World Health Organization

Collaborating Centres
ANNUAL REPORT

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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	07-2015 to 07-2016		

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 and implementation of the following ICD-11 revision related activities:
1. Review and enhancement of ICD-11 Beta draft, ICD-11 Reference Guide and ICD-11 Index
  a. To work on the mortality and morbidity review of the Beta draft through participation in the MTAG and MbTAG
  b. To work on the coding rules for morbidity and mortality
  c. To support the population of the ICD-11 content model and the development of IT tools for ICD-11

2. Prepare and implement field tests of ICD-11 Beta draft in Italy
  a. Italian translation of ICD-11 Beta draft on WHO Translation platform
  b. Italian translation of FT material (including FT manual, FT instrument, case summaries and training material)
  c. Preparation and piloting of Italian ICD FIT version (web-based platform for data entry)
  d. Conduct FT familiarization and training
  e. Implementation of FT protocols as part of the Beta testing phase in 2015/2016 and usage validation phase in 2016/2017

3. Work on the transition from ICD-10 to ICD-11 in Italy
  a. Identify and analyze transition requirements in Italy
  b. Prepare and guide the transition process in Italy

1b) Functioning properties of ICD-11 on Reference Guide
Some Italian WHO-FIC CC experts (Lucilla Frattura, Andrea Martinuzzi, Matilde Leonardi) contributed actively to the discussion on Functioning Properties within the ICD-11. More specifically discussion with fTAG members and the ICD-11 RSG SEG focused on the representation of FPs within the Coding Instructions for ICD11. Agreement was reached thank to substantial improvements and better adherence of the FPs to the ICF.

1c) 2c)
The 11th revision of the International Classification of Diseases (ICD-11), for the first time developed using ICT tools and a wide, social collaboration of experts, is due by 2018. To ensure that ICD-11 is working well, it needs to be systematically validated in different settings, across the world. This will be done by means of a number of exercises. In order to support their implementation, the Italian CC provided expertise (Vincenzo Della Mea) to design and develop a web-based system (ICDfit). The system was designed according to WHO requirements, and implemented using PHP and MySQL. Then, a preliminary technical test was designed and run in January 2016, involving 8 users. They had to carry out double coding, that is, they had to code case summaries with both ICD-10 and ICD-11, and answer quick questions on the coding difficulty. 8 users coded 632 cases, spending an average of 163 seconds per case. The proposed system seems to be technically adequate for supporting future ICD-11 field trials.

Dissemination of results:

Selb M, Kennedy C, Melvin J, Sykes C5, Bang S, Gongolo F, Sart H, Riberto M, Lee H, Millar J, Madden R, Madden RH, Martinuzzi A, Robinson Nicol MM, Stucki G. Describing the impact of a disease on functioning: Coding functioning properties in ICD-11. Submitted at the 2016 WHO-FIC Network Annual Meeting

Della Mea V., Kostanjsek N., Donada M.. ICD-FiT in different languages. In: 2015 WHO-FIC Network Meeting Booklet

Jean Marie Rodrigues, David Robinson, Vincenzo Della Mea, James R. Campbell, Alan L. Rector, Stefan Schulz, Hazel Brear, Bedirhan Üstün, Kent A. Spackman, Christopher G. Chute, Jane Millar, Harold R. Solbrig, Kristina Brand Persson: Semantic Alignment between ICD-11 and SNOMED CT. MedInfo 2015: 790-794

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.

2a. Comparison of ICD version for casemix purposes.
DRGs are secondary patient classification systems based on primary classified medical data, in which single events of care are grouped into larger, economically and medically consistent groups. The main primary classified medical data are diagnoses and interventions codes. The current lists of health conditions that guide the DRG assignment in Italy are composed of single ICD-9-CM codes, as in the US DRGs system. The conversion of these lists in ICD-10 WHO poses the issue of combined codes for the «primary (and secondary) diagnosis». The dagger-asterisk system has not been implemented by the ICD-10-CM, which solves the issue with new children in the ICD hierarchy, and with some «shortcuts» compared to WHO original version (i.e. the deletion of the asterisk). In order to study the impact of that national modification on possible new ICD-10 lists for DRGs assignment in Italy, some conversion problems were analyzed with the ICD-9-CM codes which should convert to ICD-10 dagger-asterisk codes. For example, ICD-9-CM codes (2007 version, currently used in Italy) of MDC 5 (cardiovascular diseases) were considered which convert to ICD-10-WHO dagger-asterisk code combinations. Lucilla Frattura, Flavia Munari and Carlo Zavaroni verified how the ICD-10-CM operated in these cases and how ICD-11 classifies the same entities. The complete description of ICD-9-CM codes was considered, especially when the rule was "to code first underlying disease". 39 ICD-9-CM codes of MDC

5 out 471 were transcoded by the Authors into 89 dagger-asterisk codes according to ICD-10-WHO. Volumes 1 and 3, and the full description of each ICD-10-WHO entity were considered. The US Modification provides 61 non homogeneous solutions in comparison with 89 dagger-asterisk codes. The case-mix requires to cluster the health conditions in homogeneous groups according to the absorption of resources. Specifically, coding multiple conditions following ICD-10-WHO has led to a high degree of accuracy, but also to some redundancy that may appear complex to the coders. ICD-10-CM has changed the hierarchy of ICD-10-WHO making data comparison among countries difficult. It also poses the question of the real limits that a clinical modification should have. On the other hand a new criterion should be considered: health conditions absorbing comparable resources should be grouped in codes which describe clinical manifestations. This could help avoid redundancy. It is desirable that ICD-11 diversify how to code the clinical manifestations, ensuring the specificity of detailed codes for the most costly health conditions.

Concrete outcomes: crosswalking tables from ICD-9-CM to ICD-10; ICD-10 list of health conditions for case-mix purposes.

2b. Comparison of AIDS case definition between the National Register of AIDS and National Register of Causes-of-Death.
The improvement of antiretroviral therapy has led to a decrease of the risk of death for AIDS-related conditions in HIV patients. Nevertheless the risk of dying for non AIDS-related causes still remains high. Therefore, identifying the cause of death is of key importance for addressing prevention strategies in this group. The Italian National Institute of Statistics, the National Institute of Health and the CRO Aviano National Cancer Institute carried out a linkage between cases reported in the National AIDS registry and the national cause-of-death registry considering underlying and multiple causes. The objective is to provide suggestions for ICD improvement in the classification of AIDS deaths to be used for prevention. The national AIDS registry records all AIDS cases diagnosed according to European guidelines based on a list of AIDS-defining conditions. The national cause-of-death registry uses ICD-10 coding. The linkage procedure identified 4530 individuals reported to the National AIDS registry and died between 2006 and 2012. Of these, 696 (15%) cases did not have any mention of HIV or AIDS among the multiple causes and 90 (2%) cases had only indication of HIV positive status (ICD-10=R75). In the same period, additional 3581 deaths with mention of HIV diseases (B20-B24) did not link to the AIDS registry. In order to assess potential AIDS cases among the 3581 cases retrieved from the cause-of-death registry, an in-depth analysis of causes of death was carried out both on the multiple cause codes and the text reported by certifiers. The analysis of the text was often necessary because the ICD-10 code lacked the necessary detail for the identification of AIDS-defining conditions. The analysis of the results highlighted two main weaknesses of ICD-10 in HIV diseases classification for mortality. First of all, ICD-10 does not allow a discrimination between the diagnoses of HIV infection without AIDS and full-blown AIDS which are currently both coded to B24. Secondly, ICD-10 does not provide a clear identification of AIDS-defining conditions: the block B20-B24 referring to Human immunodeficiency virus [HIV] disease, includes causes of death of HIV infected people which can be unrelated to AIDS. As an example: B20.4 - HIV disease resulting in candidiasis, can contain both oesophageal candidiasis, which is an AIDS-defining condition, as well as candidiasis of other sites which are not AIDS-defining. These results suggest that a more precise and detailed classification of AIDS-defining conditions would allow a more sensitive identification of AIDS deaths.

