



# SURVEYING THE NEW ALLERGIC AND HYPERSENSITIVITY CONDITIONS CHAPTER OF THE INTERNATIONAL CLASSIFICATION OF DISEASES (ICD)-11

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## SURVEYING THE NEW ALLERGIC AND HYPERSENSITIVITY CONDITIONS CHAPTER OF THE INTERNATIONAL CLASSIFICATION OF DISEASES (ICD)-11

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Key words: allergy, classification, hypersensitivity, International Classification of Diseases (ICD), World Health Organization (WHO)

Over the last 4 years, a strategic action plan has been put in practice for a better classification of the allergic and hypersensitivity conditions in the ongoing International Classification of Diseases (ICD)-11 revision. The actions so far have been unwaveringly acknowledged by the Joint Allergy Academies and documented by peer-reviewed publications (1-7). Meanwhile, we started a bilateral collaboration with the World Health Organization (WHO) ICD revision governance.

The main outcome of the process was the construction of the “Allergic and hypersensitivity conditions” sections under the “Immune system disorders” chapter of the ICD-11 beta draft (8) upon the WHO ICD representatives’ guidance and as a result of collaboration with all the specialties with whom we have overlapping conditions, represented by ICD Topic Advisory Groups (TAGs). By consolidating all allergic conditions into one ICD-11 single section, as opposed to spreading them out over many ICD-10 chapters, and by allowing all the relevant codes to be used to represent mortality and morbidity outcomes, our aim was to facilitate the use of such classification and codes by all relevant personnel.

To further inform these deliberations and to follow the ICD-11 revision agenda to ensure accuracy, usability and feasibility of the new structure, we proposed to evaluate the adequacy of the new “Allergic and hypersensitivity conditions” section by surveying the allergy community. For that,

a web-based survey, in English (Annex 1), was launched via Internet together with two attachments: the frozen version of the “Allergic and hypersensitivity conditions” section of the ICD-11 beta draft (May 2015 version) (8) and the published classification proposal previously validated by crowdsourcing the allergy community (4). The frozen version of the “Allergic and hypersensitivity conditions” section of the ICD-11 beta draft (May 2015 version) consists of a document of 30 pages including 306 entities following the WHO ICD content model, scattered under 6 main headings (Figure 1). The audience of this process included top experts in different fields of allergy selected on the basis of their publications over the past 5 years in the major peer-reviewed journals as first/last authors, terminology specialists and end-users. It had anonymous and voluntary nature and only one response was allowed per person. The respondents were asked to review the attachments and access the questionnaire to evaluate the accuracy and ease of use of the new classification and/or send us their impressions and suggestions by free-text space or e-mail. A reminder was sent out after 2 weeks.

Responses were categorized according to the intent as “full approval”, “not able to help” or “suggestions”. For all the responses classified as “suggestions”, we categorized as “typo”, “terminology changes”, “structural changes”, “content changes” and “blended changes”.

In the second step of the process, we evaluated the replies regarding the accuracy and ease of use of each of the groups of entities listed into the questionnaire. For it, the analysis covered just the responses for the online questionnaire.

A total of 773 e-mails were sent out and 54 (7.4%) were bounced by the server. A total of 90 (13.3%) responses were received on behalf of 98 professionals, 63 (70%) through the online survey and 27 (30%) by e-mail. The attachments have been discussed in face-to-face meetings when requested (25 persons) during the period of the survey.

Data presented here were obtained from participants from all the continents, mostly from Europe (32%) and North America (28%). The majority of respondents (86%) were experienced professionals, with more than 20 years of clinical experience. The demographic data of respondents and frequency of use of the ICD are described in Table 1. As shown in Figure 2, the ICD-10 is the classification most used worldwide, but with variances in the version and sometimes with national adaptations.

According to the intent of the responses, 53% of responses were classified as “full support”, 39% as “suggestions” and 8% as “not able to help”. As highlighted in Figure 3, from 96 suggestions, 78% were categorized as “content changes”, “structure changes” and “blended changes”.

The Figure 4 shows the actions generated from the suggestions. All typos have been corrected into the platform and 17% of the suggestions have been submitted as proposals into the online ICD-11 beta phase platform, mainly covering comments regarding terminology. The suggestions categorized as “content changes”, “structure changes” and “blended changes” generated questions under discussion with related WHO ICD TAGs and RSG representatives. Some of the suggestions not yet implemented but planned covered, *e.g.*, possibilities of field-testing or evaluation of economic impact of these changes. In total, 100% of the suggestions have been considered and will generate future actions.

