framework in multiple application and implementation areas informing the development and product refinement on how to document and code with ICF at national level.

The workline consists of the following:

- (i) use of WHO-FIC and health terminologies within the National Health System and the National Health Informative System, in close cooperation with the Italian Ministry of Health;
- (ii) set up and implementation of guidelines introducing ICF-CY in primary schools, in close cooperation with the Italian Ministry of Education, University and Research;
- (iii) ICF based data collection for job inclusion of persons with disabilities, in close collaboration with the Italian Ministry of Welfare and social Policies and the Italian Workers' Compensation Authority (INAIL)
- (iv) Definition of ICF based items to use in national administrative data and population survey on children disability, in close cooperation with the Italian Ministry of Education, University and Research.

ICD implementation strategy in Italy. On behalf of the Italian Ministry of Health, ItCC will be responsible for the coordination and implementation of a national work plan aimed to introduce ICD-10 and modify the current classification of interventions and procedures, in order to pay for hospital products through Italian DRGs (Government funded four-year project "Progetto di un nuovo sistema di misurazione e valorizzazione dei prodotti delle strutture ospedaliere. New measurement and paying systems for hospital products." IT.DRG). An analysis of the current Italian DRG system will be carried out, new case mix applications will be developed, and, upon WHO approval, groupings will be loaded into iCAT. Training programs will be realized focused on the use of the new classifications by clinicians and statisticians starting from field trials to routine.

Development of a first draft of a children version of WHODAS 2.0 and its validation through the clinical activities of the ItCC research branches Car

(i) The Italian Centre developed software applications for using WHO-FIC in data collection and analysis. New ways of interacting with FIC-based data were implemented, including collection, usage, visualization, and decision support. This includes the FABER software and the ICF machine software to collect coded data in the health and social information systems and to store data from local information systems in general repositories.

- FABER - In 2011, the alpha version of a new web application was developed using ICF-CY and other medical terminology systems as a basis for a flexible standards-based bio-psycho-social record. Conceptual design and implementation of a minimum dataset for individual records were developed in

accordance with an ad hoc bio-psycho-social evaluation protocol tested in more than 1,300 Italian outpatients during the last three years. The application includes an information model and a description model. The information model contains concrete record entries, such as socio-demographic factors, main carers list, social support, health and social care, treatments, assistive devices and other products and technologies. The description model provides templates for the bio-psycho-social record. The templates describe information that can be entered and automatically mapped to ICF-CY concepts, and specify how the concepts can be combined with natural language sentences and which concepts are mandatory or not. Extensions are provided for the ICF-CY categories of Environmental Factors (EFs), which are too broad for a precise description of the interaction between an individual and his/her surrounding environment, and for individual care planning purposes. To create a suitable bio-psycho-social lexicon, information is aligned with a terminology collection containing ICF-CY, ISO9999 (1998), national nomenclatures of medical products, and social and health intervention vocabulary. A proposal of an HL7 CDA2 specification of representation of the records will be defined following the model of specification proposals for health records approved by national bodies. The bio-psycho-social record is planned to be filled in different steps and by different professionals. Information on personal and environmental factors is collected using natural language (no skill in ICF language is needed) by health or social professionals at patient admission. The web application translates information into ICF-CY EFs and releases a neutral list of EFs as first output. The functioning/disability ICF-CY based assessment is carried out by multi-professional teams, which input information to be coded, being facilitated by the web application in matching EFs to each A&P category. The web application releases specific outputs useful to distinguish between functioning and disability in the same functioning profile and identify which EFs are involved, to provide disability certifications and to plan reasonable adaptations to overcome disability. Two types of interactions are possible: a positive interaction, which is described by a performance qualifier value 0 or 1, and a negative interaction, which is described by performance qualifier values 2, 3, or 4. The first field trial was conducted in the Friuli Venezia Giulia Region in 2011 and the second is ongoing, implementing the regional Health and Social Action Plan 2010-2012. Some results were submitted to the WHO-FIC meeting 2012.