Concrete outcome: Proposals for a better classification of AIDS-defining conditions and AIDS related terminology in ICD-11

Dissemination of results:

Frattura L, Munari F, Zavaroni C. Identification and coding of the main condition using ICD-10 for case mix purposes: comparison of national modifications. Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Enrico Grande, Barbara Suligoi, Francesco Grippo, Saverio Virdone, Diego Serraino, Martina Taborelli, Marilena Pappagallo, Vincenza Regine, Lucia Pugliese, Luisa Frova, Antonella Zucchetto - Identification of AIDS deaths in ICD10: the linkage between two national databases in Italy - causes-of-death and AIDS

registry. Poster submitted at the 2016 WHO-FIC Network Meeting

Activity 3

Title: Management of the ICD-10 and ICF update process.
Description: Provision of URC secretariat functions for 2015-2019. 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 transition from ICD-10 to ICD-11.

Paula Tonel and Andrea Simoncello served URC as Secretariat. Lucilla Frattura and Francesco Grippo have worked as voting members.
The URC work is mainly conducted through the update and revision platforms for ICD-10 and ICF, which are workflow engines designed to facilitate communication within expert workgroups and ensure transparency of the processes. Work and communications are also carried out via e-mail, conference calls and meetings, including an annual meeting during the WHO-FIC Annual Meeting. Key deliverables of the URC work include the lists of updates for WHO-FIC member classifications.
The URC ratified 60 recommendations at the 2015 WHO-FIC Network annual meeting held in Manchester, United Kingdom, for updating the ICD-10 and 20 recommendations for updating the ICF (Fig. 1 and 2).
At present, in 2016, 104 proposals have been moderated for ICD-10 and put to vote by URC members. With regard to ICF, 25 proposals have been reviewed by the FDRG and 20 of them have been put to vote by URC members.

Concrete outcomes:

Updates on the ICD update platform: https://extranet.who.int/icdrevision/nr/login.ICD.aspx
Updates on the ICF update platform: https://extranet.who.int/icfrevision/nr/loginICF.aspx

Dissemination of results:
Vogel U., Jelsma J., Simoncello A., Tonel P. Update and Revision Committee (URC) Annual Report. 2015 WHO-FIC Network Annual Meeting Poster Booklet

Vogel U., Jelsma J., Simoncello A., Tonel P. Update and Revision Committee (URC) Annual Report . Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Activity 4

Title: IT and Ontological developments for WHO-FIC.

Description: Provision of technical expertise and implementation of the following WHO-FIC IT and ontology related activities:

1. ICD-11 ontology development;

a. Harmonization between ICD-11 and SNOMED-CT, with development of methods and tools for enabling harmonization and gap analysis; common ontology study implication on relationships in the foundation layer

b. Development of IT tools related to ICD-11 quality assurance, enhancement, and usage, and experimentation of prototypes developed by WHO;

c. Participation in the joint WHO/IHTSDO table for the development of a common ontology.

2. Contribute to ICHI related ontology work

a. Maintenance of the provisional ICHI browser, and eventually participation in the development of the ICHI content model

b. development and enrichment of the functioning ICHI rubric

3. Explore ICF related ontology work

a. Updating of the analysis of the current status of ICF and discover underlying ontological principles on which is founded, starting from use-cases and term beating;

b. Continuity of the Mapping of ICF to other knowledge bases and terminologies (SNOMED CT, FMA, upper ontologies) and represent mappings in formal languages like OWL;

c. Representation, by using formal languages, of the links between measurement scales and ICF;

d. Exploration of new ways of ICF usage by means of knowledge based software.

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.

2. ICHI

2a)

In 2015-6 the Italian CC provided expertise for the functioning technical working group (fTWG) for ICHI development on stabilization of ICHI alpha draft and its 2016 revision (Andrea Martinuzzi, Lucllla Frattura, Giulio Castelpietra). Activities included periodic teleconferences with the fTWG, face to face meetings for specific topics (Trieste, February 2016: Mental Health; Padova, May 2016: Birthing interventions) and for the general strategic ICHI plan (February 2016 in Cologne, May 2016 in Conegliano).

In February 2016, a meeting focused on mental health, involving 10 experts from Italy, Sweden and Australia, was held in Trieste, Italy, organized by the Italian WHO-FIC CC. Lucilla Frattura, Giulio Castelpietra, and Andrea Martinuzzi attended the meeting involving the head of the Trieste WHO CC for Research and training in mental health. During the FDC-ICHI mid-year meeting, organized by the Italian WHO-FIC CC and held in Conegliano, Italy (3-5 May 2016), Andrea Martinuzzi, Giulio Castelpietra and Lucilla Frattura actively participated in discussions, involving participants from three WHO regions. Over the course of the year there has been substantial review and enhancement of ICHI content from a mental health perspective. In ICHI, codes for describing mental health interventions are found principally among those that target Mental functions (based on ICF categories in Chapter b1), Activity and Participation domains (based on ICF Chapters d1 to d9), and Health-related behaviours. Key changes agreed for ICHI 2016 to improve coverage of mental health interventions were made. Changes made to the classification were informed by reference to current scientific literature concerning mental health interventions. Definitions for all 'Health-related behaviour' Targets were developed, and new Targets needed for describing interventions within mental health care were added.

Concrete outcomes: Substantial contributions to the finalization of the ICHI 2016 were provided with new codes and revised description for both Mental health and Birthing interventions. In the case of mental health intervention, changes to axis categories, and corresponding revision of the tabular list of intervention codes in ICHI Alpha 2016 were done.

Dissemination of results:

Castelpietra G, Almborg AH, Fortune N, Martinuzzi A, Frattura L, Salvador-Carulla L, Madden R. Classification

of interventions in mental health care: the ICHI way. Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Almborg AH, Cumerlato M, Sykes C, Fortune N, berg L, Salvador-Carulla L, Madden R, Martinuzzi A. ICHI-Alpha2 Updated 2015. In: 2015 WHO-FIC Network Annual Meeting Booklet

2a)
Giovanni Bassi and Lucilla Frattura have studied how to take into account ISO9999 in the ICHI content model, considering how ISO999 map to ICF and avoiding to use ISO9999 directly. Since 1998, the content and the structure of ISO 9999 has been greatly modified. Some classes have been removed, other classes have a different place in the classification, some new classes have been created, many classes have changed with regard to codes and titles. ICF has been also modified, including Chapter 1 of Environmental Factors (EFs), when it was decided not to update the ICF-CY any longer (WHO-FIC resolution "Merger of ICF-CY into ICF" – 2012). The update work considered all subsequent versions of ISO 9999 up to 2011 version. The method used to map ISO 9999 to ICF second-level categories of Chapter e1 mainly followed semantic rules. The titles of ISO 9999 classes were compared with the semantic content of the titles and definitions (including inclusions and exclusions) of ICF categories. In case of ambiguity of the contents of ISO 9999 classes, the subclasses and divisions were considered. Another rule was that of assigning one single ICF category to one single division of ISO 9999. The original association made by the Italian experts between ICF categories and ISO 9999 were confirmed. With regard to new classes / subclasses / divisions added in the versions following ISO 9999:1998, the mapping rules were the same used in the first work. As a practical consequence on the ICF side, ICF should better specify the contents of Chapter e1, at least those of category e115.

