DRAFT for Discussion at WHO FIC Network Meeting 2005

Update and Revision Platform for ICD

1. Background

The International Classification of Diseases (ICD) is a global standard and international public tool to organize and classify information about diseases. ICD is a member of World Health Organization's "Family" of International Classifications (WHO-FIC) which provide the basic building blocks for health information systems. The overall vision of the WHO Classifications is to provide a suite of integrated standard tools to capture data at the delivery point with tools that are totally interoperable across systems and countries so that global communication and information exchange in health sector is possible (similar to economic or transport sectors). To keep the scientific currency and public health utility of the classifications, ICD is scheduled for 10 yearly periodic revisions and annual updates in line with the recommendations of the governing bodies of the WHO[1]. An update and revision strategy has been prepared by the WHO involving all stakeholders. The revision and update strategy[2] of the ICD will follow an approach that is similar to "software release" in that it will maintain compatibility with previous versions, allow new functionalities and developments as modules and the revision proposals will be field tested before implementation. The main objectives of the ICD update and revision process are to create a user-friendly and scientifically credible classification utilizing modern knowledge management and sharing methods to synthesize the scientific advances in the health field in a continuous manner. A common information infrastructure for the update and revision process has been created for the all ICD chapters covering various health areas to link the supporting evidence to the classification including a meta-data representation. There is, therefore, a need to provide better input into this infrastructure in terms of scientific content in various disciplines. Mainly areas such as oncology, gastrointestinal disorders, mental and addictive disorders, some aspects of internal medicine (hypertension, diabetes, mitochondrial disorders) have already been identified as main foci of the update and revision process by the WHO-FIC Network. In each area of health care the health information will be systematically reviewed in three interconnected main lines: (1) Scientific Stream (2) Clinical Stream (3) Public Health Stream. This work will be carried out by a core team of WHO investigators along with a group of international collaborators and advisors utilizing a permanent Internet-based knowledge management and sharing portal.

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[1] *The resolution can be found at hyperlink: WHA ICD Resolution (WHA 43.24).*

[2] *The term "revision" refers to the larger scale changes regarding the overall redesign of the system that is done every 10 years, whereas "updates" refer to annual quick-fixes, additions and deletions to the system which does not alter the architecture of the system. We plan to make updates every year. Cumulated annual updates will be published as ICD third and fourth editions in three year' periods.*

2. The main purpose of the Update and Revision Platform:

To create an update and revision platform for the ICD that will be based on:

1. scientific evidence
   ICD should reflect the advances in medicine and all health sciences

2. clinical utility
   ICD should be easy to use, support clinical decisions and management, have meaning for daily practice

3. public health usefulness
   ICD should be useful to record mortality, morbidity and population health parameters, assist in public health policy and decision making for resource allocation, monitoring outcomes

3. The Specific Aims:

The Specific Aims of the Update and Revision Platform, in line with the above overall purpose, are as follows:

1. To explore the scientific basis of diseases to reflect the most updated ICD in a systematic fashion. To achieve this specific aim, systematic reviews of literature will be carried out by selected expert groups. A standard protocol will be followed to identify scientific publications to be reviewed. All journals included in Index Medicus and Science Citation Index should be reviewed since the publication of ICD-10 (i.e., 1990) in a systematic search to explore the diagnostic implications of ICD categories. Specific questions will be formulated by expert groups to guide this research. For example:

   a. Do the new discoveries of infectious agents require classification or coding changes? (e.g. Helicobacter pylori, SARS Coronavirus, Ebola virus, etc…)

   b. Do the new discoveries of drugs or other interventions require specific coding changes? (e.g. coding of drug resistance, refractory treatment, similarity of treatment response in different diseases, new diagnostic procedures and therapeutic interventions?)

   c. Does the availability of the genetic information on human genome and disease specific genes alter the taxonomy? (e.g. new genes have been identified with regard to certain cancers such as lymphomas or breast cancer; the same applies for many other diseases such as Alzheimer's; Narcolepsy etc. - what implication should this information have in the design and use of the classification?)