- In order to foster the application of selected sets in information systems, we first devised an implementation profile in ClaML for the concise representation of these sets in XML. We then developed a web-based system based on ClaML representations of selected sets. The implementation profile only describes codes and not definitions and other rubrics: thus, for its application, a full ICF file is also needed, where all the needed information is stored. This allows for distribution of sets, while its deployment in an information system will also need a licensed ICF file. The implementation profile was used to produce a ClaML version for 4 questionnaires for pediatric ages (<3 years, 3-6 years, 7-12 years, adolescents) and 13 core sets (Stroke, Breast Cancer, Depression, Osteoporosis, Chronic Ischemic Heart Disease, Chronic Widespread Pain, Diabetes, Obesity, Osteoarthritis, Rheumatoid Arthritis, Spinal Cord Acute and Chronic, Low Back Pain). A web-based prototype was designed and developed based on the ClaML implementation profile to provide a first prototype of a generic web-based application for data collection. Collected data is stored on a database as a pair of codes plus qualifiers. The application was developed in PHP5, using the open source database MySQL on an Ubuntu Linux server. A version 2 has been recently developed to introduce the possibility of adding codes not present in the chosen selected set, in order to expand the subject profile according to true needs.

(ii) The Italian CC officially supports four national Ministries in introducing ICF in disability evaluation at different levels and in different policies. The Centre ensures adherence and coherence to the ICF conceptual framework in multiple application and implementation areas, informing the development and product refinement on how to document and code with ICF at national level.

During this year, the lines of work were as follows:

- The Italian Portal of Classifications was implemented to support the collaborative authoring of the electronic Italian version of WHO-FIC, according to the agreement between the Italian Ministry of Health and the Friuli Venezia Giulia Region (www.reteclassificazioni.it).
- The Italian CC was involved in the set up and implementation of guidelines for using ICF-CY in the Italian education system, in close cooperation with the Italian Ministry of Education, University and Research (MEUR) under the "ICF Project". Lucilla Frattura was appointed as a member of the National ICF Technical Group. The national two-year project began in 2010 and is scheduled to end in December 2012. It is financed by the MEUR. 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, thus avoiding the risk of a Babel of languages, and how to better accommodate diverse students. 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. The first results of the mid-term monitoring were submitted at the forthcoming 2012 WHO-FIC Annual Meeting.

- The Italian National Institute of Statistics released the first results of the survey on students with learning support teacher in primary and lower secondary schools (public and private) for the school year 2009-2010. The survey response rate was 89%, for a total of 23,451 schools participating in the study. The survey collected also information on 5,600 students with learning support teacher. The questionnaire was filled in by the learning support teacher. For the first time the ICF classification was introduced in a statistical survey carried out at national level. The ICF was used to describe the specific needs of students with learning support teacher, completed by a description of the environment in terms of buildings accessibilities, staff, and technologies available for students. The results were presented at the WHO-FIC Network 2011.

- ICF-based data collection for job inclusion of persons with disabilities, in close collaboration with the Italian Ministry of Welfare. The implementation of ICF-based assessment tools to realise the targeted employment of people with disabilities started in Italy in 2004 and it represents a work in progress. Matching a person's features with company's requirements is the key factor for a successful work placement. The common language provided by the ICF was tested to verify how the ICF model of disability could be useful to facilitate such a matching process. In 2010, a new national programme was launched on the evaluation of functioning/disability of disabled persons in order to study the conditions necessary for their inclusion in a work setting and to include a study sample. Italia Lavoro is the governmental body responsible for the programme on behalf of the Ministry of Labour. The WHO-FIC Italian CC, with Lucilla Frattura as the work line coordinator, supported Italia Lavoro in the training of professionals, in the development of the assessment protocols, and in the definition of how the information system can use ICF as a standard. Two ICF-based evaluation tools (Worker Assessment Protocol, Company Assessment Protocol) were developed. They were tested in 11 Italian Regions. A sample of 220 persons and 220 companies were recruited and evaluated. More than 700 professionals were trained. The dedicated ICF-based worker assessment protocol was developed on the basis of the ministerial schedule for the evaluation of persons with disability and was set up starting from the protocol defined by the WHO-FIC Italian CC and tested in more than 1,000 persons in Italy under a previous national programme. In March 2012, the final meeting was held in Rome, in which results were presented and perspectives for implementation were launched.

