

Folder eCC\_00007965 is in stage Annual\_Report\_Due

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** 07-2014 to 07-2015

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.

In 2014, Vincenzo Della Mea developed the web-based system aimed at supporting ICD-11 field trials (ICD-FiT), which in the last months has been updated to include multilingual support. ICD-FiT will support translation of:

- a. web interface: all text belonging to the web pages that make up the system;
- b. trial instruments: the concrete forms that will be filled up by users:
- c. case summaries: the cases to be coded, for relevant core studies (2 and 3).

In addition to that, two main new features have been introduced:

- linkage with ICD-11 Coding tool;
- enhanced customization for generic and chapter specific field testing.

Vincenzo Della Mea participated in the task force on JLMMS linearization, and provided insights and support

8/21/2015 4:38:47 PM Page (1/15)



on the identification of problematic entities and relationships starting from the work done for the WHO-IHTSDO Joint Advisory Group. In particular, entities with logical inconsistencies discovered when comparing to SNOMED CT were highlighted thanks to a web-based tool, developed for internal WHO use. To further provide tools for identifying differences between classifications, a master thesis was assigned that identified an approach in which a measure of distance between the same entity described in two different resources is provided, starting from the Jaccard distance, modified to fulfill the specific needs of ontology comparison. The measure was tested in the Circulatory system diseases of ICD-11 vs the equivalent subtree in SNOMED-CT, but possible applications include ICD-10 vs JLMMS and also, for the Italian needs, ICD9-CM vs ICD10-IT.

#### Concrete outcomes.

- A multilingual extension for the ICD-11 field trials support system has been developed.
- A tool was designed to highlight critical areas in JLMMS.

#### Dissemination of results

- 1) Della Mea V., Vuattolo O., Rector A., Ustun B. et al. A web-based tool for supporting the development of a Common Ontology between ICD11 and SNOMED-CT. Proceedings of 2nd IEEE International Conference on Healthcare Informatics (ICHI2014), 144-148, IEEE, 2014
- 2) Rodrigues J.M., Robinson D., Della Mea V., Campbell J., et al .Semantic Alignment between ICD-11 and SNOMED CT. In: Proceedings of MEDINFO 2015, Sao Paulo, accepted

#### Coding morbidity in the patient summary

In adopting the EU directive on Patient Summary, most Countries are regulating the use of coding systems, making some of them mandatory. Nonetheless, General Practitioner (GPs) massively use natural language to record health conditions in the Electronic Health Records (EHRs) [1], thus generating unstructured and not coded data, which cannot be used as they are for the compilation of the Patient Summary (PS). In fact, they require text processing and translation to a structured language before being mapped to coding systems. Moreover, data related to health conditions cannot be automatically derived from those available in the EHRs, because they need to be validated by the GP, the sole responsible for their content. In this scenario, an automated coding support system (CSS) can be of help without breaking the law. A centralized coding system management through a rule-based supporting tool [2] would solve a number of critical issues reported in the literature about the use of coding systems by GPs and other healthcare professionals. This work proposes a methodology for the creation of a CSS that will be initially experimented for the Italian PS use case. 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 CSS, an Italian collaborative work group was set up and a work plan was defined to develop the resources and tools to assist physicians in coding the PS.

### A four-step methodology is proposed:

- 1. analysis of existing projects results (e.g. epSOS) and of the automated ICD-10 coding rules for mortality data. This step will produce standardized coding rules based on general guidelines by qualified institutions (e.g. WHO);
- 2. design of an algorithm that applies coding rules to produce candidate codes and assess their accuracy; 3. creation of a cross reference terminology of structured technical and lay terms (based on existing terminological tools such as ICD-10 Alphabetical Index, the ICMV [3], ICD-11 narrower terms, and Dictionary for NLP created from a database of 295,000 EHRs [1]), as intermediate between natural language and concepts of the international coding systems. Transcoding tables will be used to manage different versions of a coding system or to map between different systems;
- 4. composition of the cited tools to build a web service-based CSS.

The following resource to be used by the CSS will be generated:

- a set of coding rules in an open format based on general guidelines defined by qualified institutions (e.g. WHO) and described by the literature, to be embedded in third-party software;
- the algorithm that applies the coding rules implemented in a suitable computable formal language for representing guidelines/rules and the domain (e.g., OWL + SWRL, Asbru, etc.);
- a set of complementary tools to support the transition from the specialized and natural language used by

8/21/2015 4:38:47 PM Page (2/15)



GPs to the coding language (i.e. the cross reference terminology);

a web service to directly support natural language text coding.

This work proposes a standardized methodology for the development of a rule-based CSS that facilitates the compilation and coding of PS by GPs. 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.

### Dissemination of results

Della Mea V., Frattura L., Chiaravalloti M.T., Pasceri E., Cardillo E., Guarasci R., Eccher C. Coding rules for the patient summary: analysis and requirements to develop an automated coding system. WHOFIC Network Annual Meeting, Manchester, October 2015, Submitted

Talin F. CONFRONTO DI ONTOLOGIE MEDICHE: I CASI DI ICD-11 E SNOMED-CT. Tesi di laurea magistrale in Informatica, Udine, 2015.

