

40	<b>Assemble the Platform into ICTM Web Portal</b>	132	
41	- Integrate ICTM-T, ICTM-C, and ICTM-I components into one platform	60	
42	- Program commenting feature	30	
43	- Program structure editing feature	30	
44	- Program frontend	30	
45	- Identify paths and rules for information flows	30	
46	- Test the web portal	12	
47	Meeting4: Working meeting on Tools and Software	10	
48	<b>Translational/Multilingual transition software</b>	345	
49	Program software to accommodate multilingual generation	120	
50	Produce a guide	45	
51	Testing	180	
52	<b>Mapping</b>	417	
53	<b>Link terminology - ontology features</b>	90	
54	- Establish cross links between ICTM platform and Ontology	30	
55	- Establish cross-ref-links with ICD and WHO-FIC	30	
56	- Program software to accommodate linkages	60	
57	<b>Test mapping - antero and retro testing</b>	30	
58	<i>Milestone3: Software tools developed</i>		
59	<i>Milestone4: Portal Developed and launched</i>		
60	<b>Pre-Alpha Draft</b>	105	
61	<b>Pre-population</b>	105	
62	- Enter compiled and raw-edited resources into platform	30	
63	Engage input from all project stakeholders	75	
64	Engage input from NGOs and Health Systems specialists	75	
65	<b>Alpha Draft</b>	642	\$425,000
66	<b>Population</b>	607	
67	<b>Assemble data</b>	60	
68	<b>Revise Terminology</b>	30	
69	<b>Multilingual interface pilot</b>	15	
70	<b>Consultation with selected experts and user representatives</b>	30	
71	<i>Meeting5: Alpha draft discussion</i>	5	
72	Incorporate Comments	15	
73	<b>Formulate Alpha Draft</b>	60	
74	<b>Organize all relevant proposals</b>	45	
75	<b>Editing</b>	60	
76	<b>Presentation to ICTM Advisory Group</b>	10	
77	<i>Meeting6: ICTM-AG Meeting on Alpha Draft</i>	10	
78	<b>Web-based Piloting of Alpha Draft</b>	15	
79	Pilot Test	15	
80	<i>Milestone5: Alpha draft completed</i>		

81	<b>Beta Draft</b>	215	\$465,000
82	<b>Revision</b>	130	
83	<b>Review existing Alpha Draft</b>	20	
84	<b>Identify strengths and issues</b>	20	
85	<b>Assemble additional data</b>	30	
86	<b>Address identified issues, as necessary</b>	30	
87	<b>Revise Content Models and Terminology</b>	60	
88	<b>Broad consultation with experts and national governments</b>	20	
89	<i>Meeting7: Beta Draft discussion with experts and governments</i>	10	
90	- Incorporate comments	10	
91	<b>Formulate Beta Draft</b>	190	
92	<b>Additional expert contracted inputs</b>	90	
93	<b>Web portal input</b>	90	
94	<b>Organize all relevant proposals</b>	20	
95	<b>Editing</b>	60	
96	<b>Presentation to ICTM Advisory Group</b>	1	
97	<i>Meeting8: ICTM-AG Meeting on Beta Draft</i>	5	
98	<i>Milestone6: Beta draft completed</i>		
99	<b>Field Testing</b>	105	\$180,000
100	<b>Produce a guide</b>	10	
101	<b>Examine multi-national feasibility</b>	60	
102	- Reliability in coding by different users	60	
103	- Utility in different health system setting	60	
104	<b>Modify Beta Draft as necessary</b>	35	
105	<i>Milestone7: Field Testing completed</i>		
106	<b>Final Drafts</b>	188	\$360,000
107	<b>Web portal based consultation</b>	45	
108	<b>Revision</b>	80	
109	<i>Meeting9: Joint ICTM meeting to discuss Final Draft</i>	10	
110	<b>Review and incorporate, as necessary</b>	10	
111	- all comments gathered through consultations and meetings	10	
112	- all comments gathered through additional focus field testing	10	
113	- all data and comments gathered through the web portal	10	
114	<b>Editing</b>	60	
115	<b>Presentation to WHA</b>	3	
116	<b>Proposal of ICTM for inclusion in ICD-11</b>	10	
117	<i>Milestone8: Project goals achieved</i>		
118	<b>Publication of documents</b>	60	
119	<b>Facilitation for translation processes</b>	30	
120	<i>Meeting10: Meeting on implementation and next steps</i>	10	
121	<b>Content managers and assistants</b>		\$1,596,000
122	<b>Operational expense</b>		\$1,134,380