Concrete outcomes: New crosswalking tables from ISO9999, 2011 version, to ICF

Dissemintation of results:

Bassi G., Frattura L.. Updates on ISO9999 mapped to ICF. Poster submitted at the 2016 WHO-FIC Network Annual Meeting

3.
ICF ontology.
An ontological analysis of ICF has been recognised as a much needed step to address the problems that along these years of ICF use and ICF updates have arisen. The Italian CC provides expertise on this issue, mainly through the two Italian co-chairs of FDRG and ITC and the Italian committe members involved.
As initial actions to start such analysis two approaches have been identified: a bottom-up approach of studying the way in which ICF is used across the world by a survey of use cases, and a top down approach starting from the existing ICF categories and relations seen through ontologizing tools.
The first action started in the summer of 2015, as a combined initiative of two committees, produced a first yield of responses that highlighted some key issues that may inform future work: the full or partial representation of components, the relation between Activities and Participation and the way in which they are represented, the relationship between Part I (the person) and Part 2 (the context), the use of the qualifiers. The limited number of responses by FDRG members however prompted further actions aimed at increasing the response rate and at providing more indicative answers to the key points.
In parallel a specific work was done in Italy to support ontological work (Frattura – Bassi)
During the FDRG mid-year meeting 2015 in Helsinki a small group of FDRG members from various countries compiled a list of ongoing ICF implementations and a provisional list of modalities by which the classification was used. The grid was used to gather information on the use of ICF in some areas of implementation: Clinic, Education, Statistics, Epidemiology, and Eligibility. Few respondents were active on the first round. Data were presented at the Manchester Network meeting (1) and in the Bangkok FDRG mid-year meeting, in 2016. In order to collect more information, a new form was designed by Lucilla Frattura and Giovanni Bassi and three online surveys were launched in Italy in 2016. The original questions were slightly modified and overall 30 questions were defined. Three surveys were launched in February 2016 and closed by the end of the same month. One survey was launched in the Piedmont region, one in the Veneto region and the third through the Italian Portal of Health Classifications. Some general information was also collected to describe the respondents. The distinction between Activities and Participation (AP) did not exist in practice. The

Environmental Factors were used jointly to AP, but also to many components. 68% of respondents used restricted lists of categories suggesting an ICF redundancy. The Capacity concept and its assessment are critical issues. This was confirmed by the fact that respondents were able to assess Performance, but not Capacity and a lot of them calculated the Capacity values «subtracting the role of EF from performance». The issue of the distinction between functioning and disability in a descripitive profile was not well covered by the respondents, suggesting that it is not clearly addressed in ICF. These materials might be used in ICF ontological work and the new questionnaire in Engligh could be revised and used in a new online survey.

Dissemination of results:

Leonardi M, Sykes CR, Madden RC, Ten Napel H, Hollenweger J, Snyman S, Madden RH, Kraus De Camargo O, Raggi A, van Gool CH, Martinuzzi A; Functioning and Disability Reference Group of the WHO-FIC Do we really need to open a classification box on personal factors in ICF? Disabil Rehabil 2016 Jun; 38(13):1327-8

Martinuzzi A., Della Mea V., Ten Napel H. ICF ontology: from theory to practice. The journey continues. Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Frattura L. Bassi G. Use case for ICF: three Italian online surveys for encouraging the ontological work, Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Talin F, Della Mea V. Comparing ontologies: an experiment with Jaccard Distance. In: 2015 WHO-FIC Network Meeting Booklet

Frattura L., Bassi G., Simoncello A. TExIEF: a thesaurus of expanded ICF Environmental Factor terms. In: WHO-FIC Annual Meeting Booklet, In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

Activity 5

Title: National work on WHO-FIC.

Description: Translation of WHO-FIC materials into Italian. The Italian WHO-FIC 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. The translation of the ICD-10 updates, especially those having an impact on mortality, is carried out in collaboration with ISTAT, institution responsible for cause-of-death official statistics in Italy.

Design and diffusion of WHO-FIC training tools and guidelines to use the WHO-FIC. The Italian WHO-FIC 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. These softwares serve to:
- support social networking-based update of WHO classifications, starting from already available classifications, terminologies and ontologies (e.g. ICD-11 as support for updating ICD-10);
- collect coded data in health and social information systems;
- deliver codes from local information systems to general repositories;
- transcode from one classification to another.
In the design process, exploitation of current standards might be involved, as well as development of specifications for communication standards.

ICD implementation strategy in Italy. On behalf of the Italian Ministry of Health, the Friuli Venezia Giulia Region, acting as Italian WHO-FIC CC, is responsible for the coordination and implementation of a national work plan aimed to introduce lCD-10 in Italy, considering the possibility to develop an Italian Modification. (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). The overall process for updating the Italian version of ICD-10 will be carried out using the web environment for collaborative translation and collaborative update on the Italian Portal of Health Classification, jointly with the web tool developed for considering candidates for updating the current version from some of the available clinical modifications. Together with the Ministry of Health and two other Italian regions, responsible for the set up of the Italian classification of procedures and interventions and the revision of the DRG grouper, an analysis of the current Italian DRG system is being carried out, new case mix applications are under 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.

Implementation of the Italian Portal of Health Classifications and of the web environment supporting 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 Ministry of Health.

National database on the ICF Implementation in Italian regional policies. According to a specific agreement between the Italian Ministry of Health and the Friuli Venezia Giulia Ministry of Health, an implementation database will be set up in order to show the multiple initiatives realized and under realization for ICF implementation. The database has been designed in order

a) ICD-10, 2016 version, translation into Italian and publication

In November 2015, an agreement for granting translation and publication rights was signed between WHO and Regional Central Health Directorate, Friuli Venezia Giuli Region. Exibits will be:

International statistical classification of diseases and related health problems, 10 th revison, fifth edition, 2016, Volume 1 (2015) (print and electronic format);
International statistical classification of diseases and related health problems, 10 th revison, fifth edition, 2016, Volume 2 (2015) (print and electronic format);

International statistical classification of diseases and related health problems, 10 th revison, fifth edition, 2016, Volume 3 (2015) (print and electronic format).

A group work was set up: Lucilla Frattura was the project coordinator. Paula Tonel provided translation; Flavia Munari and Carlo Zavaroni supported the internal revision; Francesco Grippo, Luisa Frova and Gianfranco Alicandro revised the translation using the collaborative environment on the Italian Portal of helath Classifications; Andrea Simoncello worked on the ClaML file of the Volume 1 ; Stefano Tereni and Ivano Tomainu implemented the ClaML format on the Italian Portal of Health Classifications.

Concrete outcomes: As of July 2016, the draft of the Italian version of Volume 1 and 3 have beenreleased for internal revision; the Volume 2 translation is ongoing;.

b) Design and diffusion of WHO training tools and guidelines

b1. In Autumn 2015, the Web activities participation performance inventory 1.0 (WAPPIn) was tested on 106 outpatients. WAPPIn. was developed by Lucilla Frattura, Giovanni Bassi, Andrea Simoncello and Carlo Zavaroni. It includes 52 (+6) questions for the 6 WHODAS 2.0 domains. For each question, EFs are explored. The 35 (+3) questions of WAPPIn correspond to the 36 questions of WHODAS 2.0 and produce the WHODAS 2.0 summary score. These questions map to 31 ICF AP categories and the answers correspond to 31 ICF AP categories qualified with a performance qualifier. The 17 (+3) additional questions that complete WAPPIn come from 20 ICF AP categories that are not considered in the different WHODAS 2.0 domains. Anwers were collected by web and automatically coded into ICF to describe the individual functioning profile. Data will be analysed and reported by the end of this year.

Concrete outcomes: 106 outpatients were assessed using WAPPIn. WHODAS 2.0 scores were automatically calculatated and ICF coding were automatically carriied out by ad hoc web software.

Dissemination of results:

Frattura L., Zavaroni C., Bassi G., Simoncello A. How to enrich WHODAS 2.0 considering ICF coding and EFs. The Web Activities and Participation Performance Inventory (WAPPIn). In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

b2. ICF education.

b2.1 Regional training programme for health professionals - Courses organized by the CC, with the scientific coordination and training activities of/by the Center Head (Lucilla Frattura), with face-to-face credits assigned to the seminars (Continuing Education Credits in Medicine). Aims: to train health professionals in using ICF-based assessment tools :

Friuli Venezia Giulia Region (40 hours):

24/11/2015 - Palmanova (Udine) Course ID AAS2_15154 "Il progetto personalizzato, la centralità delle persone, la condivisione dei risultati raggiunti: prime raccomandazioni per l'uso del Sistema VilmaFABERTM nei servizi distrettuali e nei Centri di salute mentale. Minori disabili ad alto carico assistenziale e loro famiglie" - 4 hours
02/12/2015 - Palmanova (Udine) Course ID AAS2_15155 "Il progetto personalizzato, la centralità delle persone, la condivisione dei risultati raggiunti: prime raccomandazioni per l'uso del Sistema VilmaFABERTM nei servizi distrettuali e nei Centri di salute mentale. Giovani con problemi di salute mentali impegnativi"– 4 hours
15/12/2015 - Palmanova (Udine) Course ID AAS2_15156 "Il progetto personalizzato, la centralità delle persone, la condivisione dei risultati raggiunti: prime raccomandazioni per l'uso del Sistema VilmaFABERTM nei servizi distrettuali e nei Centri di salute mentale. Persone con malattie neurodegenerative" – 4 hours
19/4/2016 (first edition) - Udine Course ID AAS2_16099 " Il piano d'azione OMS sulla salute mentale e il Sistema VilmaFABER: innovazione nei dipartimenti di salute mentale" – 7 hours

20/4/2016 (second edition) - Udine Course ID AAS2_16099 " Il piano d'azione OMS sulla salute mentale e il Sistema VilmaFABER: innovazione nei dipartimenti di salute mentale" – 7 hours
31/5/2016 (first edition) - Udine Course ID AAS2_16116 "Il piano d'azione OMS sulla salute mentale e il Sistema VilmaFABER: innovazione nei dipartimenti di salute mentale. Parte seconda – 7 hours
1/6/2016 (second edition) - Udine Course ID "Il piano d'azione OMS sulla salute mentale e il Sistema VilmaFABER: innovazione nei dipartimenti di salute mentale. Parte seconda – 7 hours

Health professionals tutoring for using ICF- based assessment tools: 11 editions (July-December) 2015, 52 hours (Tutor: Giovanni Bassi) - Topics : VilmaFABER Pt.2; how to administer WAPPIn 1.0; case study discussion.