## **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.

The Italian WHO-FIC Collaborating Center was working on an ICD-10 Italian Modification, for which an innovative approach has been chosen. A first exercise regarded the cardiovascular diseases as grouped under MDC5. ICD-9-CM diseases belonging to MDC5 were transcoded to ICD-10 using revised transcoding rules and software (TransIT). Then, ICD-10 codes with an approximate mapping to ICD-9 CM codes were submitted to an other software (GemmIT) to generate candidate extensions. The candidate extensions were verified by Italian experts. Extensions coming from ICD-11 were considered as the most interesting to modify ICD-10. The pilot study allowed to justify the approach for the generation of the Italian clinical modification starting from already available and clinically justified modifications. These approach may be of great help for the transition to ICD-11.

### 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.WHO-FIC Annual Meeting, Manchester, 2015, submitted

Andrea Martinuzzi leads the Technical Working Group on functioning interventions (TWG). The updated ICHI alpha2 version was presented at the annual WHO –FIC meeting in Barcelona, October 2014. The axis structure is now fully stabilized. The need for an unofficial test of the draft capacity to respond to users' needs and to adequately represent the universe of health interventions in the functioning area (rehabilitation, evaluation etc) was addressed through a call for comments from various stakeholders (international professional associations, experts). The results of the call for comments was very positive and was discussed during specially appointed teleconferences of the fTWG and at a special session held during the FDRG midyear meeting in Helsinki (June 2015).

Vincenzo Della Mea has driven the design and development of a ICHI Browser and Authoring tool, possibly aimed at being the official browser for the ICHI classification, and then updated the previously developed ICHI Browser and Authoring tool in order to incorporate the ICHI Alpha2 version. Waiting for the formal launch of the WHO-AMA ITHSDO project further steps on ICHI development will include a more in-depth analysis of mental health and public health related interventions with a broader arena of users.

Dissemination of results: a cooperative contribution to WHOFIC Network Annual Meeting, Manchester 2015, submitted

8/21/2015 4:38:47 PM Page (3/15)



### **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 the last 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.

(i) Vincenzo Della Mea continued his work as member of the WHO-IHSTDO Joint Advisory Group (JAG)

- (i) Vincenzo Della Mea continued his work as member of the WHO-IHSTDO Joint Advisory Group (JAG) nominated by WHO-FIC Headquarters. JAG meets once a month through teleconferencing, and twice a year face-to-face. Inside JAG, he also participates in the Common Ontology Joint Working group that works on ICD SNOMED-CT harmonization. This working group meets twice a month through teleconferencing. V. Della Mea participated in most meetings of both, and is in charge of the development of the software needed to carry out an exploratory mapping and common ontology definition on some test chapters of ICD11. This includes a graphical double browser for mappings (Mappet), a subsystem for collecting and distributing mappings in Excel, XML and SQL format, a subsystem for identifying mapping anomalies, and finally a subsystem for displaying candidate entities for the Common Ontology.
- (ii) Della Mea continued his work as co-chair of the Informatics and Terminologies Committee. In this role, he participated in all activities involving committee chairs, including preparing the Strategic Workplan, participating in WHO-FIC Council meetings, and teleconferencing with the co-chair Karen Carvell. To simplify the management of submissions for the annual network meetings, since 2013 the WHO-FIC network has been using a submission platform proposed, implemented, hosted and updated by the University of Udine (Vincenzo Della Mea). In April 2014, ITC also held a mid-term teleconference.
- (iii) Ontological foundation for ICF: The development of an ontology for ICF has been acknowledged as a priority item by WHO and will be object of a specific project involving all stakeholders and relying on the FDRG, FDC and ITC expertise for specific elements of relevance. The Italian CC has contributed with the cochairs of FDRG (Andrea Martinuzzi) and ITC (Vincenzo Della Mea) to the development of the action plan in which the three WHO-FIC groups/committees will be involved. In fact, at the 2014 Barcelona meeting, a small workgroup on the ICF Ontology was created that includes both A. Martinuzzi and V. Della Mea together with C. Celik (WHO). The small workgroup met a couple of times and organised a session at the FDRG mid-year meeting in Helsinki, the main result of which was the development of a survey for describing real world use cases of ICF, as foreseen in the previous year plan. The draft survey, available at http://goo.gl/forms/wc0MoCYx7U, will be refined during the Manchester meeting.

Harmonizing medical terminologies is a time-consuming but critical process to ensure information interoperability and full understanding of the meaning conveyed. A methodology for integrating different terminological resources, both standardized and non-standardized was developed in order to create a foundation terminology to be used as reference for morbidity coding in primary care. The strength of this work is given by both the establishment of relationships between natural and structured/coded languages and the integration of lay terminologies. The resulting foundation terminology can be integrated in automatic coding systems based on rules and used by general practitioners (GPs) in the search of morbidities and related encoding.

8/21/2015 4:38:47 PM Page (4/15)



### A thesaurus of expanded ICF Environmental Factors

Lucilla Frattura and her team have been active on the expansion of ICF in order to overcome the low descriptive power of the ICF EF component, a foundation thesaurus of terms (with an ICF suffix) having an increased descriptive power was developed. The methodology used takem into account: i) a preliminary ICF term extraction process, starting from descriptions and inclusions; ii) integration of the extracted glossary of terms with existing international classifications, such as ATC and ISO9999; iii) integration of the extracted glossary of terms with existing national standard terminologies such as terms for describing Health or Social systems and services: iv) semantic mapping of all terms to ICF EF second level categories; and v) creation of new "hybrid" terms with an ICF suffix.