Total: US\$5,500,380

## DRAFT Terms of Reference of the ICTM Advisory Group

The ICTM Advisory Group will serve in a primarily advisory capacity to WHO in the planning and development process in line with the overall project plan. Its terms of reference are as follows:

1. *Oversee the development process and give advice for coordination of workgroups:*  
ICTM-AG will
  - review and make suggestions about the overall progress of the development process
  - ensure adequate coverage of all areas of TM practice with relevant codes to represent different clinical practices in a parsimonious way
  - maintain congruity between the ICTM and other WHO-Family of International Classifications
  - synthesize different inputs ensuring participation from various regions, countries, languages and multiple stakeholders including NGOs.
  - Assist in the formulation and implementation of field trials and review process
  
2. *Identify uses of the classification and ensure that the development process addresses the needs of users:*  
ICTM-AG will
  - preserve coherence and consistency of the description of entities between the various WHO-Family of International Classifications
  
3. *Implement basic taxonomic and ontological principles:*  
ICTM-AG will observe the consistency and coherence of basic taxonomic and ontological principles across the overall development process, including:
  - Key definitions: examples include disease, disorder, syndrome, pattern, sign, symptom, reason for encounter, trauma, and external cause
  - Attributes, as mentioned in the Content Model ( see appendix 1)
  - Linkages to other WHO-Family of international Classifications ( in particular to ICD-11) with a view to share a common ontology and be represented as a special chapter in the ICD-11
  
4. *Generate suggestions to resolve problems and ways to field test options as necessary:*  
ICTM-AG will
  - make suggestions to solve problems or conflicts arising across different proposals
  - make suggestions for field trials to gather empirical data for their solution
  
5. *Develop plans and tools for transition from ICTM to ICD-11, Chapter 23:*  
ICTM-AG will
  - Identify requirements for users to adopt ICTM including coding guidelines, versions fit for various purposes, cross walks, electronic tools, and educational materials

## Draft Terms of Reference of the ICTM-TAGs

Topic Advisory Groups (TAGs) will serve as the planning and coordinating advisory bodies for specific issues which are key topics in the ICTM development process:

1. Classifications
  - a. Patterns and Diagnosis
  - b. Interventions
2. Terminologies
3. Informatics

It is foreseen that the Classifications TAG will have two basic working groups; a) Patterns and Diagnosis, and b) Interventions.

- The informal consultation meeting will discuss the architecture and organigram as to whether the Terminology and Informatics topic areas may be served by a single, unified body.
- The TAGs will organize **workgroups** or identify consultants to deal with relevant subtopics, as necessary. It is desirable that the chairs of the working groups are TAG members or that the consultants will be represented in the TAG meetings, as necessary.

The primary charge of each group will be to advise WHO in all steps leading to the development of topic sections of ICTM in line with the overall development process. In particular:

- Advise on particular ***topic development steps and establish workgroups and partners to involve*** -

The TAGs will advise WHO on the constitution of working groups to undertake generation of necessary evidence, to develop proposals, and to focus on specific issues, as needed. Each TAG will:

- propose content areas for the workgroups
  - identify nominees for the members and chairs of the workgroups
  - develop an initial draft mandate for each workgroup
  - establish procedures for the activities of the workgroups
  - facilitate communication and internal consistency across different workgroups
- Advise in ***developing various drafts of topic segments in line with the overall production timeline*** of ICTM -  
TAGs will review initial recommendations of the workgroups and consolidate them to achieve consistency in proposals across groups and areas.

- Advise in ***developing protocols for and in implementing field trials*** – TAGs will also propose appropriate use of the ICTM in the current and future practice of health information systems.

Topic Advisory Groups (TAG) will lead the work in different fields of expertise and agree on a common procedure and content model for the overall classification and terminology links.