- ICD implementation strategy in Italy. On behalf of the Italian Ministry of Health, Lucilla Frattura is responsible for the coordination and implementation of a national work group aimed at introducing ICD-10 and at modifying the current classification of interventions and procedures in order to pay for hospital products through Italian DRGs (Government funded four-year project "Progetto di un nuovo sistema di misurazione e valorizzazione dei prodotti delle strutture ospedaliere. New measurement and paying systems for hospital products." IT.DRG). An ICD-10 training for the Italian community of child neuropsychiatry and psychology was designed and developed: education events are planned for the autumn of the current year.

Dissemination of the results

Frattura L., Simoncello A., Bassi G., Terreni S., Health information systems learn to speak ICF: toward flexible ICF based individual records. WHO-FIC Network Annual Meeting, Cape Town 2011, D039p

Frattura L., Simoncello A., Bassi G., Soranzio A., Terreni S., Sbroiavacca F., The FBE development project: toward flexible electronic standards-based bio-psycho-social individual records. In: Proceedings XXIV Conference of the European Federation for Medical Informatics, Pisa 2012

Bassi G., Simoncello A., Frattura L. Mapping ISO9999 to ICF in health information systems. The FABER way. WHO-FIC Network Annual Meeting, Brasilia 2012, submitted

Frattura L., Bassi G., Simoncello A., Bazzo G. ICF implementation in regional policies: the case of the Friuli Venezia Giulia region, Italy. WHO-FIC Network Annual Meeting, Cape Town 2011, D030p

Frattura L., Rizzi L., Anzilutti S. Coding Environmental Factors for the component Body functions and Body structures: first results from a field trial in Italy. WHO-FIC Network Annual Meeting, Brasilia

2012, submitted

Della Mea V., Fiorese V. ICF Machine: a web-based system for collection of ICF data. In: Proceedings of Medical Informatics Europe (MIE2012), Pisa, 2012.

Frattura L. The use of ICF assessment in the information systems for global take in charge: the Friuli Venezia Giulia experimental design. Convegno ICF come linguaggio comune per la valutazione della disabilità. Roma, 6-7 giugno 2012

Frattura L. Functioning and Disability assessment with ICF and ICF CY: state of the art and perspectives. Convegno ICF come linguaggio comune per la valutazione della disabilità. Roma, 6-7 giugno 2012

Martinuzzi A. Experiences on implementation of ICF in Italy and worldwide. Convegno ICF come linguaggio comune per la valutazione della disabilità. Roma, 6-7 giugno 2012

Frattura L. Disabilità, diversità, discriminazione vs Funzionamento, diversità, inclusione: percorsi valutativi nella scuola e modello ICF. Dove andiamo? Seminari MIUR, Progetto ICF, Napoli, Roma, Brescia, Marzo 2012

Frattura L., Ciambrone R., Simoneschi G. Using the ICF to assess and promote inclusive education in Italy: a bottom-up approach for defining national recommendations. WHO-FIC Network Annual Meeting, Brasilia 2012, submitted

Battisti A., Solipaca A., Crialesi R. The use of ICF to describe the needs profile of student in primary and lower secondary schools. WHO-FIC Network Annual Meeting, Cape Town 2011, D028p

Frattura L., Conclave M., Gorini G. ICF implementation in targeted employment of persons with disabilities: the Italian work in progress. WHO-FIC Network Annual Meeting, Cape Town 2011, D031p

Frattura L. I processi di diffusione dell'ICF e l'applicazione nell'inserimento lavorativo dei disabili.

Convegno "La diffusione dell'ICF nell'inserimento lavorativo dei disabili", Roma 28 marzo 2012

Leonardi M., Martinuzzi A., Meucci P., Sala M., Russo E., Buffoni M., Raggi A. A Population Survey in Italy based on the ICF Classification: recognizing persons with severe disability. The Scientific World Journal, Volume 2012, Article ID 189097

Activity 6

Title: Awareness building and implementation support of WHO-FIC in WHO regions.