2. To explore the clinical utility of the ICD in daily practice of various clinicians and in different settings such as primary care, hospital settings, rehabilitation and long-term care settings and make the necessary adaptations to match the needs of the users so that an

appropriate level of detail is available (e.g. the classification reflects the relevant categories which are most frequently seen and treated in those settings without redundancy and with sufficient detail for differential diagnosis and guide for management). For example the same classification of ICD could be presented in primary care with a single code for appendicitis, or depression or diabetes mellitus in primary care. However, these diagnoses will not be sufficient for hospital care. One would like to know further details such as the type, treatment need and possible complications. The update and revision platform will explore the needs and practices of different users to tailor the level of detail for different users without changing the overall master standard of ICD. To achieve this there will be internet based *international discussion forums* that are open to clinical experts from different countries to base their opinions. In addition proposed changes and option will be tested involving various clinical practitioners in a prospective systematic field testing trial organized as a *Global Practice Network.*

3. To explore the public health usefulness of the ICD and make necessary updates and revisions to serve better the needs of users in the public health field. The main topics of exploration will include:

   a. How is ICD implemented to record deaths in different countries (i.e. mortality) ? What are the main codes used, the descriptive process of use, accuracy of coding practice, suggestions for improving standardization to achieve comparability, accuracy and reliability?

   b. How is ICD implemented to record morbidity in different countries (i.e. morbidity) ? What are the main codes used, the descriptive process of use, accuracy of coding practice, suggestions for improving standardization to achieve comparability, accuracy and reliability? What are the basis for clinical modifications made in different countries such as ICD-10-CM in the USA, ICD-10 AM in Australia, ICD-10 CA in Canada and ICD-10 GM in Germany? Would other countries follow such clinical modification examples? If so what is the best way to maintain standardization and comparability?

   c. What is the use of ICD for health financing and reimbursement purposes? How could it provide better input to casemix groupings such as DRGs or DPCs?

   d. How can ICD be linked with and used in electronic health records? There is a need to expand the level of detail of classification entities by linking them to standard description of signs, symptoms and other descriptors of illness. These are being formally developed over the world as standard terminologies. What would be the procedure linking/mapping with clinical terminologies such as SNOMED, GALEN or others?

4. Plan of Activities

To address these specific aims we would like to create a set of activities that will bring together the above questions in a coordinated workplan and activity that we in short call an *"update and revision platform for ICD"*.

This Update and Revision platform for ICD:

- should be coordinated by the WHO Headquarters with active participation of whole WHO Network inviting all to improve the classification in terms of its scientific basis, clinical and public health use.
- should create a network of users involving scientists, practitioners, administrators, policy makers and consumers to make better use of classification for understanding, communicating, planning and administering health care.
- should make state-of-the art evidence based reviews to reflect the most updated scientific knowledge in the classification including recent advances in medical and health sciences as well as in information technology
- should include field trials which are essential for testing the applicability of the classification as well as obtaining operational characteristics such as reliability measures. In addition they serve identifying linguistic and cultural applicability issues, and serve as knowledge dissemination mechanisms.
- should allow linking classifications and clinical terminologies through their proper knowledge representation i.e. the *diagnostic formulations* as formal operationalization of any diagnosis including signs, symptoms, laboratory findings etc. in standard vocabularies
- should serve to provide the necessary transformation to the 21st century health information system needs to monitor and evaluate health outcomes.

4.1 Organizational Structure and Detailed Plan of Activities

WHO Headquarter will coordinate the overall ICD revision in consultation with the WHO Member States and multiple professional organizations to ensure that the final revision is broadly responsive to the many different aspects of health care. The work will be mainly carried out by the Coordinating Group and the Workgroups as described below:

A. The Coordinating Group

A Coordinating Group will serve as the planning, steering and final decision-making authority in the update and revision process. The primary charge of this group will be to guide and monitor the quality of the work of workgroups. The initial responsibilities of the coordinating group will include the following: (a) determining the number and content areas of the workgroups, (b) selecting the co-chairs of the workgroups, (c) presenting an initial mandate to each workgroup, (d) establishing procedures for the activities of the workgroups, and (e) facilitating cross-fertilization of ideas and reducing redundant efforts by making workgroups aware of one another's activities.

Once the workgroups begin to develop preliminary recommendations, the responsibilities of the coordinating group will shift to the following: (f) reviewing initial recommendations of the

workgroups, (g) providing feedback to the workgroups regarding areas for further exploration of evidence and modifications to the proposed revisions, (h) making cross-cutting decisions that affect the diagnostic revisions of multiple groups, and (i) coordinating diagnostic recommendations to achieve consistency in final changes across groups and areas. The Coordinating Group will communicate on an ongoing basis by email, have monthly telephone conference calls, and will convene at least twice annually for an in-person meeting. The composition of the Coordinating Group will be as follows:

A1. Core Group: will include the WHO responsible officers and WHO-FIC Network as well as key stakeholders such as the international Non-Governmental Organizations (NGOs) and major scientific partners.