Ten rules will ensure consistent quality of work across all groups:

- |   |
|---|
| <ol style="list-style-type: none"><li>I. <b>Definition of the diagnostic entity as a medical disease, pattern, or disorder</b></li><li>II. <b>Clustering of signs, symptoms, findings, and operational characteristics</b></li><li>III. <b>Link to underlying causes and mechanisms when applicable</b></li><li>IV. <b>Clinical utility of the classification entity</b></li><li>V. <b>Reliability of the use of the classification entity</b></li><li>VI. <b>Validity of the classification entity</b></li><li>VII. <b>Separation of severity of the pattern/disease and functional impact on activities</b></li><li>VIII. <b>Cultural elements that need to be attended</b></li><li>IX. <b>Threshold considerations: e.g. When does something transition from normal to disease?</b></li><li>X. <b>Other classification issues relevant to each proposed entity</b></li></ol> |
|---|

## **Terms of Reference of the ICTM WorkGroups**

WorkGroups will serve as the key functioning unit for the generation of main proposals and review of evidence on a specific topic. For example, the TAG in the Classification of Interventions will be responsible for all TM interventions, whether medication or practice based, and their linkages, and it may generate 2-3 working groups to carry out the systematic work on acupuncture, herbal medications, or manual interventions.

The workgroups are asked to consider 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 existing knowledge from all over the world. 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.

The broad range of activities can be described by a set of tasks:

- TASK 1. Develop a preliminary position statement on each core diagnostic issue. Blocks of ICTM may be suitable entities.
- TASK 2. Review the empirical evidence.
- TASK 3. Generate summary proposals on the development platform for comment by other groups, the ICTM-AG, and the global community.
- TASK 4. Revise reports.
- TASK 5. Propose Field trials.
- TASK 6. Final revisions and recommendations.

### **TASK 1. Develop a preliminary position statement on each core diagnostic issue**

The initial set of core diagnostic issues to be considered by each workgroup are listed in box I - these may be taken as an example by each workgroup to expand further on the key classification issues on the topic of interest.

- I. **Definition of the diagnostic entity as a medical disease, pattern or disorder.** Given the key taxonomic guidelines and definitions each group should draw a line around the entity of interest, identifying its critical properties. How does the workgroup fundamentally view the full spectrum of patterns/disorders/diseases in this chapter/field in terms of their classification? 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 pattern/ disease/disorder, based on the common model of ICTM.
- III. **Link to underlying causes and mechanisms, when applicable.** Identify the intra-individual markers that are associated with the pattern/disease/disorder, considering their biological plausibility, their measurement properties (e.g., specificity, predictive power), and their role in treatment response.
- IV. **Clinical utility of the classification entity.** Consider the usefulness of the classification entity in diagnosis, predicting treatment response, course, and outcome.
- V. **Reliability of the use of the classification entity.** Consider the stability of the classification entity over time and its consistency of detection across assessors and measurement instruments.
- VI. **Validity of the classification 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 severity of pattern/disease and functional properties.** Identify the features that signal the presence of the pattern/disease/disorder, defining the pattern/disease/disorder without reference to the distress, impairment, or other consequences that it produces. Suggestions to link to WHO ICF and specifically operationalize the criteria on disability and distress related rubrics.
- VIII. **Cultural elements that need to be attended.** Consider variability in the presentation of the pattern/disease/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 classification entity. Consider the nature of the boundary separating the pattern/disease/disorder from normality, including evidence for the categorical/continuous distinction. Consider the classification entity boundaries with other classes, including challenges of differential diagnosis.
- X. **Other classification issues relevant to this entity** Identify any other aspects of the classification entity that the workgroup believes to be in need of evaluation, including potentially controversial aspects of the pattern/disorder that will need to be addressed. This list of additional issues may change as the evidence related to this pattern/disorder is reviewed.

## **TASK 2. Review the empirical evidence**

Workgroups will survey the available evidence for each diagnostic entity to address the ten diagnostic issues described above. Evidence will be reviewed using a three-tiered, iterative process that maximizes input from sources that are most readily accessible, while not neglecting others.