Description: Promotion of the WHO-FIC members as reference framework in disability assessment, data collection and eligibility, including monitoring of the UN Convention on the Rights of Persons with Disabilities within international initiatives on health and disability policies.

The main networks in which the present activity is executed are the following:

(i) The Assembly of European Regions: attendance as a WHO-FIC reference to Committee n. 2 Social Policy and Public Health (current president: the Friuli Venezia Giulia Minister of Health and Social Policies, V. Kosic).

(ii) Alps Adriatic Working Community. It counts 10 member Countries and Regions: Friuli-Venezia Giulia Region, Baranya (AUT), Burgenland (AUT), Carinthia (AUT), Croatia, Lombardy (ITA), Slovenia, Styria (AUT), Vas (HUN), Veneto Region (ITA).

(iii) Network promoted by the RHETI Project and financed by the EU PROGRESS Programme on the implementation of the objectives of the European Union in employment, social affairs and equal opportunities.

(iv) The Eastern European Countries (primarily Albania and Kosovo) involved in the implementation of the Friuli Venezia Giulia Operational Plan 2010 - 2013 "The international dimensions of FVG Regional Health Policy" on five priority fields of action: a) disability; b) social and psychosocial disadvantage; c) motherhood and childhood; d) advanced biomedical technologies; e) healthcare management.

(v) EUREGHA: open network of regional and local authorities, including the Friuli Venezia Giulia regional Ministry of Health and Social Policies, focused on public health.

(vi) Clinical Network of "Eugenio Medea" Scientific Institute for Research in extra-European Countries. Serve as resource of persons for WHO-FIC related training and capacity building activities as requested by WHO-HQ or Regional Offices.

The Italian Collaborating Centre takes part in the COURAGE Project in Europe, for development and validation in three European countries of ICF-based measures of health and health-related outcomes for an ageing population.

The Italian CC promotes the WHO Family of International Classifications as a reference framework in disability assessment, data collection and eligibility, including monitoring of the UN Convention on the Rights of Persons with Disabilities within international initiatives on health and disability policies.

It serves as a resource of persons for WHO-FIC related training and capacity building activities as requested by WHO-HQ or Regional Offices.

KOSOVO

The Italian Development Cooperation has intervened 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. 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. 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).

a) Within the general framework of the project "Support to the National Disability Action Plan in Kosovo" by the Italian Ministry of Foreign Affairs and Development Cooperation, the Italian WHO-FIC CC financed and hosted in Udine, at the end of November 2011, the international seminar "Autumn school for/with Kosovo" aimed at building awareness of the ICF and at implementing consistent functioning and disability assessment tools in Kosovo. The seminar was coordinated by Lucilla Frattura, Francesco Gongolo and Giulio Antonini and followed previous missions of Italian CC experts in Kosovo during which training on ICF was given (Francesco Gongolo, Gianni De Polo). The seminar was by invitation only and was attended by 30 professionals, 12 from Kosovo Ministries and the Municipality of Gjilan, 14 from the local health authorities of the Friuli Venezia Giulia Region and main PWD associations, the others from the Italian CC HQ. The seminar was jointly organized in order to share experience on different functioning/disability related topics. A final report was drafted, revised and jointly approved in form of recommendations, which are the result of a full agreement between the organizers and the Kosovo delegates. As a result of this understanding, other activities were planned to assess the barriers to participation of children in the pilot Municipality of Gjilan.

b) In 2012, a descriptive study was designed by a group of experts coordinated by Dolores Mattossovich 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. The experts of the Italian Collaborating Centre HQ and the Department of Statistics of the University of Udine were involved in the revision of the questionnaire and the study design. The sample was selected with the support of local institutions. 322 children applied, from July 2009 to March 2012, to the Commission for Benefits granted by the Material support law (100 Euro a month). 60 % were males. One third was 6-12 years old. 59 children with disability were attending local schools, 40 of them are currently on material benefits while some have already fallen in the category 18-65, which means a lower pension (45 Euros). Data will be collected during summer 2012.