A2. Expert Members: The Coordinating group will also include key experts representing the three streams including scientific evidence, clinical and public health streams to ensure the synthesis of knowledge in the best possible combination.

The Coordinating Group will also invite consultants and other members of the workgroup as necessary to take part in their meetings.

B. Workgroups

The workgroups will consist of experts within each major domain of the mental health field. The primary charge of these groups will be to review and synthesize the available evidence in each domain and to make revision recommendations to the coordinating group.

Workgroup Components. Each workgroup will function at three levels: *co-chairs*, *workgroup members*, and if necessary a *subgroup structure*. Work at each level will be assisted by a *workgroup coordinator* and *a staff assistant* and will involve regular communication within and between levels by the KMS portal as well as phone and e-mail. Each workgroup will be led by two co-chairs. These individuals will be responsible for selecting the members of the workgroup and establishing the membership and focus of the subgroups. They will supervise the work of the workgroup, monitoring progress and ensuring quality control. If necessary each workgroup may include subgroups corresponding to subclasses of disorders or other areas requiring focused attention within the workgroup domain. The number and size of the subgroups will be determined by the specific needs of each workgroup and are expected to vary substantially across groups.

Workgroups are expected to include approximately 10-12 members. Subgroups can include participants who are not members of the workgroup, but must be chaired by a member of the workgroup. An effort will be made to draw members of workgroups and subgroups from multiple disciplines and nations. The particular blend of professional disciplines represented will depend on the areas of expertise relevant to that group. In assembling the workgroups, an effort will be made to balance the most expert candidates with the goal of broad interdisciplinary and international representation.

Each workgroup will be assigned a *workgroup coordinator* who will provide substantive support and assistance to the workgroup co-chairs and members. Coordinators will be postdoctoral fellows who

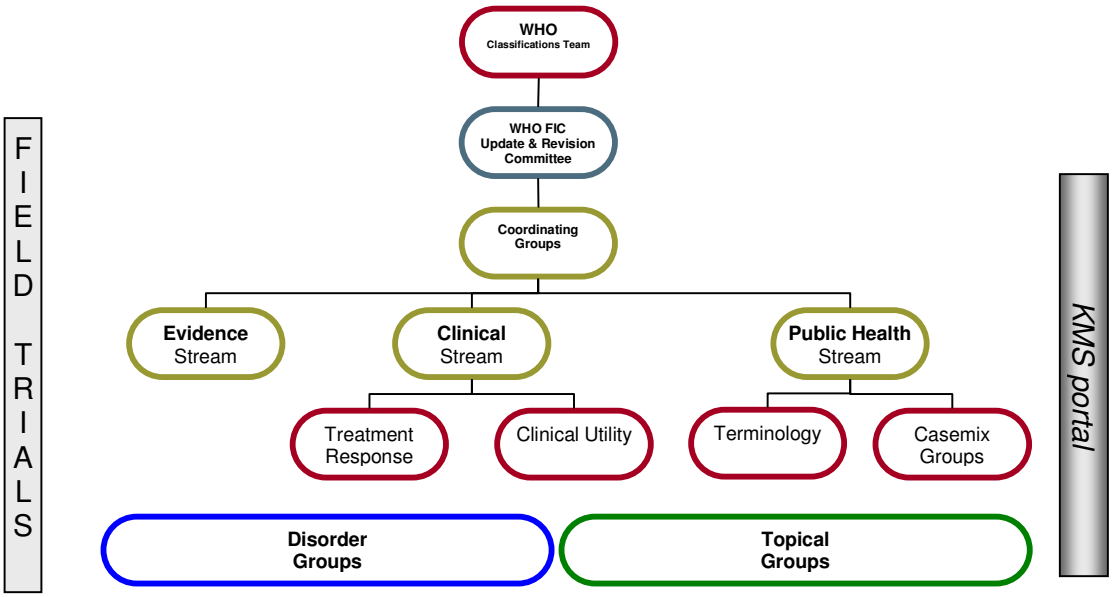
are employed by WHO and whose activities will be coordinated by a WHO study manager in consultation with the workgroup co-chairs. Responsibilities of the workgroup coordinator will be flexible and will be determined by the needs of individual workgroups. However, all coordinators are likely to assist in some way in carrying out the systematic reviews of the relevant research literature (e.g., identifying search terms, conducting the literature review, obtaining the papers, reading or allocating the papers among workgroup members) and may assist with preparing first drafts of workgroup reports. At the beginning of the process, all the postdoctoral researchers will come to Geneva for an intensive three-month orientation period, after which they will return to carry out their work at collaborating sites throughout the world. The WHO coordinator will be in constant email and phone contact with the postdoctoral researchers we well as with the Workgroup co-chairs. The Workgroups will review and synthesize the materials generated by the postdoctoral researchers and subsequently by the members of the international research community who participate in the commentary, debate, and sequential refinements of the revisions posted on the KMS Portal.