The Thesaurus of Expanded ICF Environmental Factors (TExIEF) comprises:

- 1. 176 terms in natural language defining subjects that provide support and assistance to the patients were defined according to the descriptions provided by ICF and each term was mapped to ICF codes in Chapter 3 (Table 1)
- 2. 20 terms in natural language defining nutrition and dietetics, including products identified by national regulations and then classified by product groups, were mapped to ICF code e110 (Table 2);
- 3. 3247 drugs, classified according to ATC codes, were mapped to ICF code e110;
- 4. 841 ISO-9999 coded products were mapped to ICF codes in Chapter 1 (references 1-3)
- 5. 87 Essential Levels of Health Care terms, delivered by the Italian National Health System were mapped to ICF code e580;
- 6. 80 regional social services terms from the Social Services Information System were mapped to ICF code e575.

TexIEF included 5224 Expanded ICF-EF terms compared to 74 ICF-EF at the second level categories. It might be considered as a basis for a common multilanguage thesaurus. The thesaurus was developed in Italian. The English version might be incorporated into a new version of ICF.

## mICF project consortium

The Italian WHOFIC CC participated with two bodies (Udine headquarter and Besta Foundation) at the mICF consortium. A project was submitted under the Horizon 2020 Programme at the end of April 2015 by the project coordinator from the Nordic WHOFIC CC (Finland, THL).

#### Indicators of functioning

One of the main problems in functioning/disability description using ICF is to compare persons that are described using different code subsets and different ways for operationalizing the ICF functioning/disability constructs. The aim is to introduce the Family of Functioning Indicators (FaFI), useful to compare individual functioning profiles and to show the functioning-disability continuum using numbers and colours. 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, and 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.

IoF is comprised of two sub-indicators: IoF with EFs presence and role, and IoF without EFs role. The first indicates how much of a role the EFs play in generating functioning. The second shows the healthy individual. Similarly, IoD is made up of two sub-indicators: IoD with EFs presence and role, and IoD without EFs role. The first indicator show how many problems still remain to be overcome despite EFs presence. The second shows the abandoned aspects.

All the indicators may be calculated separately for the BS, BF and AP components. The CFR is calculated

8/21/2015 4:38:47 PM Page (5/15)



starting from the partial FR values. Its total value is 1. The sum of IoF and IoD is 1. If IoF value is 1, then CFR value is 1. This means that the profile is green, and there is no disability in the individual profile. The higher the IoF, the better the functioning. Five classes of «functioning» were defined by CFR or FR value ranges. Data were collected on 489 outpatients.

#### Dissemination of results

Rodrigues JM, Schulz S, Rector A, Spackman K, Millar J, Campbell J, Ustun B, Chute CG, Solbrig H, Della Mea V, Persson KB. ICD-11 and SNOMED CT Common Ontology: Circulatory System. Stud Health Technol Inform. 2014;205:1043-7.

Schulz S, Rodrigues JM, Rector A, Spackman K, Campbell J, Ustun B, Chute CG, Solbrig H, Della Mea V, Millar J, Brand Persson K. What's in a Class? Lessons Learnt from the ICD - SNOMED CT Harmonisation. Stud Health Technol Inform. 2014:205:1038-42.

Cardillo E., Chiaravalloti M.T., Pasceri E., Guarasci R., Eccher C., Della Mea V., Frattura L. A foundation terminology at the basis of morbidity coding in primary care: methodological issues. WHOFIC Network Annual Meeting, Manchester October 2015, submitted

Frattura L., Bassi G., Simoncello A. TExIEF: a thesaurus of expanded ICF Environmental Factor terms. WHOFIC Network Annual Meeting, Manchester 2015, submitted

Frattura L., Simoncello A., Castelpietra G., Bassi G. The infographic Family of Functioning Indicators (FaFI). WHOFIC Network Annual Meeting, Manchester 2015, 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.

In this fourth year of activity, the Italian CC provided for the Update and Revision Committee secretariat functions (Paula Tonel and Andrea Simoncello), and membership (Lucilla Frattura and Francesco Grippo). In the timeframe July 2014-July 2015, the Italian CC continued to support the ongoing process of ICF update on the items coming from the ICF-CY. Purpose of the Update and Revision Committee (URC) is to support WHO and WHO-FIC Network in keeping the WHO Family of International Classifications "Reference Classifications" up to date in line with current knowledge. The functions of the URC are the development of Update policies, Update coordination & decision making, and participation in the revision work in order to ensure synchronization from one revision to the other and consistency within the members of Family of International Classification. The URC work is mainly conducted through the update and revision platforms, 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 deliverable of the URC work include the lists of updates for WHO-FIC member classifications. Concrete outcomes:

In 2014, 63 updates to ICD and 7 updates to ICF were approved by the URC and endorsed by the WHO-FIC Council at the annual meeting held in Barcelona, Spain 11-17 October, 2014. In 2015, in terms of annual updates to ICD, 59 proposals have been moderated and put to vote by members. In terms of annual updates to ICF, 31 proposals have been reviewed by the FDRG and 20 of these have been put to vote by URC members: many of these updates still regard ICF-CY items reviewed in order to become part of a foundation ICF. Functions, activities and completeness of deliverables are represented in the latest version of the Strategic Work Plan submitted to the WHO-FIC Council.