ALBANIA

Training courses on ICF prepared by the Italian WHO FIC CC and ICF dissemination in Tirana (Albania). This activity was funded by an international cooperation project between the Besta Institute, the government of Albania, and Dokita (a NGO operating locally) for the evaluation of disability in a Rehabilitation Center built by Dokita in Tirana. The first ICF course was given in April 2010 to health and social professionals in the Tirana area. The theoretical principles of the UN Convention on the Rights of Persons with Disabilities and the ICF bio-psycho-social model were used as a framework for the course. The second ICF course was given in January 2011 to 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 ICF biopsychosocial model and the ICF-Checklist were used as a framework for the course. The trainer adapted and modified the course material to increase the applicability of the protocol to the cultural and social reality of Tirana. The very first phase of this project indicates that the use of the ICF checklist is feasible also in a Rehabilitation Center in Tirana.

ICD in Albania. The collaboration between the Italian WHO-FIC CC and the WHO European Country Office on ICD-10 implementation in Albania started last year under the auspices of WHO-HQ and continued during the timeframe considered in the present report. Francesco Gongolo was made available as classification expert by the Collaborating Centre for the biennium 2012-2013. A mission to Tirana took place on 22-25 May with the following aims: to discuss with the authorities the technical aspects related to the introduction of ICD-10 on a national basis; to identify individuals who can

perform various tasks within the process; to identify strategic areas in which to implement a pilot introduction of ICD-10; to identify the materials needed in order to start training in coding with ICD-10 in these strategic areas; to highlight the methodological steps needed to be taken into account in the translation of the ICD-10 updates. After completing the tasks a comprehensive end of mission technical report was produced and submitted to the WHO Albania Country Office and to WHO-EURO.

EGYPT

Clinical Network of "Eugenio Medea" Scientific Institute for Research in extra European Countries - WHO Egypt and the Egyptian Ministry of Health, with the support of the "Eugenio Medea" Scientific Institute for Research (Andrea Martinuzzi), launched a scaling up plan to test and introduce an ICF-based disability surveillance system in Egypt. Objectives of the plan are to identify information needs and technical requirements for a disability surveillance system in Egypt and to set the stage for a locally based ICF training dissemination. The final goal is the development of a national ICF-based disability surveillance system. The project was organized into 2 phases.

Phase 1: training, pilot testing. In November 2011 the program started with a training workshop which involved 19 professionals with different backgrounds (mainly doctors involved in rehabilitation and mental health for both children and adults) and from various Institutions (see attached list). The aim of the workshop was to introduce the participants to the ICF and train them in the use of ICF for describing and reporting functioning and disability information at the clinical level.

The workshop achieved the expected results at that stage. During the interval between the conclusion of the first phase and the following phase, a pilot testing took place, in which each participant tested the ICF in his clinical setting. This practical implementation experiment was also intended for providing the information needed to frame the definitive common ICF-based form to be used in the following phase. ICF profiles were completed in 6 Centers for 240 cases. Most of these were children and adolescents, mainly with neuro-developmental and psychiatric disorders. Coding was mainly completed from available medical records. Different methodologies were followed. The main problem was the lack of non-medical but functionally relevant information. The main benefit was the change in perspective brought by the need to describe the person in all his functioning aspects and in interaction with the context.

Phase 2:

1) development and testing of the common ICF form. In June 2012, the same group of professionals involved in Phase 1 reviewed the results of pilot testing and defined a commonly agreed ICF form that had already been "lab-tested", confirmed in its validity, and was ready for extensive systematic implementation at the selected testing sites.

Starting in July 2012 till February 2013, the phase 2 implementation testing will proceed. ICF forms will be used in the 6 identified Centers already experienced in ICF use plus 3 new entries: the Army Rehabilitation Centre, the Health Insurance Organization and the Hearing and Speech Institute.

2) identification and testing of local trainers. 7 participants to the workshops were tested for their proficiency in training others on ICF using the training material provided by the Consultant and already used in the first round of training. The material will be translated into Arabic to ease its use and dissemination among various participants with different backgrounds. All prospective trainers will have held at least 1 training course involving selected participants at the local level by next February. Training efficacy will be objectively tested with pre/post test questionnaires.