Co-chairs of all workgroups will have privileged access to the KMS portal and will participate in a monthly telephone meeting with the Coordinating Group so that co-chairs from each workgroup can learn about the activities of other workgroups. In addition, co-chairs will meet individually with WHO postdoctoral fellows on a periodic basis to keep them apprised of workgroup progress. Within-workgroup communications will include ongoing KMS portal access and regular updates via email and periodic telephone conference calls on a schedule established by the workgroup co-chairs. A similar set of communication strategies will be used by subgroups within the individual workgroups.

Types of workgroups. Two types of workgroups will be involved in the ICD update and revision process: disorder groups and theme groups. The disorder groups will together represent all of the major chapters of ICD. Each chapter that is presently included in ICD-10 will be assigned for review by a unique workgroup. The workgroups will be charged with reviewing the literature on their disorder(s) and organizing this evidence to address the ten key diagnostic issues described below. In consultation with the relevant theme groups, the disorder groups will use this body of evidence to recommend changes to the classification within their content domain.

Several common themes cut across the different chapters of ICD. To ensure consistency in handling these cross-cutting themes, theme workgroups will be created that interface with all of the chapters. The theme workgroups will focus on specific manifestations of diseases (such as epidemiology, phenotypes, treatment response, age: children's, youth and elderly manifestations of diseases) . Each theme workgroup will consult with each disorder-specific workgroup to ensure comparable attention to the theme across the disorders. To this end, the theme groups will be charged with: (a) serving as expert advisers on the themes to the disorder workgroups, (b) providing information to the disorder groups about useful theme-related ideas and solutions of other disorder workgroups, and (c) ensuring consistent consideration of these themes across disorder workgroups. In addition we plan to start a theme workgroup on Public Health /Administrative Implications that will specifically address issues of mortality and morbidity statistics, clinical modifications, links to clinical terminology and case mix groupings

Figure 1: Overall Representation of the ICD Update and Revision Platform



Tasks for the Workgroups:

<u>Task 1</u>. Develop a preliminary position statement on each core diagnostic issue

Prior to commencing their review of the evidence, the chapter workgroups will be asked to consider each of ten core issues that they will seek to address for each diagnostic entity in their content domain, and to develop a preliminary position on each issue based on their preexisting knowledge of this domain. It is expected that this position statement will evolve over time in response to information gleaned through the examination of evidence. The initial position statement will effectively set the agenda for the workgroup and will define the range and scope of questions that the workgroup will consider. In composing this statement, it is important for workgroup co-chairs to be aware that proposals should be made as an update of the ICD-10 structure. To ensure that the scope of the work proposed by the workgroups is consistent with the WHO vision for the ICD update and revision process, it is important for the coordinating group to work closely with workgroup co-chairs to develop draft position statements for each workgroup prior to the time the workgroups begin their systematic literature reviews.

The *core diagnostic issues* to be considered by each workgroup are as follows:

I. **Definition of the diagnostic entity as a medical disease or disorder.** Draw a line around the disorder of interest, identifying its critical properties. How does the workgroup fundamentally view the diseases in this chapter? Identify key criteria and level of evidence.

II. **Clustering of signs, symptoms, and operational characteristics.** Identify the features that are necessary and sufficient to define the disorder.

III. **Link to underlying pathophysiology and genetic markers.** Identify the intra-individual markers that are associated with the disorder, considering their biological plausibility, their measurement properties (e.g., reliability, specificity, predictive power), and their role in treatment response.

IV. **Clinical utility of the diagnostic entity.** Consider the usefulness of the diagnostic entity in predicting treatment response, course, and outcome.

V. **Reliability of the diagnostic entity.** Consider the stability of the diagnostic entity over time and its consistency of detection across assessors and measurement instruments.

VI. **Validity of the diagnostic entity.** Consider the associations of theoretically relevant variables with measures of the disorder and the support they provide for the validity of the diagnostic construct.