#### Dissemination of results

Vogel U., Jelsma J., Simoncello A., Tonel P. Update and Revision Committee (URC) Annual Report. WHOFIC Network Annual Meeting 2015, Manchester, submitted

8/21/2015 4:38:47 PM Page (6/15)



### **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

The Italian Portal of Health Classifications.

The Italian Portal of Classifications 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. Its name was changed in Italian Portal of Health Classifications (www.reteclassificazioni.it).

8/21/2015 4:38:47 PM Page (7/15)



### ICD implementation strategy in Italy

On behalf of the Italian Ministry of Health, since 2010 Lucilla Frattura has been responsible for the coordination and implementation of a national work plan aimed to update and modify ICD-10 for clinical purposes in order to define national 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). The Italian Institute for Statistics provides expertise and practical support (Francesco Grippo, Luisa Frova) in the ICD-10 updating process. A formal agreement was signed between the Ministry of Health, ISTAT and the Italian CC in order to take part in a unique coordinated national group for updating 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 has been designed which allows to retrieve index entries with all the informative content included in the ICD-10 alphabetical index (lead terms, relevant and non-essential modifiers, coding notes and hints). In the last year, Istat collaborated with the Italian CC for the translation of ICD-10 updates until 2013. The collaboration will result in the web-based updated version of the ICD. Moreover Istat was involved in the revision of the Italian translation of chapters and annexes related to mortality coding of volume 2, 2013 version. The ICD-10 version 2016, in particular the instructions for the underlying coding selection (volume 2), contains relevant innovation for mortality coding. Several terminological and content changes were introduced in volume 2, implying a deep revision of coding practices. In 2014-2015, Istat revised the dictionary of medical terms used for mortality coding according to 2016 version of ICD. Moreover, relevant material for a training course for official mortality coders was selected from volume 2, 2016 version.

Concrete outcome and dissemination of results: ICD 10 Online within sistemaclassificazioni.istat.it

### ICF implementation in Italy

Lucilla Frattura is the coordinator of a new national project funded by the Italian Ministry of Health aimed to: define a technical national group of regional representatives in charge of introducing for the first time a specific mid-term evaluation; collect data on how the Italian regions are using ICF in health, social, education and labor policies; review the way to collect ICF- based data and report on them; study the advantages of introducing a common data set to uniform data collection for national purposes; study if and how an ICF data collection and analysis might be at the basis of new modes to determinate disability in Italy. A preliminary study was carried out before involving specific regions. Data were collected on laws, regulations, assessment tools and projects in which ICF was the conceptual framework and the basis for the collection of coded information at individual level. Preliminary results showed thatICF has been used in Italy for more than a decade, without any specific case use. Despite clinical and research uses, its use for eligibility purposes is not clearly recognized. The few national regulations state that Regions are responsible for implementation in certain policies, but they do not provide implementation guidelines. The current Italian Action Plan in favor of persons with disabilities asks to reform the disability assessment criteria. ICF is considered a standard but few data from the Regions are available to reach a consensus on how to proceed.

Only two regions collected data through information systems and were able to analyze them in order to publish reports (Friuli Venezia Giulia and Veneto). Some of the regions used 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 of children with "handicap grave" or special educational needs;
- to support work inclusion for adults certificated as "invalidi civili".

Only one region developed a method to use ICF at the basis of a new information system in order to open individual biopsychosocial records and assess the outcomes of integrated care plans (Friuli Venezia Giulia). Different national initiatives were planned to introduce ICF, without any interministerial coordination. The role of the Italian WHOFIC collaborating centre was growing.

First recommendations for an effective ICF implementation are:

- a task force is necessary to monitor ICF implementation;
- the task force needs to be coordinated by the Italian WHOFIC CC;

8/21/2015 4:38:47 PM Page (8/15)



- a minimum data set should be defined to minimize the interregional differences, starting from those available;
- a large amount of solid data are necessary to reform any policy.

#### Dissemination of results

Frattura L., Bassi G., Roppa L. Is ICF useful to guide the reform of disability determination in Italy? Preliminary results of a study of the regional state of the art. WHOFIC Network Annual Meeting, Manchester, October 2015, submitted

New tools for interviewing about the environmental factors role in functioning.

In 2015, a new version of the WAPPIn questionnaire for adults was developed. WAPP.In is an acronym meaning "web activities participation performance inventory". The questionnaire is part of the VilmaFAber system to describe functioning and disability considering them as "outcome" indicators. It was developed taking into account:

- the identification of the list of activities explored by WHODAS 2.0 questions come lo introduco?
- the mapping to ICF according to WHODAS 2.0 domains and subdomains and verification of the symmetry level
- the integration of the questionnaire with other questions formulated using the same syntactic structure and natural language of WHODAS 2.0, especially about facilitators and barriers, to apply to each activity analysed
- the definition of the rules to transcode answers to WHODAS 2.0 into complete ICF AP categories with the performance qualifier and EF categories with the facilitator/barrier qualifier
- the updating of the web assessment tool
- the realization of a field test in a sample of adult outpatients.