The evaluations of ease of use and accuracy have been analyzed exclusively based on the online survey responses. It was not possible to analyze these data based on the suggestions addressed directly by e-mail. We observed a similar pattern of responses among the 6 sections of the ICD-11 “Allergic and hypersensitivity conditions” new section. All of the sections had a mean score of 8 (out of 10) in both categories “easy to use” and “accuracy”. The “Anaphylaxis” section received the best scores in both criteria (Figure 5).

Although the ICD-11 revision is not completely set (9), the proposed survey is a step forward to the validation of the new Allergic and Hypersensitivity conditions section. This process provided key points to ensure feasibility and accessibility to end-users. Considering the fact that every change into the current framework can have consequences for the allergy specialty and for the “sister-specialties”, all modifications have to carefully and deeply thought and agreed with the concerned parts.

We limited the time of the survey (to follow the revision timeline), which could have influenced the number of replies. Additional limitations may be related to the extension and the complexity of the documents to be evaluated. However, having a limited number of responses does not, in fact, negatively influence the validation process since we received very high quality technical comments and suggestions from experts in allergy. Beside, non-respondents may well have read the attached documents and are now fully aware of the initiative. In general, most of the participants who have expertise of specific areas of the allergy field decided to address the comments and suggestions directly by e-mail. Not all

professionals who suggested changes replied to the online survey, but we analyzed all the suggestions. Although the fraction of responses per region was not proportional, the e-mails sent covered all the continents providing us a global perspective and may reflect the coding behavior of all surveyed regions.

The current survey was perfectly aligned to the period in which the ICD-10 was launched in the USA (October 2015) and the replies precisely reproduce this move. The comments received from all the continents allow us to capture the main differences between the ICD-10 and ICD-11 frameworks and philosophy contributing to a smooth transition to the ICD-11 whenever it will happen in the different countries.

Most “structure changes” suggestions were probably related to three facts: (I) The respondents had access exclusively to the “Allergic and hypersensitivity conditions” section. Many differential diagnosis seen by allergists in clinical practice are scattered in other chapters across the ICD-11 framework. (II) The launched frozen ICD-11 beta draft document was dated May 2015. We decided for this document since it is the official frozen version provided by the WHO. However, some of the proposals of the respondents had already been discussed or submitted into the online platform since May, including all items to be post-coordinated (*e.g.*, disease severity, allergen sources). (III) Many respondents argued as to why we had duplications in the launched document. The “allergic and hypersensitivity conditions” chapter is one of the most complex within the ICD-11 structure because it is a parented chapter, meaning that we share conditions with other chapters. For example, “Food-induced anaphylaxis” can fit in both the “Anaphylaxis” section and the “Complex allergic or hypersensitivity conditions”, under the “Food hypersensitivity” heading. When the ICD versions are frozen, it is provided as a “tabular” document with all the entities included. However, they are linked in the multi-hierarchy framework available into the online platform and no redundancies are expected.

Appropriate usage of codes for recording disorders is a key issue to prevent misclassification. The results of the current document underline the need of strengthening awareness regarding the recently built classification as well as the need of educational programs to support the ICD end-users. These are two other goals of the “Allergy in ICD-11” initiative.

We believe that more than contributing to the validation process of the new “Allergic and hypersensitivity conditions” ICD-11 chapter, all the comments provided the substrate for further improvements and will support forthcoming actions to quality assurance of clinical practice managements of allergic and hypersensitivity patients by different disciplines.

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## LIST OF FIGURES

**Figure 1: The new ICD-11 “Allergic and hypersensitivity conditions” section subheadings**

**Figure 2: Mapping the use of the International Classification of Diseases (ICD) across the continents**

**Figure 3: Categorization of the responses and types of suggestions**

**Figure 4: Current actions resulted by the survey suggestions**

**Figure 5: “Easy to use” and “accuracy scores given to the new ICD-11 “Allergic and hypersensitivity conditions” chapter sections**

## LIST OF TABLES

**Table 1: Frequency of use of the International Classification of Diseases (ICD) and demographic data of the respondents**

## ANNEX

**Annex 1: Web-based questionnaire to survey the ICD-11 new Allergic and hypersensitivity conditions section**

### AUTHOR CONTRIBUTIONS’:

Luciana Kase Tanno and Pascal Demoly contributed to the construction of the document (designed the study, analyzed and interpreted the data, and wrote the manuscript). Moises A Calderon, Nikolaos G. Papadopoulos, Mario Sanchez-Borges, Juan Carlos Sisul, Edgardo Jares, James L. Sublett, Hee-Bom Moon, Thomas Casale contributed in tuning the document and with the revision of the manuscript.