Liguria Region (32 hours):

10/07/2015 (second edition)- Genua "L'adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione casi e analisi dei progetti di intervento in atto e dei risultati raggiunti nei minori valutati con il sistema VilmaFABER2 - 6 hours
26/10/2015 (third edition) - Genua L'adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione casi e analisi dei progetti di intervento in atto e dei risultati raggiunti nei minori valutati con il sistema VilmaFABE- 6 hours
25/09/2015 (first edition) - Genua "Adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione di casi" – 4 hours
25/09/2015 (second edition) - Genua "Adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione di casi" – 4 hours
18/11/2015 (third edition) - Genua "Adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione di casi" – 4 hours
10/12/2015 (fourth edition) - Genua "Adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione di casi" – 4 hours
10/12/2015 (fifth edition) - Genua "Adozione sperimentale del sistema di valutazione VilmaFABER. Analisi e discussione di casi" – 4 hours

b2.2 Courses on how to use ICF organized by other institutions with training activities by CC head and network members:

Lucilla Frattura geve advanced ICF Courses for teachers with the aims to review some coding malpractice and to encourage a more precise assessment of the role of education environment in pupils performance:
22/1/2016 – Torino (7 hours): 100 attenders, organized by the University of Turin, Special Needs Education Dep
26-27/2/2016 – Cuneo (14 hours): 200 attenders, organized by the Ministry of Education, Cuneo Dep
5 and 7/3/2016 – Perugia (14 hours): 200 attenders, organized by the Ministry of Education, Perugia Dep
31/3, 7/4, 26/4 2016 – Webinars for more than 100 attenders, organized by the Terni network of schools

Matilde Leonardi presented introductory module in ICF Course for teachers:
24/11/2015 – Genova, Corso Formazione ICF – "Applicazioni ICF nella scuola"
25/11/2015 – Monza, Corso Formazione ICF – "ICF e possibile applicazione"
13/4/2016 – Como – Corso Formazione ICF – "Ridefinire la disabilità in base al progetto educativo e di vita"
15/1/2016 – Moncalieri – Corso Formazione ICF – "Applicazioni ICF nella scuola"
5/4/2016 – Appiano Gentile - Corso Formazione ICF
Topics were: ICF and the biopsychosocial model of health and disability, ICF and UN Convention on Rights of People with disability, The National Disabilitity Action Plan, ICF for goal settings in education: profile of funtioning role of environment, The PEI ICF for children with special needs' functioning profiling, Principles of Disability Case management.

b3. ICD-10 training for morbidity coding.

An appropriate use of ICD-10 allows users to keep the classification as a diagnostic tool and to fully code all conditions and reasons for encountering health services. Although ICD-10 is not mandatory for morbidity

coding in Italy, Italian scientific societies have adopted the derived Multiaxial Classification (MAC) of Child and Adolescent Psychiatric Disorders as a diagnostic tool. This has led to two misconceptions on ICD-10: ICD-10 is only a diagnostic tool and is limited to the categories of the MAC (Chapter V, some codes of Chapter XXI, few codes from other Chapters).

A training programme was organized by the Bologna Local Health Authority on behalf of the Emilia Romagna Region to implement the full use of ICD-10 in the Emilia Romagna region (Italy), where MAC is used for collecting data from child/adolescent neuropsychiatry services. The training activities were made by the Center Head (Lucilla Frattura), with face-to-face credits assigned to the seminars (Continuing Education Credits in Medicine). Aims: to train health professionals in using ICD-10. The 2015-2016 experience in Emilia Romagna Reigon is the second initiative in Italy involving the Italian WHO-FIC CC (the other was in Piedmont in 2012) aimed at the implementation of full ICD-10 for morbidity coding in children with mental and behavioural disorders and problems.

Emilia Romagna Region (42 hours):

27 /10/2015 Bologna "ICD-10 in the services for children with mental and behavioural problems" – 7 hours
27 /11/2015 Modena "ICD-10 in the services for children with mental and behavioural problems" – 7 hours
21 /12/2015 Rimini "ICD-10 in the services for children with mental and behavioural problems" – 7 hours
21 /1/2016 Parma "ICD-10 in the services for children with mental and behavioural problems" – 7 hours
12 /2/2016 Ferrara "ICD-10 in the services for children with mental and behavioural problems" – 7 hours
4 /3/2016 Forli "ICD-10 in the services for children with mental and behavioural problems" – 7 hours

In particular, the ICD-10 training was organized in 7 training plenary sessions (total duration: 49 hours) and a feedback report (duration: 4 hours) at the central level, in 6 different locations in Emilia Romagna (Bologna, Modena, Rimini, Parma, Ferrara, Forlì). The professionals involved in morbididy coding in the Children psychiatric services were invited. The programme duration was 7 months, from September 2015 to March 2016. Each training session was divided into two parts: introduction to regional coding guidelines and updates on ICD-10; clinical case discussion with the active participation of the trainees. The programme released Continuing Education Credits for health professionals (Face-to-face credits). A preliminary regional data analysis was carried out to verify the current use of multiple coding. A final report was scheduled with a list of FAQ. 310 professionals (clinicians, psychologists, rehabilitators operating in the public community-based services for children with neuro-psychiatric problems) attended the 7-day training programme. 24 clinical cases were collected and 14 were analyzed.

Topics discussed: Differences between full ICD-10 and Multiaxial classification (MAC); Distinction between making a diagnosis and coding health conditions using a standard coding system; Differences between using ICD-10 for diagnostic purposes and using ICD-10 for coding health conditions according to the WHO coding rules; The added value to code signs and symptoms using full ICD-10 (this is not possible using MAC); New possibilities in ICD-10 Z codes and the mistakes in MAC Axis 5; Coding issues; How to browse ICD-10 online through the Italian Portal of Health Classifications (3) and to print the three volumes in pdf format using the Portal; Problems in different Italian translations of the same ICD-10 parts (in particular Chapter V), realized by different translators; Obsolescence of MAC in general and in particular with respect to Axis 6 (Functioning); The new ICD-11 hierarchy and the new Chapters of Mental and Behavioural Problems; Epidemiological consequences in coding multiple conditions according to MAC and the comorbidity artefact. Some issues remained open: a) How to implement functioning description using ICF, in order to collect and store comprehensive data by information systems. b) ICD-10 limits for coding health conditions under Chapter V in 0-3 year children. c) Type and duration of an "episode of care" in community mental health services: when should morbidity be coded, if an episode of care has a very long duration? d) The risk of labelling children using ICD-10 coding.