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. During the field test, the tool was used in a sample of adult outpatients. The tool allows operators to collect information in natural language and in a user-friendly way.

#### 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). WHOFIC Network Annual Meeting, Manchester October 2015, submitted

The Italian WHO CC research Branch Besta coordinated by Matilde Leonardi has been active on:

- the implementation of ICF-based assessment tools in neurosurgical patients and neurological patients, in particular migraine, myasthenia and multiple sclerosis;
- the implementation of the ICF PEI, an ICF-based assessment instrument for the development of a tailored educational plan for children with disability: a qualitative study was employed to select core themes, then questions were developed and the assessment instrument was developed and a paper published:
- the development of an ICF based questionnaire to investigate needs and issues related to transition from childhood to adulthood in patients with neurological disorders seen at Besta during the past 5 years. This work was developed within the national project COTEAM, coordinated by WHO CC research Branch La nostra Famiglia and funded by the Ministry of Health.
- the description of functioning and disability in patients with disorders of consciousness. Differences in functioning between patients in Vegetative state and Minimally conscious state were analysed in longitudinal national studies.
- the organization of a Disability/Case Manager University Course was in collaboration with the Bioethics Centre of the Catholic University in Milan. Based on the bio-psychosocial model of ICF, the 3-week training intensive course develops new ICF-based professional skills for professionals in the fields of health, welfare, labour, education, policy, environmental architects, bioethics. Twenty-five new disability/case managers were trained in 2014/2015.

Dissemination of results:

8/21/2015 4:38:47 PM Page (9/15)



Leonardi M, Koutsogeourgou E. Meucci P. Measuring function and disability in children and adolescents with disability with the biopsychosocial model of ICF-CY. In: (edited by) Kourkoutas E. Hart A. Innovative Practice and Interventions for Children and Adolescents with Psychosocial Difficulties and Disabilities. 2015; 46-59, Cambridge Scholars Publishing; ISBN: 978-1-4438-7250-8

Brunani A, Raggi A, Sirtori A, Berselli ME, Villa V, Ceriani F, Corti S, Leonardi M, Capodaglio P, Group IO. An ICF-Based Model for Implementing and Standardizing Multidisciplinary Obesity Rehabilitation Programs within the Healthcare System. Int J Environ Res Public Health. 2015;12(6):6084-91

D'Amico D, Grazzi L, Bussone G, Curone M, Di Fiore P, Usai S, Leonardi M, Giovannetti AM, Schiavolin S, Raggi A. Are depressive symptomatology, self-efficacy, and perceived social support related to disability and quality of life in patients with chronic migraine associated to medication overuse? Data from a cross-sectional study. Headache. 2015;55(5):636-45

D'Amico D, Grazzi L, Curone M, Di Fiore P, Proietti Cecchini A, Leonardi M, Scaratti C, Raggi A. Difficulties in work activities and the pervasive effect over disability in patients with episodic and chronic migraine. Neurol Sci. 2015;36(Suppl 1):S9-S11

Ferroli P, Caldiroli D, Leonardi M, Broggi M. Complications in neurosurgery: the need for a common language. J Neurosurg. 2015;122(4):983-84

Giovannetti AM, Černiauskaitė M, Leonardi M, Sattin D, Covelli V. Informal caregivers of patients with disorders of consciousness: experience of ambiguous loss. Brain Inj. 2015;29(4):473-80

Koutsogeorgou E, Nyquist F, Nygard M, Cerniauskaite M, Quintas R, Raggi A, Leonardi M. Social capital and self-rated health among older adults: a comparative analysis of Finland, Poland and Spain. Ageing Soc 2015;35(3):653-667

Koyanagi A, Moneta MV, Garin N, Olaya B, Ayuso-Mateos JL, Chatterji S, Leonardi M, Sainio P, Galas A, Haro JM. The association between obesity and severe disability among adults aged 50 or over in nine high-income, middle-income and low-income countries: a cross-sectional study. BMJ Open. 2015;5(4): e007313 Koyanagi A, Stickley A, Garin N, Miret M, Ayuso-Mateos JL, Leonardi M, Koskinen S, Galas A, Haro JM. The association between obesity and back pain in nine countries: a cross-sectional study. BMC Public Health. 2015;15:123

Leonardi M. Burden of migraine: what should we say more? Neurol Sci. 2015;36(Suppl 1):1-3

Raggi A, Covelli V, Leonardi M, Meucci P, Scaratti C, Schiavolin S, Willems M, Sattin D. Determinants of disability using count-based approaches to ICF-based definition of neurological disability. NeuroRehabilitation. 2015;36(1):23-9

Raggi A, Leonardi M, Covelli V, Sattin D, Scaratti C, Schiavolin S, Willems M, Meucci P. The ICF as a framework to collect and interpret data on the extent and variety of disability in neurological conditions. NeuroRehabilitation. 2015;36(1):17-22