**Review the published literature** - A standardized system should be chosen to guide the compilation and coding of published results. This system will be researched and suggested by the ICTM-Advisory Group and provided to co-chairs early in the development process. Participants will also receive guidelines concerning the parameters to be used in the literature reviews (e.g. inclusion criteria, exclusion criteria, review, and reporting style). Workgroup coordinators will then carry out these reviews at collaborating sites throughout the world. Study managers based at WHO Headquarters will remain in constant contact with the workgroup coordinators and the workgroup co-chairs throughout the development process.

**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 which may not yet have 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, or in books or articles to be published by WHO on the ICTM development process.

**Collection and analysis of new data** - When no data sets are available to address unanswered questions of the workgroups, new data must 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 Global Health Practice Network 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. Generate summary proposals on the development platform for comment by other groups, the ICTM-Advisory Group, and the global community.**

Documenting the evidence on which recommendations are based and using the results of their evidence-based reviews, the workgroups will formulate suggestions for developing ICTM diagnostic and ontological categories, operational criteria, and/or overall coding structure.

**Reporting interim and final results** - Each working group will be asked to write and to post on the development platform an interim report of its progress every six months, as well as a concluding report documenting final results and recommendations. The ICTM-Advisory Group, in consultation with the TAG and 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 journals.



In addition to their review by the ICTM-AG, interim and final reports of the workgroups will be posted on the development platform. 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 ICTM 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 ICTM 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, and then screened for content and relevance before being forwarded 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 ICTM-AG and the world community for a health field, and revise their work in response to feedback. The ICTM-AG will propose 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 completed 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. Field trials will be conducted in collaboration with existing global networks.

***Proposing questions for the field trials*** - Given the key questions identified in the development process, workgroups will be asked to develop feasible questionnaires that could be applied within the Global Network.

***Evaluation of the feedback from the field trials*** - Results of the field trials will be provided to the workgroups to facilitate development of the final revisions and recommendations.

#### **TASK 6. Final revisions and recommendations**

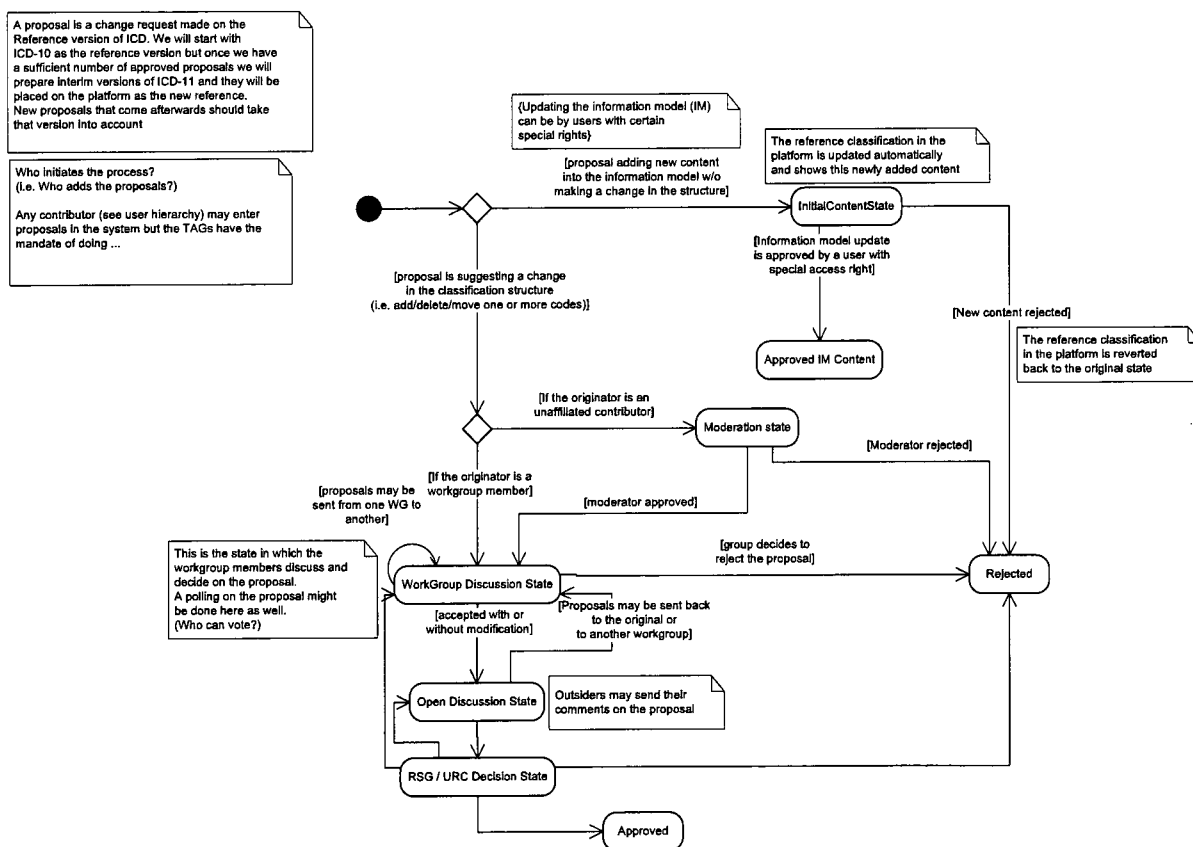
***Preparing a final report*** - Based on the results of field testing, the workgroups will finalize the ICTM diagnostic criteria/external causes and prepare a final report summarizing their results and recommendations. The report will be presented to the ICTM-Advisory Group and posted on the Internet platform.