Concrete outcomes: New educational materials were developed; coding errors due to the outdated translation of the MAC were addressed; wrong coding habits were corrected. The distinction between diagnosis and coding of a health condition was made clear. At the end of the programme, trainees were seamlessly switching from the use of the outdated MAC to the use of the full ICD-10.

b4. Dissemination initiatives:

Lucilla Frattura participated by invitation as speaker on ICF and ICF data collection to the following meetings:
5 November 2015 - Lodi "Regione lombardia e l'Autismo: orizzonti di un percorso"
18 December 2015 - Trieste International seminar "Community withour seclusion"
6 June 2016 – Terni " Il progetto di vita indipendente"

Matilde Leonardi participated by invitation as speaker to the following meetings:
22/7/2015 – Scalea - "Programmare un centro educativo con percorsi individualizzati basati su ICF per bambini e ragazzi con DSA, Autismo, Disabilità"
9-11/9/2015 – Munchen - "Jahrestagung Deutsche Gesellschaft fuer Medizinische Psychologie" "Determinants of disability on an aging Europe"
1-2/10/2015 – Monopoli - "Il neurologo del territorio tra prevenzione, assistenza e complessità-fragilità-non autosufficienza delle malattie neurologiche croniche". Lecture on: "Un linguaggio comune per il funzionamento della salute e della disabilità: ICF"
18/11/2015 – Roma, MAECI Affari Esteri – International Conference "Including Disability in Development Cooperation: Experiences of collaboration between Governments, NGOs, and DPOs" "The inclusion of disability into emergency projects"
1-2/12/2015 – Vienna - European Congress of Neurorehabilitation "Measuring disability using the International classification of functioning, disability and health in the rehabilitation setting?"
7/4/2016 – Ascoli Piceno – SIRN Workshop: "Goal setting in neuroriabilitazione con l'utilizzo di ICF"

c) Software applications for using WHO-FIC in national data collection and analysis

c1. VilmaFABER system
During 2015, the Family of Functioning Indicators (FaFI) was implementd by the software developed by the Italian WHO-FIC CC, in order to automatically code in ICF and compare individual functioning profiles, New data were collected on 106 outpatients and the functioning-disability was shown by the softawere otuputs, using an infographic way. The Family of Functioning Indicators are calculated according some algorithms developed by the team led by Lucilla Frattura.
The functioning/disability distinction is made on the basis of the first ICF qualifier value in the BF, BS, and AP components. Functioning is related to the qualifier values 0 and 1, whereas disability is related to the qualifier values 2, 3, and 4. BF categories were grouped into five domains. AP categories were grouped as the ICF does. Different weights were attributed to different categories, referring to a weight table used in another Italian Region that has been implementing ICF. The weighted categories were summed up considering the distinction between functioning and disability in order to calculate indicators individually. All the indicators describing Functioning are shown in shades of green, all those describing Disability are shown in red and yellow. The infographic FaFI is composed as follows:
• Cumulative Functioning Ratio (CFR) in shades of red and green;
• Index of Functioning (IoF) in shades of green, comprising Index of Functioning, environment related (IoFER) in dark green; Index of functioning, environment free (IoFEF) in light green;
• Index of Disability (IoD) in shades of red, comprising Index of Disability, environment related (IoDER) in red; and Index of Disability, environment free (IoDEF) in yellow.
Five classes of «functioning» were defined by CFR or FR value ranges.

Concrete outcomes:
Mapping tables to automatically code into ICF information collected in lay language; algorithms to calculate the Family of Functioning Indicators; implementation of the indicators in an ad hoc web system; new data collected on 106 outpatiens.

Dissemination of results:

Frattura L., Bassi G, Castelpietra G, Simoncello A. Disability/functioning balance and levels of disability: some evidences of a continuum. Poster submitted at the 2016 WHO-FIC Network Meeting

Frattura L., Simoncello A., Castelpietra G., Bassi G. The relevance of functioning indicators in distinguishing clusters of outpatients. Poster submitted at the 2016 WHO-FIC Network Meeting

c2. Support system for coding health conditions in the Patient summary

During 2015, some work was done on a standardized methodology for the development of a rule-based support system that facilitates the compilation and coding of Patient Summary by GPs. According to the EU Guidelines, the PS is the minimum set of information needed to assure healthcare coordination and the continuity of care. PS reference elements, tagged as mandatory or optional, can be reported as free text or by using dedicated coding systems. Because of its highly structured content, the PS could be well coded using formal rules and implementing a challenging automated support system. In order to set up an automated support system, a formal agreement was signed in June 2016, an Italian collaborative work group was set up, and a work plan was defined. The advantages of a sound rule-based CSS are: (i) it is based on internationally updated standard coding systems and standardized methodology to code health conditions; (ii) it could significantly reduce coding time and costs; (iii) it improves the quality of coding by reducing the variability due to different subjective interpretations. Limitations are mainly related to the computational costs of the system and to the complexity of the domain, since it could be necessary to formalize a huge amount of rules. Although developed for the Italian PS, this methodology could be further adapted to other UE Countries.

Dissemintation of results:

Cardillo E, Chiaravalloti MT, Eccher C, Pasceri E, Della Mea V, Frattura L, Guarasci G. Towards a Rule-based Support System for the Coding of Health Conditions in the Patient Summary. BDM2I@ISWC 2015

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Della Mea V., Frattura L., Chiaravalloti M.T. Coding rules for the patient summary: analysis and requirements to develop an automated coding system. In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

Frattura L., Bassi G, Castelpietra G, Simoncello A. Disability/functioning balance and levels of disability: some evidences of a continuum. Poster submitted at the 2016 WHO-FIC Network Meeting

Frattura L., Simoncello A., Castelpietra G., Bassi G. The relevance of functioning indicators in distinguishing clusters of outpatients. Poster submitted at the 2016 WHO-FIC Network Meeting

d) ICD implementation strategy in Italy

d1 It.DRG Project

On behalf of the Italian Ministry of Health, since 2010 Lucilla Frattura is responsible for the coordination and implementation of a national work plan aimed to introduce ICD10 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). By means of the It.DRG project, the Italian Ministry of Health is going to move from the current DRG system, based on ICD-9-CM, to a new Italian system based on an Italian modification of ICD-10 and an improved procedures classification. The Italian WHO-FIC Collaborating Center is now working on a first draft of a clinical modification, for which an innovative approach has been chosen. Extensions coming from ICD-11 were considered as the most interesting to modify ICD-10.

Concrete outcomes: Crosswalking tables from ICD-9-CM to ICD-10; new lists of ICD-10 health conditions for case mix; some ICD-10 chapters clinically modified.

Dissemination of results:
Della Mea V., Frattura L., Munari F., Simoncello A. From ICD-10 to ICD-10-IT through ICD-11: a pilot study on cardiovascular diseases. In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

d2. ICD-10 Mortality coding and implementation

The Italian National Institute of Statistics (ISTAT) disseminates data on mortality statistics based on the ICD-10 version 2009. ISTAT provides an electronic version of the ICD which includes a web-based browser for the navigation of both the analytical classification (Volume 1) and the alphabetical index (Volume 3). For Volume 3, a specific search tool allows to retrieve index entries with all the informaton content included in the ICD-10 alphabetical index (lead terms, relevant and non-essential modifiers, coding notes and hints). The version 2009 of Volume 1 was revised with the cooperation of the Italian CC headquarter in Udine, and then was introduced into the ISTAT ICD-10 web browser. In 2015-2016 ISTAT revised the dictionary of medical terms used for mortality coding according to 2016 version of ICD and conducted some tests on the performance of new systems. Moreover, relevant material for a training course for official mortality coders was selected from the Volume 2 2016.

Concrete outcome and dissemination of results: ICD 10 Online within sistemaclassificazioni.istat.it, update 2009 version.

e) The Italian Portal of Health Classifications
The Italian Portal of Health Classifications (www.reteclassiifcazioni.it) was implemented to support the collaborative authoring of the updated electronic Italian versions of WHO-FIC, according to the agreement between the Italian Ministry of Health and the Friuli Venezia Giulia Region (www.reteciassificazioni.it).

f) National database on the ICF implementation in Italian regional policies

f1. Results of the first implementation assessment in Italy

ICF use in Italy is widely heterogeneous. It has been used in Italy for more than a decade, without any specific case use. The few national regulations state that Regions are responsible for ICF implementation, but they do not provide implementation guidelines. The current Italian Action Plan in favour of persons with disabilities asks to reform the disability assessement criteria. ICF is considered a standard but few data are available to reach a consensus on how to proceed. The WHO FIC implementation database poses some problems if we considered the multifaceted Italian situation. In March 2016, a one year national project funded by the Italian Ministry of Health was concluded. Lucilla Frattura, as WHO-FIC Center head, was the project coordinator. The aims were: to collect data on how the Italian regions are using ICF in health, social, education and labour policies; to review the way to collect ICF-based data and report on them; to study the advantages of introducing a common data set to standardize data collection for national purposes; to study if and how an ICF data collection and analysis might be at the basis of new ways to determine disability in Italy. . Data were collected on laws, regulations, assessment tools and programs in which ICF was the conceptual framework and the basis for the collection of coded information at individual level. Only two regions collect data through information systems and are able to analyse them in order to publish reports. Some of the regions use ICF to individuate target populations for different purposes: to distribute social services or social benefits (using different eligibility criteria); to assess the functioning status for school inclusion; to support work inclusion. Only one region (Friuli Venezia Giulia) has developed a method to use ICF at the basis of a new information system, to open an individual biopsychosocial record and assess the outcomes of integrated care plans. Different national initiavites have been planned to introduce ICF, with an intermittent interministerial coordination. WHO-FIC Implementation database seems to consider the implementation as a linear process. The Italian multifaceted reality is difficult to represent. An attempt was made by using the comment sections. Great problems were found in answering questions about disability statistics. ICF is considered as a framework for questions in surveys on "functional limitations" according to Eurostat.