Raggi A, Leonardi M. Burden and cost of neurological diseases: a European North-South comparison. Acta Neurol Scand. 2015;132(1):16-22

Raggi A, Schiavolin S, Leonardi M, Giovannetti AM, Bussone G, Curone M, Di Fiore P, Grazzi L, Usai S, D'Amico D. Chronic migraine with medication overuse: association between disability and quality of life measures, and impact of disease on patients' lives. J Neurol Sci. 2015;348(1-2):60-6

Raggi A, Schiavolin S, Leonardi M, Grazzi L, Usai S, Curone M, D'Amico D. Approaches to treatments of chronic migraine associated with medication overuse: a comparison between different intensity regimens. Neurol Sci. 2015;36 Suppl 1:5-8

Schiavolin S, Quintas R, Ferroli P, Acerbi F, Brock S, Cusin A, Schiariti M, Visintini S, Broggi M, Leonardi M, Raggi A. Quality of life measures in Italian neurosurgical patients: validity of the EUROHIS-QOL 8-item index. Qual Life Res. 2015;24(2):441-4

Sebastiano DR, Panzica F, Visani E, Rotondi F, Scaioli V, Leonardi M, Sattin D, D'Incerti L, Parati E, Strambi LF, Franceschetti S. Significance of multiple neurophysiological measures in patients with chronic disorders of consciousness. Clin Neurophysiol 2015;126(3):558-564

Tyrovolas S, Koyanagi A, Garin N, Olaya B, Ayuso-Mateos JL, Miret M, Chatterji S, Tobiasz-Adamczyk B, Koskinen S, Leonardi M, Haro JM. Diabetes mellitus and its association with central obesity and disability among older adults: A global perspective. Exp Gerontol. 2015;64:70-77

Tyrovolas S, Koyanagi A, Garin N, Olaya B, Ayuso-Mateos JL, Miret M, Chatterji S, Tobiasz-Adamczyk B, Koskinen S, Leonardi M, Haro JM. Determinants of the components of arterial pressure among older adults – The role of anthropometric and clinical factors: A multi-continent study. Atherosclerosis. 2015;238(2):240-24 Willems M, Sattin D, Vingerhoets AJ, Leonardi M. Longitudinal changes in functioning and disability in patients with disorders of consciousness: the importance of environmental factors. Int J Environ Res Public Health.

8/21/2015 4:38:47 PM Page (10/15)



The Medea Research Branch guided the re-evaluation of the ICF-CY based form for children with disability in the school inclusion process for the Province of Treviso. After 5 years of implementation of the new ICF based format, the revision of the inter-institutional agreement that by law regulates the identification of children with disability and their plan of intervention is ongoing. A more accurate evaluation of the environmental factors is the prime goal of the working group that is due to deliver the new proposal within 2015.

Within the Medea Research Branch the well established experience of inpatient rehabilitation projecting using ICF has now moved to the informatization step. After a 3-month testing of an alpha version, the beta version fully integrated within the personal health record (SISSI) is now under extensive trial in the two units for neurorehabilitation. A parallel process of ICF implementation to guide the functional diagnosis and the rehabilitation in out-patients has also been developed and was reported in an accepted publication. Coteam Project: The collaborative project named "COTEAM" which gathers partners involved in various stages/levels of care provision for this population in different Italian health service providers launched on Nov 2012 was concluded in Nov 2014. The main features resulting from the project are detailed in the final report submitted and approved by the Ministry of Health and the Veneto Region. Shortly, ICF was shown to provide a comprehensive profile of the critical aspects of transitioning. The implementation of the FABER protocol in the tested population (persons with disabilities and complex needs aged between 14 and 20) offered the opportunity for a more extensive testing of that protocol and of a detailed view of the changes in the services responses occurring during transition. An excerpt of the results was presented at the National congress on Neurorehabilitation in Novara, May 2015.

### Dissemination of the results

Martinuzzi A, De Polo G, Bortolot S, Pradal M. Pediatric neurorehabilitation and the ICF. NeuroRehabilitation. 2015;36(1):31-6. doi: 10.3233/NRE-141188

Martinuzzi A. Paralisi Cerebrali Infantili: Il bambino che diventa adulto: prognosi a lungo termine. Proceedings of the XV congress of the Italian Society for Neurologic Rehabilitation, Novara May 2015

### 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 (primarly 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.

ICD 10 implementation in Albania.

Albania is currently preparing to go through ICD-10 implementation within a wider process to update the information and communication technologies in order to enhance the quality of health data. The WHO Regional Office for Europe asked the Italian WHO-FIC Collaborating Centre to make available expertise to the

8/21/2015 4:38:47 PM Page (11/15)



Albania WHO-Country Office in order to support the implementation of ICD-10 at national level. After a preliminary step in 2011, the cooperation was renewed by organizing a site visit in Italy to update the state of art of the transition to ICD-10 in Albania and in Italy and to define a possible collaborative work plan. Members of MOH Albania visited the WHO Italian Collaborating Centre in Udine (May 2015) to discuss about Collaborating Centre organization, activities, challenges and electronic tools for the maintenance and development of ICD-10 classification. The Albanian delegates evaluated the implementation status of ICD in their Country. The collected information regarded the different data flows in the health system, the classifications in use at the moment, the willingness to change to ICD-10 and the roles of the different institutions in the process. Comparisons with the Italian transition to ICD-10 were made, searching for similarities and differences. Tools developed by the Italian WHO-FIC Collaborative Centre to manage the ICD-10 translation and update were examined and considered useful to Albania implementation process. Recommended actions and next steps were drafted, considering two different combined actions: to include in the Italian WHOFIC CC work plan an activity specifically devoted to support EURO Region in supporting Albania; and to verify the possibility to sign a direct agreement between the Albanian and Friuli Venezia Giulia Ministry of Health.