***Setting an agenda for future work*** - While it is hoped that the comprehensive survey and synthesis of the literature will yield important advances in our understanding of patterns/disorders and their external causes, it is also expected that many questions will remain unresolved and that some new questions will become apparent as the development 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. The resulting proposals will be published in one or more of several possible forums, including the ICTM text itself, the ICTM web page, the knowledge portal, books published by WHO on the ICTM development process, or a companion workbook accompanying the newly-published ICTM.

## 1 Workflow

Proposals for ICTM information can be generated by workgroups, or anyone accessing the development platform. The proposals can relate to modifications of the structure of ICTM, or to modification of definitional content of ICTM, or to both. Any structural changes will be decided before definitional content is formulated. In some cases, definitions will be present in existing internationally agreed sources, thus guiding decisions that may lead to structural changes. The graphics below depicts the flow of a proposal:



## **Chairing of TAGs and Workgroups**

Co-chairs of all workgroups will have privileged access to the ICTM Development Portal and will participate in a monthly telephone meeting with the TAG so that co-chairs of each workgroup can learn about the activities of other workgroups.

Chairs are liable to WHO that rules and regulations of the revision process are followed by their groups.

Chairing is a proactive undertaking, and the range of activities and responsibilities that a chair must perform is huge. The chair of a TAG is accountable to WHO. The chair of a committee must realize that the success or failure of that committee rests squarely on his/her shoulders. The primary duty is to guide the group's discussions. He/she should encourage every member to participate in the work and keep the discussion focused on the matter at hand. The chair ensures there are agendas and structured reports.

In particular, the chair ensures development procedures are applied by the TAG and its workgroups, including:

- Creation of workgroups
- Workflows
  - Proposals
  - Comments
  - Conflict resolution
- Evidence based review guidelines
- Communication with ICTM-AG/WHO

The chair is also responsible for encouraging opportunities for interactions between the members. Group should be provided the opportunity to get to know each other, as groups tend to work better if the members are familiar with one another.

Members of workgroups should be carefully selected. These are the people who will help resolve issues for the relevant specialty. They should be knowledgeable in the area of the group's responsibility.

# Draft Terms of Reference of the TAG- Informatics

## Terms of reference for a TAG for Informatics

The development plan for ICTM includes linkages between the TM classification scheme and related terminologies. Each category is, in fact, defined by further details with more refined concepts (e.g. a disease is made up of certain signs and symptoms, it has a cause and mechanism etc). ICTM will have explicit rules that will explain each disease/pattern in a standard way with underpinning terms. These terms will be presented as standard terminologies and be represented in ontologies built-in for computer systems. In this way, we aim to develop definitions which are both human-readable and machine-readable.

Depending upon the purpose of the use of the classification, the ICTM concepts may allow different extractions for the classification, similar to the ICD (i.e. mortality, morbidity, case-mix grouping etc).