VII. **Separation of disease and disability elements.** Identify the features that signal the presence of the disorder, defining the disorder without reference to the distress, impairment, or other consequences that it produces.

VIII. **Cultural elements that need to be attended.** Consider variability in the presentation of the disorder across cultures. Identify ways to achieve cross-cultural comparability and utility of diagnostic criteria rather than listing separate culture-bound syndromes or formulations.

IX. **Threshold considerations.** Identify the number and nature of diagnostic criteria that should be required to qualify for the disorder. Consider the nature of the boundary separating the disorder from normality, including evidence for the categorical/continuous distinction. Consider the disorder's boundaries with other disorders and disorder classes, including challenges of differential diagnosis. Consider the latent structure of the disorder and how this might inform the organization of symptoms and criteria within the diagnostic algorithm.

X. **Other nosological issues relevant to this disorder.** Identify any other aspects of the disorder that the workgroup believes to be in need of evaluation, including potentially controversial aspects of the disorder that will need to be addressed. This list of additional issues may change as the evidence related to this disorder is reviewed.

TASK 2. Review the empirical evidence

Workgroups will survey the available evidence for each diagnostic entity to address the nine diagnostic issues described above. Evidence will be reviewed using a three-tiered, iterative process that maximizes input from sources that are most readily accessible.

2.1) Review the published literature. At the start of the process, all workgroup coordinators will receive intensive training in the state of the art of literature reviewing. Participants will attend a WHO-sponsored virtual training session to learn the standardized system chosen to guide the compilation and coding of published results. This system will be selected by the coordinating group and provided to co-chairs early in the update and revision process. Participants will also receive guidelines concerning the review parameters to be used in the literature reviews (e.g., inclusion criteria, exclusion criteria, review and reporting style). The workgroup coordinators will then carry out these reviews at collaborating sites throughout the world. The study manager based at WHO headquarters will remain in constant contact with the workgroup coordinators and the workgroup co-chairs throughout the review process.

2.2) Targeted secondary analysis of existing data. If no published studies are available to answer a particular question identified by a workgroup, workgroup members will search for existing data that would address this question but that have not yet been analyzed or published. Workgroup co-chairs will seek appropriate data by (a) directly contacting researchers in the field who may have relevant data and (b) putting out an open call for data relevant to the question at hand. When researchers with relevant data are identified, the co-chairs will, at their discretion, arrange with these researchers to share or analyze their data or to collaborate with workgroup members on analyses to address the knowledge gap. Results of these analyses will be evaluated using the same standardized rules used to evaluate published results in the literature reviews. Informative results may be published in the online Classifications Journal *{see below 4.3 d - page 12}* or in books or chapters to be published by WHO on the ICD update and revision process.

2. 3) Collection and analysis of new data. When no data sets are available to address unanswered questions of the workgroups, new data need to be collected. Because time and resources for new data collection are limited, such efforts will likely be restricted to questions that are relatively circumscribed and that can be fruitfully addressed through basic descriptive studies. Workgroups will generate proposals for data collection to address unanswered questions through rapid distribution of target measures to clinicians in the GHPN *{see below 4.2 page 11}* that can be completed by the clinicians themselves or administered to their patients. These data will then be analyzed and their results systematically coded and integrated with evidence gathered in the first two tiers.

Task 3 . Report results and recommendations to the coordinating group and global community

3.**1) Documenting the evidence on which recommendations are based.** Using the results of their evidence-based reviews, the disorder workgroups will formulate suggestions for updating and revising the ICD-10 diagnostic categories, operational criteria, and/or overall coding structure.

3. **2) Reporting interim and final results.** Each disorder group will be asked to write and to post on the KMS portal an interim report of its progress every six months as well as a final report documenting its final results and recommendations. The Coordinating Group, in consultation with the workgroup co-chairs, will establish explicit guidelines for the workgroups to use in preparing these reports, including separate templates for interim and final reports. The purpose of these guidelines will be to ensure completeness of desired information and consistency across documents submitted by different workgroups. As an incentive to engage in the report-writing process, workgroup members will have the opportunity to publish interim reports in special issues of the online Classifications Journal.