#### Dissemination of results.

Frattura L., Lazeri L., Odeta L., Ekonomi M., Kakarriqi E., Novi S., Bejtja G., Thoma T., Munari F., Tonel P., Simoncello A., Della Mea V., Orsi C.. ICD-10 implementation in Albania: a collaborative roadmap. WHOFIC Network Annual Meeting 2015, submitted

Measuring Disability and Health in Emergencies: implementing a disability survey using WHODAS 2.0 in the Typhoon Yolanda affected areas of the Philippines.

Matilde Leonardi has been active on the first disability survey in the Philippines. After natural disasters, the most commonly reported data are the number of deceased and displaced and the economic damage. Disability data are lacking although they are necessary for better person-based reconstruction plans. Our study assessed disability in the survivors of Haiyan/Yolanda typhoon. The WHODAS 2.0 was administered to 2000 adults and we addressed the impact of demographic variables, effects of the typhoon and individual health state on disability. Disability in typhoon survivors was mostly predicted by respondents' age, health condition and urban residence. Disability data after emergencies might help identifying the most vulnerable groups, thus guiding reconstruction strategies, health and social interventions.

### Dissemination of results

Leonardi M, Raggi A, Schiavolin S. Disability in emergencies: survey with WHODAS2in the post thypoon Yolanda populations of the Philippines WHO-FIC Annual Meeting, Manchester, October 2015, submitted Leonardi M., Kostanjsek N F. Measuring Disability and Health in Emergencies: implementing a disability survey using WHODAS 2.0 in the Typhoon Yolanda affected areas of the Philippines WHO-FIC Annual Meeting, Barcelona, October 2014

### ICF implementation in Macedonia

Andrea Martinuzzi acted as a consultant in the project "Assessment of Capacity of Services provided by Health, Education and Social Sectors for Inclusion of Children with Disabilities in the former Republic of Macedonia". The consultation started in December 2014 and included two visits to Macedonia meeting all relevant stakeholders and visiting institutions and services. The project objectives were: to give the government of Macedonia an updated gap analysis of the present country way to approach the needs of children with disabilities; to identify areas of needed improvement; to suggest possible strategies for improvement. The ICF was the conceptual reference and the tool identified as guiding element both in the situation analysis and in the proposed improvement actions.

#### ICF implementation in China

Two professionals from the Medea research branch (Dr Gianni De Polo and Sonia Bortolot) held on April 10-18 2015 a one-week ICF training course for rehabilitation and education specialists in Beijing, China within the Europe Aid project IT2009-FMS-0503413738 "Holistic and right-based approach to people with disability as poverty reduction strategy in China". The course was attended by over 80 Chinese professionals of the health and education sector and explored the areas of ICF implementation most relevant to the clinical and education sectors.

8/21/2015 4:38:47 PM Page (12/15)



### **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.

Moving from the 2011-2015 terms of reference (TORs) of the Italian WHO-FIC CC, a performance monitoring plan was defined to yearly assess the CC's performance. 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.

In the fourth year (21 July 2014-21 July 2015), the Italian WHO-FIC CC was active on five lines of work at international, national and regional level: (i) revision of the International Classification of Diseases; (ii) IT and ontological development for WHO FIC; (iii) coordination and management of the ICD-10 and ICF update process; (iv) national work on WHO-FIC; and (v) awareness building and implementation support of WHO-FIC in WHO regions.

New projects inside the WHO-FIC network: participation in mICF collaborative project; involvement in SNOMED-CT and ICF common ontology efforts; development of tools for automated ICF coding. Updates at national level: the CC is formally engaged, as leader of the ICD-10-related line of work, in the national project of revision of the Italian case-mix system (IT-DRG project); ICD-10 cumulative updates were translated into Italian and the relevant ClaML file was maintained both in English and Italian through the Italian Portal of Health Classifications; launch of the national project on ICF implementation.

Updates at WHO Euro Region level: support to implement ICD 10 in Albania.

Updates at regional level: the adoption of the VilmaFABER system in the Friuli Venezia Giulia Region and a fourth field test in the Liguria Region.

The communication power was evaluated considering presentations, seminar and meeting organization, and active users of the Italian Portal of Health Classifications.