To enable this objective of creating an ICTM with systematic links to terminology and ontologies, a specific group is constituted to advise WHO and the ICTM Advisory Group on the following issues:

- Identification of a simple, understandable and logical "Content Model" (a.k.a. information model) which represents the knowledge of Traditional Medicine diseases/patterns by operationally defined parameters. These parameters may identify ICTM classes *with their attributes* such as Site, Manifestations, Cause, Temporal Relations, Extent/severity, Impact/disability, etc.).
- Identification of the logic rules of how different bits of information come together to define a concept – i.e. knowledge representation of ICTM categories.
- Linking ICTM categories and terminologies with existing terminology and ontology projects to contribute to the ICTM development (e.g. NCBO, ...).
- Design of the specifications and requirements of a tooling environment that accommodates the use case needs for the development process. This will include a **web based tool** that allows for creation and editing of the semantic structure of the classification through controlled, distributed development by multiple groups. Design and production will start using the ICD structure as a rough template and enable use of available tools such as Collaborative Protégé (e.g. iCAT).

## Content Models: *standard representation of knowledge*

Dr T. Bedirhan Üstün  
Dr Molly Meri Robinson

### What is a Content Model (CM)?

- Captures the **key parameters** for the definition of an ICTM entity
  - *What is a concept – **entity** in TM?*
  - *How do you define it: basic **attributes**?*
  - *What different **values** it can take?*
- in a **standard & systematic** way

### What is a CM Parameter ?

- A group name for **Common Characteristics / Attributes**
- Describes a **particular component or perspective**
  - kind, scope, size, location, origin, ...
- Useful to understand the entity mentally and define it in an **unambiguous** way
- Refer to the entities in a **systematic** way
  - Allow **sorting** into classes, **grouping**, indexing, searching...
  - Useful to teach computers (*also humans !!*)

### Example Parameters

- Symptoms and Manifestations
  - signs, symptoms and findings
- Etiology
  - underlying explanatory mechanism(s)
- Course and Outcome
  - distinct pattern of development over time

## ICD Content Model

**TITLE of ENTITY:** Name of disease, disorder, or syndrome...

1. Textual definition
2. Synonyms - Inclusion - Exclusion - Index terms

### Descriptive characteristics

1. **Type**  
Classical, disorder, syndrome, injury, sign/symptom, external cause, anatomical structure (pathophysiology)
2. **Body Part(s)** (anatomical site)
3. **Body Part(s)** (anatomical site)
4. **Manifestation Attributes**  
Signs & Symptoms  
Signs  
Symptoms
5. **Etiology**  
Causal Mechanisms / Agents  
Genomic characteristics
6. **Temporal Properties**
7. **Severity and/or Extent**
8. **Functional Impact**
9. **Treatment**

## What is a Value Set?

- This list of possible terms or options within each parameter
  - Every word, phrase, or statement that can be used by a computer or a human to describe a diagnostic entity or intervention

## Example Value Sets -

Stages of Disease Transformation

- Tai Yang Stage
- Shao Yang Stage
- Yang Ming Stage
- Tai Yin Stage
- Shao Yin Stage
- Jue Yin Stage
- Destroyed Stage

## Example Value Sets - Body Systems

- Cardiovascular System
- Digestive System
- Endocrine System
- Integumentary System
- Musculoskeletal System
- Neurological System
- Reproductive System
- Respiratory System
- Urinary System

## **Why do we need a Content Model?**

- To organize TM knowledge in a consistent, structured way
- To facilitate efficient and productive drafting
- To prepare for computerized terminologies and ontologies
  - Electronic Health Records
- To ensure the most useful document for end-users