In addition to their review by the coordinating group, interim and final reports of the workgroups will be posted on the KMS Portal. This platform will serve as a public forum in which end-users can provide feedback to the workgroups throughout the development process, increasing the likely usefulness of the revised ICD for the wide range of constituents for whom it is being devised. To that end, comments on reports will be solicited from the scientific community and other ICD stakeholders. In addition to general comments, workgroups may request suggestions for future directions or call for information or data on a particular topic. Public comments will be continually collected and reviewed by postdoctoral fellows, who will screen them for content and relevance before forwarding them to the appropriate workgroups. These comments will be considered and weighed using the same criteria as those used in the review of empirical evidence.

TASK 4. Revised reports

Workgroups are likely to complete multiple rounds of reports in an iterative process in which they report their findings, receive feedback from the Coordinating Group and the world mental health community, and revise their work in response to feedback. The coordinating group will establish a set of criteria for evaluating workgroup reports and may bring in external consultants to assist in the evaluation process. Evaluations may be followed by requests for clarification of competed work or for additional work in particularly important, controversial, or understudied areas. In addition, workgroups will complete annual updates of their literature reviews to ensure that the information in their final report—and the evidence on which final recommendations are based—is as comprehensive and up-to-date as possible.

TASK 5. Field trials

The provisional revised diagnostic criteria recommended by the workgroups will be tested in one or more iterations of field trials *{see below 4.2 page 11}*. Field trials will be conducted in collaboration with the international network of mental health practitioners who will apply the provisional criteria in their clinical practice. Results obtained through this Global Health Practice Network (GPHN) will be used to provide additional feedback to the workgroups about aspects of the diagnostic criteria that could be further improved.

5. 1) Proposing questions for the field trials. Given the key questions identified in the review process workgroups will be asked to develop feasible questionnaires that could be applied within the Global Health Practice Network(GPHN)

5.2) Evaluation of the feedback from the field trials Results of the field trials will be provided to the workgroups to serve in developing the final revisions and recommendations.

TASK 6. Final revisions and recommendations

6. 1) Preparing a final report. Based on the results of field testing, the workgroups will finalize the ICD-11 diagnostic criteria and prepare a final report summarizing their results and recommendations. The report will be presented to the Coordinating Group and posted on the internet platform.

6.2) Setting an agenda for future work. While it is hoped that the comprehensive survey and synthesis of the psychopathology literature will yield important advances in our understanding of mental disorders, it is also expected that many questions will remain unresolved and that some new questions will become apparent as the update and revision process draws to a close. Having just reviewed and contributed to the available literature, the workgroups will be in an ideal position to identify remaining gaps in knowledge, chart the steps needed to fill these gaps, and set an agenda for the field for future research in these areas. The resulting proposals will be published in one or more of several possible forums, including the ICD text itself, the ICD web page, the online Classifications Journal, books published by WHO on the ICD update and revision process, or a companion workbook accompanying the newly-published ICD-11.

4. 2 ICD Update and Revision Field Trials

An international network of practitioners will be created in collaboration with the WHO FIC Network and different NGO's in relation with WHO. This Global Health Practice Network (GHPN) will include numerous health professionals throughout the world who agree to participate in quarterly e-surveys aimed at providing diverse kinds of information about patient characteristics that can be used to inform the ICD update and revision process. Both clinician ratings of individual patients and patient self-report questionnaires collected by the participating clinicians will be used as part of these ongoing surveys. The GHPN will enable real-time collaboration to obtain direct patient assessments on crucial diagnostic questions among current patients within practices throughout the world. In addition to providing a venue for quick, large-scale data collection to inform the review of evidence and development of diagnostic criteria, the GHPN will also serve as the main platform in

field trials that will allow us to test the provisional revised criteria and evaluate their reliability, validity, and clinical utility in a range of clinical settings around the world

4.3 Knowledge Management and Sharing (KMS) Portal for ICD Update and Revision

To facilitate communication among the members of the workgroups, and make the expert group processes transparent to the field by requiring expert groups to post interim products of their deliberations on a regular schedule for public comment we intend to create a permanent internet platform, which we call the Knowledge Management and Sharing (KMS) portal.

Many experts from all over the world will participate in different aspects of the update and revision process. In order to facilitate better **communication** and **collaboration** this platform will be open to public and to working groups at different levels of access. The portal will be the *single point of access* for the update and revision process. However, the communication will not be one way as in as in classical web sites. On the contrary most of the contents of the site will be generated by the users. The site will be composed of different components such as a calendar of activities, discussion forums, collaborative document creation platforms document libraries, etc.