Concrete outcomes: WHO-FIC implementation database updated; national ICF implementation archive set up.

f2. Regional ICF implementation.

f2a) Piedmont Region

Some in itinere monitoring activities in the Piedmont region (Italy) have been realized, where ICF is used as defined by regional rules and forms for disability determination of children in order to define individual educational plans. In the past eight years, Piedmont Region has organized a massive ICF training

programme, introduced new forms to assess children using ICF, but has not monitored their implementation. The lack of a database with ICF data was considered a weakness of these policies.

This first attempt to monitor how the professionals use the new tools provided a lot of suggestions for better using ICF in practice. In January 2016 two different online questionnaires were designed and launched by Lucilla Frattura and Giovanni Bassi, in agreement with Regional counterparts, in order to collect information by different users. One aimed at describing how health professionals and teachers use the ICF, and the other at investigating how the forensic clinicians take into account the sections of the regional forms filled in by health professionals for the disability determination of children. A selection of forms filled in by the teachers involved in inclusive educational planning was analyzed in a qualitative way; two focus groups were also organized with teachers and the Authors. At the end of February 2016, 135 online questionnaires were collected and analyzed; 22 forensic clinicians answered the specific questionnaire. Data showed heterogeneity in ICF use, partial knowledge of the regional rules, non- homogeneuos competences in using the ICF model of functioning. The forensic clinicians continued to use the narrative sentences, thinking that ICF codes did not add any added value to their judgement. The qualitative analysis of the documents showed different ways to use the regional forms. ICF was useful to organize description but the comparison between the narrative text and the codes showed that, in same cases, the two texts had different meanings. Many teachers were not specifically trained to use ICF for educational purposes. Most of the attention was on the children's problems instead of on capacity of the teachers (considered as Environmental Factors) to solve the children's problems using educational methods and strategies (other Environmental Factors). A new awareness has emerged about the need to better understand the difference between using ICF and collecting information for ICF coding. The regional forms, similarly to many other available in Italy, are about ICF and do not guide the collection of information in "natural language". Environmental factors and their roles were not central in the assessment.

Concrete outcome: Piedmont Region asked the WHO-FIC CC for a proposal on how to provide technical assistance in monitoring ICF implementation in all regional policies.

f2b. Umbria region

ICF Project targeted to networks of schools was launched at national level in 2010 by the Italian Ministry of Education, University and Research (MEUR). The network set up in Umbria to implement the local winning project has been continuing in a local programme for implementing knowledge and tools developed under the MEUR programme. The original network of schools was led by MEM and SC, with LF as ICF expert, trainer and supervisor. The programme target was a network of 10 schools out of 34 operating in 7 different municipalities, supported by the Head of the WHO-FIC Italian collaborating centre. A scientific board of 13 teachers was defined. Different groups of teachers (and some health professionals) were involved over the years in different steps, using the training of trainees approach. In 2016 a set of webinars were organized. ICF case use: individual educational plan, containing an ICF-based assessment for guiding the decision on how to modify the baseline, was set up. A&P component was used in conjunction with EFs. A specific analysis was realized to expand the ICF EF categories regarding teachers, educational methods and strategies, and educational products. Specific case studies were set up to train teachers to describe functioning at school, to read the functioning profile and understand its meaning. Both narrative description and coding were provided in order to verify the coding quality.

More than 880 teachers were involved, 40% of them dedicated to special educational needs. More than 100 new teachers expert in inclusive education were involved in webinars made in 2016.

Concrete outcome: in all the schools of the network, the ICF-based tools were used to define and evaluate the individual educational plans for children with special educational needs.

f3. The Besta Foundation (Matilde Leonardi) was active on the implementation of ICF-based assessment tools in neurosurgical patients and neurological patients, in particular migraine, myasthenia, disorders of consciousness and multiple sclerosis. The description of functioning and disability in patients with disorders of consciousness was also made. Differences in functioning between patients in Vegetative state and Minimally conscious state were analysed in longitudinal national studies. "ICF PEI", an ICF-based assessment instrument for developing a tailored educational plan for children with disability was defined.
In particular, the ICF-based instruments developed and implemented were:

• MSQ Job for evaluation of functional problems in the work sector of patients with multiple sclerosis
• Disability management Besta protocol for evaluation of needs and environmental factors of neurosurgical patients
• MG-DIS functioning and disability assessment tool for patients with Miastenia Gravis
• Functioning and disability protocol for neurosurgery patients: the protocol was validated and combined QoL, Well Being, coping strategies and disability were measured with WHODAS2
The Besta team also worked on:
• disability and ageing issues; together with the international network on Bridging Disability and Ageing, a meeting was taking place to develop common areas of work in Europe and in Canada.
• PATHWAYS project: is a EU 3-year project that using the biopsychosocial approach is trying to develop European guidelines for integration and reintegration in the labour sector of people with chronic diseases
• Measuring disability in emergencies. Using WHO-DAS 2.0 in natural and man made disasters. The paper on data from Typhoon Yolanda in the Philippines has been published. A presentation of this work was given in December 2015 at the Italian Ministry of Foreign Affairs, in April 2016 at Raul Follerau meeting in Pompei, in May 2016 at the London School of hygiene and Tropical Medicine in London.

Dissemination of results:
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Covelli V. , Raggi A., Leonardi M.. Functioning and Disability of Ageing People with Down Syndrome : a national study Poster submitted at the 2016 WHO-FIC Annual Meeting

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Activity 6

Title: Support WHO-FIC implementation in EURO and other WHO regions
Description: Plan and implement technical assistance projects in support of WHO-FIC implementation
• Support Euro WHO region in introducing ICD-10 in the health national service and in the health information system. (Albania, Russia)
• Provide resource of persons for WHO-FIC related training and capacity building activities as requested by WHO HQ or Regional Offices.

6a) WHO Office in Albania: request of support in realizing ClaML format of Albanian ICD-10.

Following the study visit of Who Albania and Albanian Ministry of Health in Spring 2015, in December 2015 a draft was prepared by the Italian CC head on the steps to follow.
a) Available material (input): Albania will provide Italian WHO-FIC CC with a DOC and PDF version of ICD-10 Volume 1 already translated in Albanian. We have a doc file in Albanian, but we are not sure of the version year (2010?).
b) Final material (output): Italian WHO-FIC CC will provide Albania with a ClaML version of ICD-10 both in English and Albanian.
This ClaML file allows:
• To upload it into the Italian Translation Tool to check the correct translation for the first release and for the release of the updated version of ICD-10 in Albanian
• To browse the ICD-10 in Albanian into a browser (it would be possible to host the Albanian ClaML into the Italian Portal of Health classifications).
Steps (Italian WHO-FIC CC):
1. Setup a WHO version (English) of the ClaML with empty spaces for the Albanian translation
a. For this step it is crucial to know the exact version of the Albanian PDF translation to have the exact match between labels to be translated
2. Upload the ClaML file in the CTK Birck tool (a specific software not free for users) to create a database for translation
a. This step is feasible only if we work on our machines
3. Insert each Albanian translated label next to the corresponding English label
a. A test will be feasible
4. Export the CTK Birch database to the ClaML format with double language (ICD-10-EN-AL)
5. Adapt the Italian Translation Tool to accept the ICD-10-EN-AL in ClaML format
a. The command label (such as: approve, delete, new proposal, etc) will remain in English
6. Import the ClaML version of ICD-10-EN-AL into the Italian Translation Tool
7. Provide proper access grants for Albanian users that will check the translation
8. Train Albanian users to perform the translation check
a. It will be relevant to select the translation reviewers
b. We will define how and who decide that a translation has to be approved, being the administration of the translation platform in Italy
9. Report back Translation modifications to the ClaML format using CTK Birch.
Duration : At least 6 months to have a ClaML format in Albanian, after the reception of a valid DOC or PDF from the Albanian team. It is an estimate, to verify after the test (2a) set up by the Italian WHO-FIC CC. A numbers of weeks/months to verify the translation into the Italian portal environment (by Albanian reviewers); Two weeks to return back a pdf format of the final Albanian version of ICD-10 (by the Italian WHO-FIC CC) from the final version of the ClaML file.