## **CONTENT MODEL - ICD**

- 1) **Title of Entity**
- 2) **Hierarchy, Type and Use**
  - a) **Parents**
  - b) **Type**
    - i) **Disease**
    - ii) **Disorder / Syndrome**
    - iii) **External Cause and / or Injury**
    - iv) **Sign / Symptom**
    - v) **Reason for Encounter**
    - vi) **Unspecified**
  - c) **Use**
    - i) **Primary Care**
    - ii) **Mortality**
    - iii) **Morbidity**
    - iv) **Research**
    - v) **Specialty Adaptation**
    - vi) **Clinical Modification**
- 3) **Textual Definition(s)**
- 4) **Terms**
  - a) **Index Terms**
    - i) **Synonyms**
    - ii) **Inclusion Terms**
  - b) **Exclusions Terms**
- 5) **Clinical Description**
  - a) **Body System(s)**
  - b) **Body Part(s)**
- 6) **Manifestation Properties**
  - a) **Signs and Symptoms**
  - b) **Findings**
- 7) **Causal Properties**
  - a) **Etiological Type (etiology)**
    - i) **Infection**  
(1) **Agent(s)**
    - ii) **Injury**  
(1) **Mechanism(s)**
  - b) **Risk Factors**
  - c) **Genomic Characteristics**
- 8) **Temporal Properties**
- 9) **Severity Properties**
- 10) **Functional Properties**
- 11) **Specific Condition Properties**
- 12) **Treatment Properties**
- 13) **Diagnostic Criteria**



# Content Model Specifications and User Guide

## ICD-11 alpha draft

The "**Content Model**" identifies the basic properties needed to define any ICD concept (unit, entity or category) through the use of multiple parameters:

1. ICD Concept Title
2. Hierarchy, Type and Use
  - 2.1. Parents
  - 2.2. Type
  - 2.3. Use
3. Textual Definition(s)
4. Terms
  - 4.1. Index Terms
    - 4.1.1. Synonyms
    - 4.1.2. Inclusion Terms
  - 4.2. Exclusion Terms
5. Clinical Description
  - 5.1. Body System(s)
  - 5.2. Body Part(s) [Anatomical Site(s)]
6. Manifestation Properties
  - 6.1. Signs & Symptoms
  - 6.2. Findings
7. Causal Properties
  - 7.1. Etiology Type
    - 7.1.1. Infection
      - 7.1.1.1. Agents
    - 7.1.2. Injury
      - 7.1.2.1. Mechanisms
  - 7.2. Risk Factors
  - 7.3. Genomic Characteristics
8. Temporal Properties
9. Severity Properties
10. Functioning Properties
11. Specific Condition Properties
12. Treatment Properties
13. Diagnostic Criteria

The content model and these parameters are identified to systematically define a concept with its various attributes. To capture these attributes, the possible **value sets** are identified for each parameter to populate this database in a relational way. Each parameter needs not to be filled for each concept/category/entity.

Full formal population of this content model for each concept will result in an "**Information Model**".

The style guide provides an explanation of the content model in operational terms to guide the users to better use the model for its intended purposes. It is an evolving document, which will be periodically updated in response to evolving evidence.

## THE CONTENT MODEL

*Any Category in ICD is represented by:*

### **1. TITLE of ENTITY: Name of disease, disorder, or syndrome...**

#### **Descriptive characteristics**

2. Hierarchy, Type and Use
  - a) Parents
  - b) Type (Disease, Disorder/Syndrome, External Cause and/or Injury, Sign/Symptom, Reason for Encounter, Unspecified)
  - c) Use (Primary Care, Mortality, Morbidity, Research, Specialty Adaptation, Clinical Modifications)
3. Textual Definition(s)
4. Terms
  - a) Index Terms (Synonyms, Inclusion Terms)
  - b) Exclusion Terms
5. Clinical Description
  - a) Body System(s)
  - b) Body Part(s) (*anatomical site*)
6. Manifestation Properties
  - a) Signs & Symptoms
  - b) Findings
7. Causal Properties (*etiology*)
  - a) Etiology type
    - I. Infection
      - A) Agents
    - II. Injury
      - A) Mechanisms
  - b) Risk Factors
  - c) Genomic characteristics
8. Temporal Properties
9. Severity Properties
10. Functional Properties
11. Specific Condition Properties
12. Treatment Properties
13. Diagnostic Criteria

#### **Maintenance attributes**

- A. Unique identifier
- B. Mapping relationships  
Linkages to other systems like SNOMED etc.
- C. Other rules

## A. Operational Guidelines for each parameter of the ICD-11 Alpha Draft Content Model

### 1 ICD Concept (unit, entity or category) Title

The "Title" is the *term* for any ICD concept (unit, entity or category), which labels the intended concept in a meaningful, unambiguous way. The title stands for:

- The name of the ICD concept
- The part of the ICD such as a chapter, block, category or sub-category.