The Italian CC has actively participated in leading positions in the WHO-FIC management. Specifically: Advisory Council (CC Head: Lucilla Frattura 5 teleconferences); FDRG Co-Chairmanship: Andrea Martinuzzi (10 teleconferences, 1 mid-year meeting, Helsinki 4-7 June 2015); FDRG membership: Matilde Leonardi (FDRG mid-year meeting, Helsinki 4-7 June 2015); SEG participation: Andrea Martinuzzi (7 teleconferences, 1 one SEG face to face meeting SEG, Geneva May 11-12, 2015); ICHI fTWG: Andrea Martinuzzi (2 teleconferences); ITHSDO functioning: Andrea Martinuzzi (2 teleconferences); ITC Co-chairmanship: Vincenzo Della Mea (1 mid-year meeting, 3 teleconferences)

MRG Co-Chairmanship: Francesco Grippo (1 mid-year meeting Budapest, 3-5 March 2015)

#### Dissemination of results

Frattura L: Updates on the performance monitoring plan of the Italian WHO-FIC Collaborating Centre, WHO-FIC Annual Meeting, Manchester, October 2015, submitted

8/21/2015 4:38:47 PM Page (13/15)



Informatics and Terminology Committee (ITC). Vincenzo Della Mea acted as co-chair.

The key activities of the Informatics and Terminology Committee (ITC) since the Barcelona meeting in October 2014 a mid term teleconference to collect committee members updates. The work of the ITC is aligned with four objectives of the strategic work plan. These objectives are: 1) maintain browsers for WHO Classifications; 2) engage WHO-FIC network and broader e-health community in the development of a multi-language framework for WHO-FIC classifications; 3) enable the electronic exchange of WHO classifications by providing necessary technical standards; 4) enhance formal knowledge representation of WHO classifications and their linkages to related terminologies.

### Dissemination of results

Miller K., Della Mea V, ITC report. WHO-FIC Networl Annual meeting, Manchester, October 2015, Submitted

Mortality Reference Group (MRG). Francesco Grippo acted as co-chair.

During the Annual WHO-FIC meeting 2014, Francesco Grippo, delegate of the Italian CC, was nominated cochair 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. In fact, the selection of the underlying cause of death is a complex process which implies a deep knowledge of the ICD and a rigorous application of the rules provided by the Classification. Due to this complexity, the mortality coding can be affected by variations which lower the comparability of data across time and space. For some causes of death, the lack of specific instructions can lead to different interpretations of medical certification, resulting in an additional source of variation. The issues to be discussed in the MRG derive 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 contacts, mortality forum, national coders enquiries, automated coding users.
- Moderation of the discussion via email and at the annual meeting (October 2014, Barcelona) and mid-year meeting, March 2015 in 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 proposals (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. Concrete outcome

In the year 2014-15, 18 issues were discussed and moderated during the MRG meetings and 17 proposals were submitted to the URC.

### Dissemination of results

Hoyert DL, Grippo F, Johansson LA. Mortality Reference Group Annual Report, 2014-2015. WHO-FIC Network Annual Meeting, Manchester October 2015, submitted

Functioning and Disability Reference Group. Andrea Martinuzzi acted as co-chair.

The co-chairs met bi-monthly by teleconference. FDRG members and collaborators were informed of progress on the projects during the year and met by teleconference in March 2015 and September 2015. A mid-year meeting was held on 6 June 2015 at National Institute of Health and Welfare (THL), Helsinki, Finland, attended by 30 members and collaborators from 16 countries. In conjunction with the FDRG meeting, other meetings were held in the same location: the mICF project; the First International Symposium on ICF Education; and a one-day meeting with the Education and Implementation Committee (EIC). 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. Three pieces of work are underway to inform the development of an ICF ontology:

- 1. a survey seeking use cases of ICF has been designed and circulated to FDRG members and collaborators. Results of the survey will be collated and reported at the meeting in October 2015;
- 2. FDRG has discussed activity theory as a basis for the development of an information model starting from a

8/21/2015 4:38:47 PM Page (14/15)



consideration of the categories from the Life Areas (activities and participation) component of ICF presenting problems during the updating process. This work is preliminary and will be explored further at the meeting in October 2015 and a plan for further work developed;

- 3. the update proposals that have been rejected based on inconsistency with the current ICF were reviewed to identify ontological issues. The main issues were:
- overlap and multiple parenting;
- relationship between simple and complex tasks;
- granularity;
- temporal issues/development.

During the 2014-2015 year there were 20 update proposals moved on to the closed discussion layer in the ICF Update Platform for voting, 14 of these with an FDRG recommendation for adoption, with or without modifications. There were 6 with a recommendation for rejection. There are 11 update proposals still remaining in the open discussion layer for further work. These proposals will be discussed during the FDRG meeting in October 2015.

As a means of dealing with problematic proposals in the ICF update platform it was proposed that criteria, in addition to those currently available, could be introduced in the short term pending completion of an ontology for ICF. The proposed criteria will be discussed at the FDRG meeting in October. It was proposed that, in the longer term, a white paper be written examining the need for a second version of ICF addressing the ontological issues and making recommendations based on the experience of updating ICF to date. FDRG members and collaborators continue to work with the FDC on the development of the International Classification of Health Interventions. A review of the functioning component has resulted in:

- a new definition of an intervention;
- 220 new interventions;
- revised definitions and inclusions and exclusions to enhance clarity of some interventions.
   FDRG continues to be represented on the functioning Technical Advisory Group informing the ICD 11 development.
- 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 calls, 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.

8/21/2015 4:38:47 PM Page (15/15)