6b) The WHO European Regional Office together with the local office in Tashkent organized a training course on ICD-10 held in Taskent on the 14-18 December 2015.
The aim of the training was to provide information and instruction on the use of the ICD-10 for mortality and on the selection of the underlying cause of death and to provide a standardized and internationally recognized methodology for the production of the underlying cause of death based on the WHO international certificate of death.
Four full days of training were held by the experts Francesco Grippo and Monica Pace. The course was supported by extensive training material (power point and other additional documents) prepared by the experts and translated into Russian. At the end of the course each participant received the material in electronic format from WHO.
The level of knowledge of the ICD-10 and its rules and provisions was not homogeneous in the class,

therefore some participants faced more difficulties than others, however the level of participation and interactions and feedbacks wasonsidered to be very satisfactory by the experts.
The presence of different kind of professionals (clinicians, statisticians and doctors in charge of medical statistics and organization of statistical services) was particularly appreciated by the trainees, being this opportunity considered very valuable for the further improvement of the quality of statistics on causes of death.

In brief these were the main areas covered by the training:
- Improving the quality of Certification of causes of death
- Importance of good causes of death certification and information for Public Health at National and International level
- Correct reporting of the cause of death and other requested information: how to fill in the death certificate
- Structure and use of ICD-10 for mortality; the concept of sequence
- Selection and modification rules for the selection of the underlying cause of death
- Use of ACME decision tables for the selection of the underlying cause of death
- Special coding instructions for neoplasms, external causes (such as transport accidents, accidents, suicides, homicides, intoxication by drugs), maternal and perinatal mortality
- Main indicators for maternal mortality
- Importance of statistical presentation and comparability of data in view of data dissemination at National and International level
- Final "tour de table" in groups where the participants were asked to answer to three questions:
1. Positive benefits of the training in your area of work
2. Difficulties encountered during the training
3. Ideas on how to implement the new knowledges learnt during this training and current existing limits.

6c) WHO Country Office in Turkmenistan requested support to use ICF for disability determination. A study visit was organized in Conegliano and Udine, 9-11 December 2015. Andrea Martinuzzi and his staff and Lucilla Frattura and her staff presented and discussed different topics in agreement with the WHO Country Office.

6d) ICF use to monitor the UN Convention on the rights of people with Disability: in Turkmenistan in 2015, and in Kyrgystan in June 2016 missions were organized by WHO EURO that invited as expert on ICF and UNCRPD Matilde Leonardi together with expert from the Russian Collaborating centre (DR Shoshmin). Dr Leonardi was invited on her personal capacity as expert on the needed issues for these countries and only her travel and accomodation (through per diem) were covered according to WHO rules. The agenda for the missions was organized by WHO EURO in collaboration with country representatives and local authorities that requested the mission itself. Missions were followed by a report prepared by WHO EURO and revised by the experts. The activity is in line with global WHO FIC activity of dissemination of basic knowldge of ICF and related principles and instruments, and how the issue of disability (in eligibility and monitoring in these cases) should be developed at country levels to fulfill UNCRPD articles and principles.

6e) Implementation of the Model Disability Survey (MDS), in collaboration with the Disability and Rehabilitation Unit of the WHO HQ. The preparation of the training on MDS was done by Besta Foundation (Matilde Leonardi) in collaboration with WHO HQ, WHO EMRO, Ludwig Maximilian University Munich. In October 2015 a mission in Oman was done to train people on the use of MDS and on the principles of ICF (12-16/9/2015 – Oman – "Model Disability Survey - MDS OMAN - Piloting of the Model Disability Survey").

Dissemination of results:
Frattura L., Lazeri L., Odeta L. et al ICD-10 implementation in Albania: a collaborative roadmap. In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

Leonardi M, Vladimirovich Shoshmin A., Besstrashnova Y, Karriyeva B, Myratdurdyyeva A., Agayeva B, Rakovac I. ICF Implementation and UNCRPD monitoring in Turkmenistan. In: WHO-FIC Network Annual Meeting Booklet, Manchester October 2015
Activity 7

Title: Contribution to WHO-FIC network activities.
Description: According to the roles of the WHO-FIC Network to promote the implementation, use, maintenance and updating of WHO reference health classifications and to assist WHO in the revision and development of the reference classifications, the Italian WHO-FIC CC assures contribution to the key products of the WHO-FIC Network Committees and Reference Groups, providing technical expertise, participating actively in the annual and mid-year meetings, chairing working groups and committees, being involved in key projects inside the network.
It currently provides:
Advisory Council: Head, and three Co-Chairs
Small Executive Group: one co-chair
URC: Secretariat (ICF since 2010 – third mandate; ICD-10 since 2014 – first mandate), and two voting members
ITC: Co-Chair (until 2016, second mandate) and one voting member
FIC: one voting member and one observer
EIC: one voting member and one observer
MRG: Co-Chair (until 2016, first mandate)
FDRG: Co-Chair (until 2016, second mandate), one voting member

The Italian CC has actively participated in leading positions to the WHO-FIC management.
Specifically:
Advisory Council (CC Head: Lucilla Frattura, scheduled teleconferences);

URC: Andrea Simoncello and Paula Tonel supported the URC in the steps before and after the 2015 meeting, and worked to accompany the update process in 2016

MRG coChairmanship: Francesco Grippo (MRG and MRG Table Group March 15-18, 2016 Whashington DC March 2016)

ITC coChairmanship: Vincenzo Della Mea (ad-hoc meetings of the co-chairs, WHO liaison and Secretary).

FDRG: CoChairmanship: Andrea Martinuzzi (10 teleconferences, 1 mid year meeting, Bangkok 4-5 June 2015);
Voting member: Lucilla Frattura worked in the ICD-11 Reference guide, Functioning properties, and on supporting the ICF ontological work; Observer: Giovanni Bassi worked in updating the map to ICF of ISO9999 and on supporting the ICF ontological work; WHO member: Matilde Leonardi worked in the ICD-11 Reference guide, Functioning properties.

FDC and ICHI : fTWG: Andrea Martinuzzi (3 Teleconferences, 2 topic meetings: Trieste 10-11 February 2016, Padova 23 June 2016, 2 general strategic meetings: Cologne 15-16 February 2016, Conegliano 5-6 June 2016)
Members: Andrea Martinuzzi organized and hosted on behalf of the Italian CC the FDC mid year meeting in Conegliano May 3-4 2016; Lucilla Frattura supported the work on Mental health interventions (Conegliano 5-6 June 2016); Observer: Giulio Castelpietra supported the work on Mental health interventions (Conegliano 5-6 June 2016)

SEG participation: Andrea Martinuzzi (7 teleconferences, 1 one SEG face-to-face meeting SEG, Geneva May 2, 2015).

URC: see Activity 3

ITC:
The Informatics and Terminology Committee (ITC) was established in 2010, combining the Electronic Tools Committee and the Terminology Reference Group into one WHO-FIC committee. Ad-hoc meetings of the co-chairs, Karen Carvell and Vincenzo Della Mea as well as WHO liaison Can Celik and Secretary Jun Nakaya were held throughout the year. There was no face to face mid-year meeting held.
Jun Nakaya from the Japanese Collaborating Center accepted the role of ITC secretary at the Manchester meeting. This is viewed as a positive hand over the work of ITC to the new co-chairs when existing co-chairs

complete their terms in October 2016.