### CONFLICT OF INTERESTS:

The authors declare that they do not have any conflict of interests related to the contents of this article.

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## The “Allergic and hypersensitivity conditions” section ICD-11 beta draft (December 2015 version)

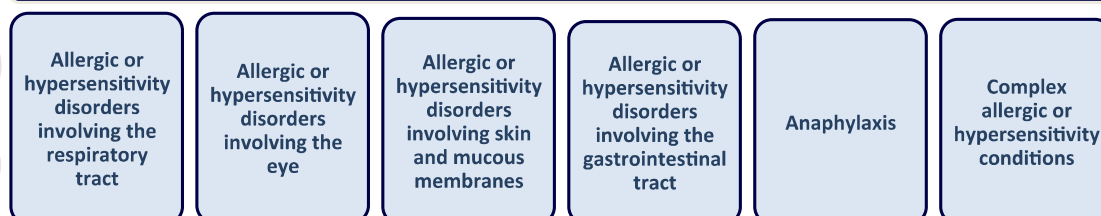


Figure 1: The new ICD-11 “Allergic and hypersensitivity conditions” section subheadings

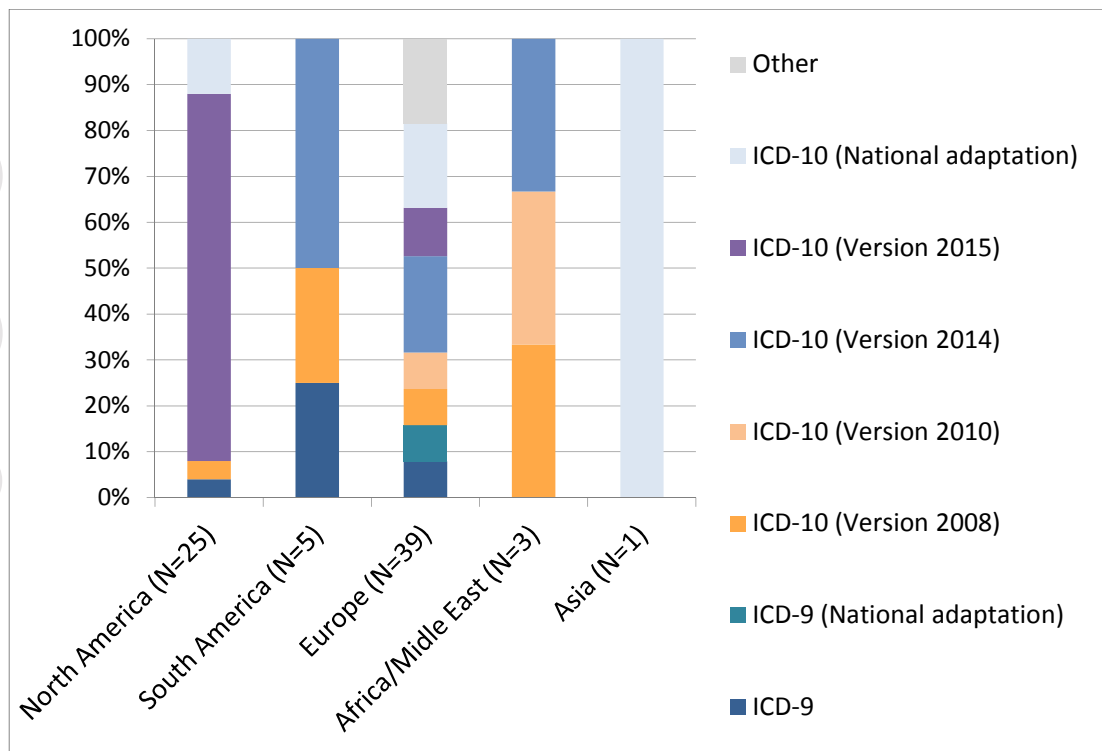


Figure 2: Mapping the use of the International Classification of Diseases (ICD) across the continents