Larger and more systematic training will take advantage of these initial experiences but will be organized and managed centrally.

COURAGE

The Besta Institute (lead partner; Matilde Leonardi, Coordinator), the Italian CC HQ (partner; Lucilla Frattura, Scientific Head), and the Eugenio Medea Institute (partner; Andrea Martinuzzi, Scientific Head) taken part in the COURAGE Project in Europe for the development and validation, in three European countries, of ICF-based measures of health and health-related outcomes for an ageing population. The COURAGE in EUROPE Project is a European Commission project funded within the Seventh Framework Programme Number HEALTH-F2-2009-223071. It involves 12 partners from 4 European countries and the World Health Organization. It was inspired by the need to respond to the pressing need to integrate international studies on disability and ageing in light of an innovative perspective based on a validated data-collection protocol. 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 was conducted by the

partners in Finland, Poland and Spain where the survey was administered to a final sample of 10,800 persons. Preliminary analysis strategy was developed and first overall results were produced. COURAGE in EUROPE is not proposing "another" ageing study, but it has produced a useful tool to measure health and health-related outcomes for an ageing population in relation to quality of life and well-being outcomes as well as considering the role of built environment and social networks as health determinants.

Dissemination of the results

Frattura L., Gongolo F., Antonini G. (edt) Seminario internazionale Autumn School for/with Kosovo su ICF e nuove prospettive per la presa in carico e l'inclusione nella società delle persone con disabilità / Seminari ndërkombetar Autumn School for/With Kosovo Mbi KNF-në dhe perspektivat e reja për marrjen në ngarkim dhe përfshirjen në shoqëri të personave me aftësi të kufizuara. Sintesi dei lavori e raccomandazioni /Sintezë dhe rekomandime, Udine 2012

Gongolo F., De Polo G., Mattossovich D., Ibrahim H., Miftari I., Lomuscio M., Martinuzzi A., Frattura L.. ICF in framing the National Action Plan for People with Disabilities in Kosovo. WHO-FIC Annual Meeting, Cape Town, 2011, D010p

Mattossovich D., Frattura L., Gongolo F., et al. Using the ICF framework for collecting information on barriers to children's inclusion in the Republic of Kosovo. Design and preliminary results. WHO-FIC Annual Meeting, Brasilia, 2012, submitted

Gongolo F. Implementation of ICD-10 in Albania – Technical report (submitted 4 June 2012 to WHO-EURO)

Gongolo F., Loyola Elizondo E.G., Miho V., Jakob R. Preliminary analysis for a process of implementation of ICD-10 in Albania, WHO-FIC Annual Meeting, Cape Town, 2011 D042p

Leonardi M., Meucci P., Cerniauskaite M., Quintas R. ICF training in Albania and Bosnia and Herzegovina. Cape Town, 2011 D029p

Meucci P., Leonardi M., Preliminary results of ICF dissemination in a Rehabilitation Center in Albania. WHO-FIC Annual Meeting, Brasilia, 2012, submitted

Leonardi M., Raggi A., Koutsogeorgou E., Cerniauskaite M., Quintas, R. Understanding ageing and determinants of health and disability in ageing to guide public health policies: the COURAGE in EUROPE Project. Cape Town, 2011 D006p

Martinuzzi A., El Hennawy H., Hassan Al-Gasseer N., and the Egypt ICF working group. Implementation plan for an ICF based disability surveillance system in Egypt. WHO-FIC Annual Meeting, Brasilia, 2012, submitted

Activity 7

Title: Strengthening of Italian WHO-FIC Network and contribution to WHO-FIC network activities.

Description: Italian CC maintains, on the basis of an institutional agreement, an Italian network between the institution designated as WHO-FIC Collaborating Centre and three research branches, throughout two steering bodies: the Italian WHO-FIC CC network Scientific Committee, made by the Italian CC Head (coordination) and the three scientists delegated by the three institutions; the Italian WHO-FIC CC Steering Committee, made by the legal representatives of the four parts of the ItCC network and coordinated by the legal representative of the Institution designated as ItCC. The Italian WHO-FIC CC Network Scientific Committee organizes annual face to face meetings, in order to verify, prior reporting to WHO, full adherence to the WHO vision and scopes in the different planned activities.