The important elements of this *KMS Portal* will be:

a) *An Internet Platform* that will both facilitate communication within expert workgroups and will make the expert workgroup processes transparent to the field by requiring expert groups to post interim products of their deliberations on a regular schedule for comment through use structured notes in form of "blogs" (short for web-logs to annotate the evidence behind the decision making); and "wikis" (joint authoring tools to write in a predetermined style over internet including many participants and reviewers) for wider participation and linking evidence to proposals (e.g. participants will be asked to back their comments with publications from PUBMED and other open sources).
b) A *public forum* in which end-users can provide feedback to expert groups all throughout the development process;
c) *Structured field trials* focusing on key questions on mental disorders, testing of various options for their feasibility, utility and relevance.
d) *On-line Classifications Journal*: an Internet based open source peer-reviewed and PubMed cited journal on classifications which will include the systematic reviews, meta-analysis and expert group recommendations on ICD-Revision for sharing with academic community. Certain selections of this journal could be used for publication in other languages and formats (e.g. books, reprints etc).

All of these components will be grouped according to a grouping structure that will be generated by experts of the field. Each user entering the portal will see a custom page for him/her depending his/her roles in the update and revision process. This is important because the participants will have expertise on a diverse number of topics. We would like to show them the information that is relevant to their area of expertise so that they can function in a more efficient way. The level of participation of the users will be different as well. For example, some users may be only participating in the discussions where as others may be in charge of editing the documents in the light of the discussions.

In summary, we should be able to define **roles** and assign users to these roles so that each user accesses the portal from a perspective specified by his/her roles.

We expect that through the KMS portal the final revision will be broadly responsive to many different aspects of health care, and provide unprecedented access to the ICD by users who were unable to access previous editions because of financial constraints or limited distribution of hard copies. This kind of transparency and constant back-and-forth exchange between the expert groups and the field represents our best hope of making the final ICD revisions useful to its wide range of likely constituents.

Each step of the ICD update and revision process will be documented in an Internet knowledgebase platform. There will be open access to this system in order to allow online data sharing and unrestricted discussion among participants from any relevant discipline throughout the world as the revisions evolve. Although the ultimate goal of this system is to refine successively evidence-based conclusions, an important component of this system will be the posting of data gaps. As noted in the last paragraph, our aim in doing this is to make relevant researchers aware of these data gaps in the hope that relevant data will sometimes be available and that targeted secondary analysis can be carried out to shed some light on a number of important knowledge gaps.

The activity will thus produce *permanent internet based workspace* that will document the evidence-based systematic reviews, meta-analysis of available data and discussion forum open to international multi-disciplinary participants. We will create an Internet Platform in multiple languages (English, Spanish, French, Chinese, Russian, Arabic as UN Standard Languages and other languages that may be supported by other partners - such as in Japanese) to enable participation of all interested parties using transparent knowledge management and sharing mechanisms. We will use the same internet platform to help disseminate the products of our labors throughout the world as an international public good. This kind of transparency and constant back-and-forth exchange between the expert groups and the field represents our best hope of making the final ICD revisions broadly useful to the wide range of constituents for whom it is being devised.

The KMS portal will allow increased feedback from the global health community. In the past, draft versions of proposed revisions were reviewed only by workgroups. WHO advisors saw only the penultimate and final versions of the proposed revisions, whereas the revised criteria were not seen by anyone else prior to their publication. This arrangement will be modified in the ICD update and revision process to provide earlier feedback. Specifically, interim drafts of the proposed ICD revisions will be reviewed by the coordinating group as well as posted on the KMS Portal for the public for comment and debate as soon as they become available. In addition, steps will be taken to involve the broader community in the update and revision process and to make workgroup activities open and transparent. The workgroups will review and synthesize the feedback offered by the coordinating group and by the members of the international research community who participate in the commentary, debate, and sequential refinements of the revisions posted on the KMS Portal. Thus the impact of annual meetings will be multiplied with the establishment of a permanent platform that enables continuous input and quality improvement.

4.4 Public Health /Administrative Implications

In addition we plan to start a theme workgroup on Public Health /Administrative Implications that will specifically address issues of mortality and morbidity statistics, clinical modifications, links to clinical terminology and case mix groupings

We are also in collaboration with MAP of MEDICINE (see http://www.medic-to-medic.com/) to utilize this link as visualization of formal diagnostic algorithms that would enable doctors or care-providers to capture and process information electronically.