WHO headquarters and collaborating centres work to enable standardized maintenance, update and revision of WHO classifications.

Work has continued on the classification update platforms and on the ICD Revision Platform:

a) A Coding tool, developed to allow searching of codes in the ICD-11 Mortality and Morbidity Statistics using natural language expressions. The tool has been continuously revised and enhanced during the last year.

b) ICD-11 coding exercises tool (ICD-FiT). Formal technical testing was completed on the tool. This involved 8 raters coding from case summaries to test the capabilities of the tool. A multi-language version of the web-based system is now available to support ICD-11 coding exercises.

c) Technical standards to enable the electronic exchange of WHO classifications.

During the last year, work has been carried out in the following directions:

a) URI API: URIs (Uniform Resource Identifiers) are standard identifiers for ICD entities, with a corresponding Application Program Interface (API) platform for software to access information about the classifications. Experimentations have been started on the coding API, based on the coding tool software, to enable code search also on third party software.

b) ClaML (Classifications Markup Language) The classification markup language ClaML is the WHO recommended format to exchange classifications between developers and users. It is an ISO standard used worldwide. In 2015 the standard started to undergo revision in the ISO process. Its result will be ClaML 3.0 with an aimed date of completion in 2018. The WHO-FIC-Network is actively involved in the revision through the ITC. It will try to ensure that emerging classification needs for the exchange standard are considered.

A small working group, led by ITC began preliminary steps toward an ICF ontology. A survey of FDRG members on ICF uses was conducted to inform the preparatory work for an ICF ontology.

A meeting was held in the spring 2016 to discuss the next steps to create ICF category structures which will provide a better understanding of the components of ICF and their logical relationships. As output of the meeting, an action started from previous work by H. Ten Napel on a categorial structure for ICIDH and from the results of the ICF Ontology workshop held in Venice in 2009, to give new life to the formalization of ICF.

The web site for the 2016 WHO-FIC Network meeting poster submission was maintained.

Some members of ITC are also members of the ICD-11 MMS Task Force, where they collaborated to define ITC related aspects of the ICD-11 Reference Guide.

MRG:

Francesco Grippo has carried out his second year of the mandate as co-chair of the Mortality Reference Group (MRG) together with Lars Age Johansson (Nordic countries).

The main objective of the MRG is to contribute to the harmonization of the application of the ICD10 in mortality. In order to achieve this goal the MRG clarifies the application of consolidated international rules, discusses practical examples and proposes updates of the ICD10 if necessary.

The issues to be discussed in the MRG derived from the Mortality Forum, MRG members enquires, ICD10 users for mortality and users of automated coding systems.

Specific activities carried out during 2014-2015 within the MRG include:

- Assessment of issues to be submitted for discussion to the MRG coming from personal email contact, mortality forum, national coders enquiries, automated coding users.

- Moderation of the discussion via email and during annual meeting, Barcelona and mid-year meeting, March 2015, Budapest.

- Revision of version 2016 of volume 2 ICD10; in particular revision of the coding instruction for multiple cause coding for neoplasm.

- Revision of the URC proposas (voting expressed by Lars Age Johansson on behalf of the MRG).

As specified in the strategic work-plan, a relevant part of the activity consists in the elaboration of recommendation for internationally standard decision tables within automated mortality classification systems. Therefore, one of the major tasks of the MRG is to make recommendations for the updating of the decision tables. This tool constitutes also the supporting material during the manual coding, allowing an increase in the harmonization of the selection across geographical areas, in line with the major goals of the MRG. As MRG co -chair, the activities in this field included the collection and revision of table updates proposals and the formatting of the updates. Other work on tables was addressed to the following objectives:

- to outline the actions needed in order to update the tables to the 2016 version of the ICD: revision of causal relationships between codes and conditions, obvious causes implementation and linkages updating.

- to identify the strategies for handling the relationship and behavior of surgery coding in mortality and

implementing the rules for a correct selection of cases containing surgery codes in the decision tables.
In year 2015-16, 150 issues were discussed and moderated during the MRG meetings and 33 proposal were submitted to the URC. Recommendation for 53 updates and several proposals under discussion.

FDRG:
The co-chairs met monthly by teleconference. FDRG members and collaborators were informed of progress on the projects during the year and met by teleconference quarterly in March, June and September. A mid-year meeting was held on 4-5 June 2016 in Bangkok. The experience of the join meeting with the EIC was repeated with success with a half-day meeting with the Education and Implementation Committee (EIC).
In conjunction with the FDRG meeting a satellite meeting was dedicated to the advances in the mICF project. With the ICF Practical Manual and ICF e-Learning introductory module awaiting finalisation through WHO processes the FDRG and EIC discussed new options and opportunities for ICF education and collaboration with the DAR in responding to their requests of training material for ICF. The focus of discussion was on progresses of the ICFeducation.org web-based repository of ICF training material and on the established criteria for curricular information on ICF experts and trainers.
Three pieces of work are underway to inform the development of an ICF ontology.
1. the survey seeking use cases of ICF has been designed and circulated to FDRG members and collaborators. Results of the survey have be collated and reported at the meeting in October 2015. A new version with enriched questionnaire will be available by next October on the WHO platform.
2. FDRG has discussed activity theory as a basis for the development of an information model starting from a consideration of the categories from the Life Areas (activities and participation) component of ICF presenting problems during the updating process.
3. Term beating activity was discussed for moving ahead the ICF ontology work.
Lucilla Frattura, Andrea Martinuzzi, Matilde Leonardi contributed actively to the discussion on Functioning Properties within the ICD11. More specifically discussion with fTAG members and the ICD11 RSG SEG focused on the representation of FPs within the Coding Instructions for ICD-11. Agreement was reached thank to substantial improvements and better adherence of the FPs to the ICF. FDRG members and collaborators continue to work with the FDC on the development of the International Classification of Health Interventions. FDRG continues to be represented on the functioning Technical Advisory Group informing the ICD 11 development.
Collaboration to the MICF Project, mobile ICF development was assured by Matilde Leonardi and Lucilla Frattura: a paper is under preparation to define the empirical and theoretical bases for the development of a mobile ICF application to be used as mHealth tool.

Dissemination of results:

Note:The specific posters presented or submitted at the 2015 and 2016 WHO-FIC Network meeting are distributed in relation to the specific activities. In this section, the posters related to the Network activities are listed.

Frattura L., Italian WHO-FIC CC annual report. Poster submitted at the 2016 WHO-FIC Network Annual Meeting
Vogel U., Jelsma J., Simoncello A., Tonel P. Update and Revision Committee (URC) Annual Report . Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Carvell K., Della Mea V. Informatics and Terminology Committee – Annual Report. Poster submitted at the 2016 WHO-FIC Network Annual Meeting

Hoyert DL, Grippo F, Johansson LA. Mortality Reference Group Annual Report, 2015-2016. Submitted at the 2016 WHO-FIC Network Annual Meeting

Sykes C., Martinuzzi A. Annual report FDRG 2015-16. Submitted at the 2016 WHO-FIC Network Annual Meeting.
Frattura L. Updates on the performance monitoring plan of the Italian WHO-FIC Collaborating Centre. In: WHO-FIC Annual Meeting Booklet, Manchester October 2015

Vogel U., Jelsma J., Simoncello A., Tonel P. Update and Revision Committee (URC) Annual Report. 2015 WHO-FIC Network Annual Meeting Poster Booklet

Hoyert DL, Grippo F, Johansson LA. Mortality Reference Group Annual Report, 2014-2015. In: 2015 WHO-FIC Network Annual Meeting Poster Booklet

Carvell K., Della Mea V. Informatics and Terminology Committee - Annual Report. In: 2015 WHO-FIC Network Annual Meeting Poster Booklet

Sykes C., Martinuzzi A. Annual report FDRG 2014-15. In: 2015 WHO-FIC Network Annual Meeting Poster Booklet

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, 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.

4. Please briefly describe any type of technical, programmatic, advisory or other support received from WHO during the past 12 months for the implementation of the agreed activities listed above (if any).

The Centre has maintained a strict relationship with WHO in relation to the implementation of this workplan.