Contribution to the key products of Committees and Reference Groups. Providing technical expertise to assist WHO in the development, testing, implementation, use, improvement, update and revision of WHO-FIC members within the WHO-FIC network.

More in detail this activity allows the ItCC members to contribute through all the ItCC planned activities and in particular the following are not already mentioned in other relevant activities of the present form: statistical implementation of ICF classification according to international and national experience on health and social statistics; development of contents and statistical implementation of ICD according to international and national experience on mortality statistics; dissemination and training in mortality statistics.

ItCC members actively participating in the network activities, through face-to-face and on-line meetings as well as remote work, according to the specific work plans of each group and specific agreements.

The Italian CC maintains an Italian network between the institution designated as WHO-FIC Collaborating Centre and three research branches. The Italian WHO-FIC CC Network coordination organized face-to-face and on-line meetings as well as remote work, in order to verify, before reporting to WHO, full adherence to the WHO vision and scopes in the different planned activities. It contributed to the key products of Committees and Reference Groups and provided technical expertise to assist WHO in the development, testing, implementation, use, improvement, update and revision of WHO-FIC members within the WHO-FIC network. 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. 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. A few preliminary performance indicators were defined. 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.

ICF User guide - The Italian CC-HQ and its research branches provided active momentum to the development of the ICF User Guide in order to be presented in its completed draft at the WHO-FIC meeting in Brasilia. The revision of the existing documents presented in Cape Town was carried out in a workshop held in Zurich in January 2012 with the participation of Andrea Martinuzzi, FDRG co-chair Ros Madden, Judith Hollenweger, and Nenad Kostanjsek from WHO. The user guide structure was defined, and the timetable for the next steps was delineated with the goal of presenting a complete document for review to the whole FDRG and EIC by August 2012.

On 28-30 June 2012, an FDRG Workshop for the finalisation of the ICF User Guide was hosted in Udine by the Italian CC. Although the workshop was operative and therefore closed to a small number of attendees, the participation ensured representation of 7 Collaborating Centres: Italy (Andrea Martinuzzi, Matilde Leonardi, Lucilla Frattura, Andrea Simoncello), North America (a delegate from Canada and one from US), Brazil, Australia, Germany, The Netherlands, and South Africa. The activities were aimed at re-drafting the ICF User Guide, starting from an earlier version which was circulated and commented prior to the meeting by participants and other members of the FDRG. The systematic review of the document, through discussion and clarification of points raised by the attendees, brought to a completely re-drafted version, which is now under review by FDRG and EIC as scheduled.

Dissemination of the results

Frattura L, Gongolo F. Building bridges for knowledge sharing: the performance monitoring plan of the Italian WHO-FIC Collaborating Centre. WHO-FIC Network Annual Meeting, Brasilia 2012, submitted

2. Please briefly describe your collaboration with WHO in regards to the activities of the WHO collaborating centre during the past 12 months (e.g. means of communication, frequency of contact, visits to or from WHO). Please feel free to mention any difficulties encountered (if any) and to provide suggestions for increased or improved communication (if applicable).

See the activities as described above for a full specification of the persons and time made available to WHO at WHO-HQ and to WHO-EURO for other missions. As far as the means of communication are specifically concerned, the collaboration took advantage of e-mails (contacts on average on a daily basis), shared work-spaces (iCAT collaborative platform for ICD-11, iCAT users' group, RSG shared workspace, Mayo Clinics Redmine, ICF Update Platform, ICD Update Platform and telephone including conference calls facilities used on average on a biweekly basis.

3. Please briefly describe any interactions or collaborations with other WHO collaborating centres in the context of the implementation of the above activities (if any). If you are part of a network of WHO collaborating centres, please also mention the name of the network, and describe any involvement in the network during the last 12 months.

The interactions with other WHO Collaborating Centres took place almost completely within the general framework of the WHO-FIC Network Strategic Work Plan as illustrated per every single above described activity.