It is essential that the ICD diagnosis should be further elaborated using clinical terminologies to formalize the diagnosis with operational definitions. For example, F32 Depressive Disorder will be captured as SNOMED CT terms each coded and defined such as (Low mood, loss of interest, low energy, sleep problems (insomnia, early awakening,…) appetite problems (low appetite, binging…) sexual problems (libido loss); guilt ; thoughts of death and suicidal ideation or acts. Similarly Tuberculosis will be further detailed by primary infection, positive tuberculin test, infection site (lungs, bone, kidney etc…) symptoms (coughs, sputum, fever, sweating, weight loss…) and findings (bacillus positive, culture positive etc). Same will be done as capturing all the diagnostic schemes for all areas of medicine under the WHO classification guidelines together with international experts in the related fields.

The formal representation of ICD in terminologies will allow two possible ways of processing the health information (1) declarative searches: allowing automated coding of medical records in electronic environment identifying the presence of a constellation of symptomatology and if present a probability towards the ascertainment of an official diagnosis. (2) Procedural searches: As in the case of Map of Medicine the coded information will build a template for verification of diagnostic explorations similar to a computerized diagnostic support system.

5. TIMETABLE

The active phase of the ICD update and revision process will begin in 2005. This work will go in two streams.

ICD -10 Updates: every year annual updates will be made to ICD. Every three years major updates and cumulated updates will be published.

ICD- Revision: Towards an ICD-11 two major drafts will be developed. An *alpha draft* for view by the internal users (e.g. WHO FIC network and experts) and a *beta draft* for the whole world for field testing. It is envisaged that a beta version could be developed by 2009 and will be similar to the ICD-10 fourth edition with options. This convergence will allow users to switch from ICD-10 to ICD-11 in a seamless fashion.

The ICD 11 - beta draft will be subjected to systematic field trials for feasibility, reliability, clinical utility and validity. Following the field trials, a penultimate version will be released for public review and response prior to a revised final version being submitted to the World Health Assembly for approval.

It is critical that we start the active phase of the ICD update and revision process in 2005 in order to complete the proposed work by the WHO required deadline for release of the ICD-11. This means that we have an urgent need for funding so that we can quickly move forward with international consultations and start to feed into multiple streams of the workplan to arrive at a platform to compile scientific implications of major areas of work. This work needs to result in a beta version of ICD-11 in 2009 for systematic field trials for feasibility, reliability, clinical utility and validity. Following the field trials, we need to have a penultimate version for public viewing and response that then will be revised for a final version that must be submitted to the World Health Assembly for approval.

6. Budget & Resources:

WHO has established funding sources from other countries and WHO FIC Network Members for different segments of the update and revision process. So far we have already been provided with the following support from other sources:

1. International Union of Psychological Sciences to provide at least two post-doctoral psychologists to assist WHO in the creation and implementation of the field trials throughout 2005-2011.

2. World Psychiatric Association and its global national member societies have committed in taking part in the update and revision process and field trials. They have committed to hold a meeting per year. First meeting was already held in April 2005 in Toulouse.

3. We have agreed in principle a grant for Mental Health Chapter of ICD-11 with the National Institute of Mental Health (NIMH) and submitted a grant application for 250.000 USD total direct costs for five years. This will be reviewed in June and final decision will be made. It is likely that we shall submit a similar grant to the National Institutes of Drug Abuse (NIDA) and National Institute of Alcoholism and Alcohol Abuse (NIAAA).

4. We are supporting a grant application by a US consortium called cBIO (National Center for Biomedical Ontology) which is for 20,175, 451 US$ for over five years. This grant will enable ICD -terminology link as described in the detailed activities.

5. We are supporting an European Union grant application on e-health for Semantic Interoperability Road Map. This grant is for 2 million Euros over 2 years and is likely to continue for the following years for the implementation of the Road Map at a much larger scale.

6. German Government is supporting the WHO FIC Collaborating Center and this center is undertaking the electronic tools for update and revision to a large extent. They provide approximately four person years each year and also hold an annual meeting on cancers starting with lymphomas in 2005. First meeting was already held in March 2005 in Cologne.

7. German informatics company SAP is supporting the revision process by making a systems analysis of the update and revision platform. If the protocol is agreed between WHO and SAP they are willing to donate a large scale software for Knowledge Management and Sharing (KMS portal).

8. Nordic Center is supporting the update and revision process by holding an annual conference on External Causes of Mortality and Morbidity. First meeting was held in 16 -17 June 2005 in Copenhagen.

9. Australian Collaborating Center is convening an annual meeting for the review of Diabetes in the ICD and national modifications.