The title is selected from existing titles in the ICD-10. This will be the default option as a beginning approach; however, in line with the revision process it is possible to propose changes in titles.

If a new concept is created or a change in the title is proposed, existing titles in international agreements (such as Classifications, Nomenclatures and Terminologies) will be examined and the relevant Topic Advisory Group will make recommendations.

As a general rule, naming conventions for traditional concepts used in previous ICD editions will be respected.

- **Use of singular vs. plural:** The singular form is preferred for isolated entities, while the plural form is preferred for disease groups.
- **Use of alternative spellings:** Within WHO-HQ, British rather than American spelling is normally used. The general rule is to follow the spelling listed in the latest edition of *The concise Oxford dictionary*. There are, however, a number of exceptions. For more information on WHO house style for spelling of words commonly used in WHO information products, see the "Spelling" entry in this section and the WHO spelling list.  
<http://sites.google.com/site/icd11revision/home/documents/WHOHouseStyle.pdf?attredirects=0&d=1>  
&  
<http://sites.google.com/site/icd11revision/home/documents/WHOHouseStyleSpellingList.pdf?attredirects=0&d=1>
- The title should fully specify the category. It should NOT assume the meaning of the parent.
  - For example:
  - C03 is "**Malignant Neoplasm of gum**"
  - C03.0 Should NOT read as "**Upper gum**"
  - but should read as "**Malignant Neoplasm of upper gum**"
- **Use of diacritics:** Diacritics (a mark above or below a printed letter that indicates a change in the way it is to be pronounced or stressed—Acute and grave accents, tildes, and cedillas are examples of diacritics) and should be retained in titles. However, ICD concepts that contain diacritics should be searchable and recognizable without including them, for users who may not have the keyboard or font functions.  
<http://apps.who.int/classifications/apps/icd/icd10online/>
- **Use of hyphens:** Should we write "muscle eye brain syndrome" or "muscle-eye-brain syndrome"? Please see the WHO house style guide, in the section "Hyphen (-), em rule (—) and en rule (–)".  
<http://sites.google.com/site/icd11revision/home/documents/WHOHouseStyle.pdf?attredirects=0&d=1>

- **Use of Arabic or Roman numerals in subtypes:** Arabic numbers should be used at all times. This will be the option for citing chapters (e.g. Chapter 19 instead of Chapter XIX).
- **Use of letters in subtypes:** Latin letters (type A, type B) should be capitalised. (The usual practice, AFAIK.) For Greek letters (type alpha, type beta), the name of the letter be used, and not its shape.
- **Use of eponyms:** The naming of diseases after proper nouns or people (e.g. eponyms) are explicitly discouraged, except in historical cases where the eponym is already well-established (Alzheimer, Parkinson, etc.). However, eponyms can be entered into the tool as synonyms.
- **Use of acronyms:** The use of acronyms is discouraged; except when used to shorten long names (most often lists of synonyms). This is common practice and may be accepted on a case-by-case basis (SARS: severe acute respiratory syndrome). Acronyms are commonly used for rare diseases (e.g. MERRF, MELAS, CADASIL, ICF syndrome).
- **Use of relational adjectives vs. free compound nouns:** Titles should follow preferred medical nomenclature. All combinations can be included in the synonyms. e.g. "hepatic, cardiac, renal failure" vs. "liver, heart, kidney failure".
- **Final rejection of distinguishing characteristics:** Normal English word-order requires determining constituents to come first, but pragmatic considerations may favour an inverted order progressing from general to particular. All combinations can be included in the synonyms. When in doubt, no commas are preferred. E.g. "Proximal spinal muscular atrophy, adult type" vs. "Adult type of spinal muscular atrophy". "Autosomal dominant spinocerebellar ataxia" vs. "Spinocerebellar ataxia, autosomal dominant".

If for any reason they are retired, they will be indicated accordingly and included in the inclusion terms and indexes as appropriate. Particular names such as proper nouns for diseases or syndromes should be avoided.