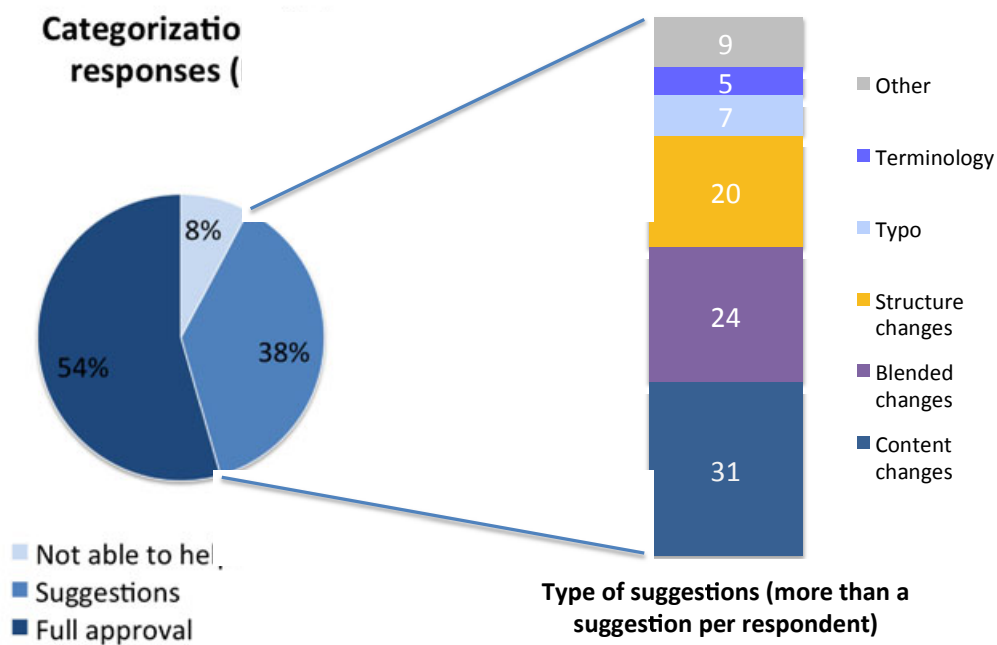


Figure 3: Categorization of the responses and types of suggestions

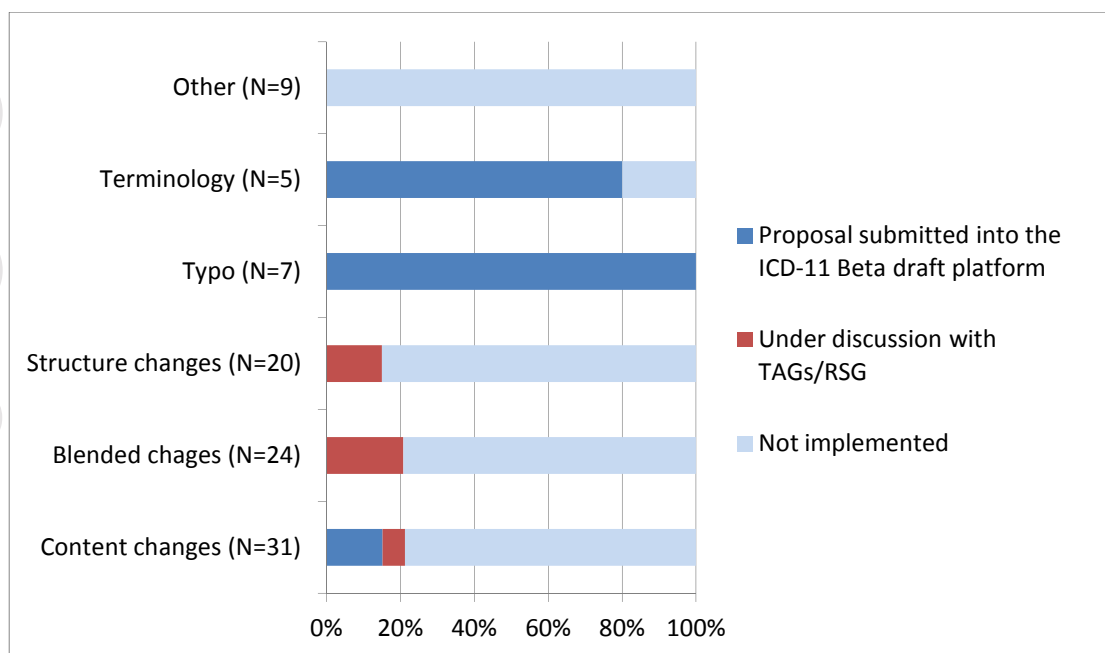


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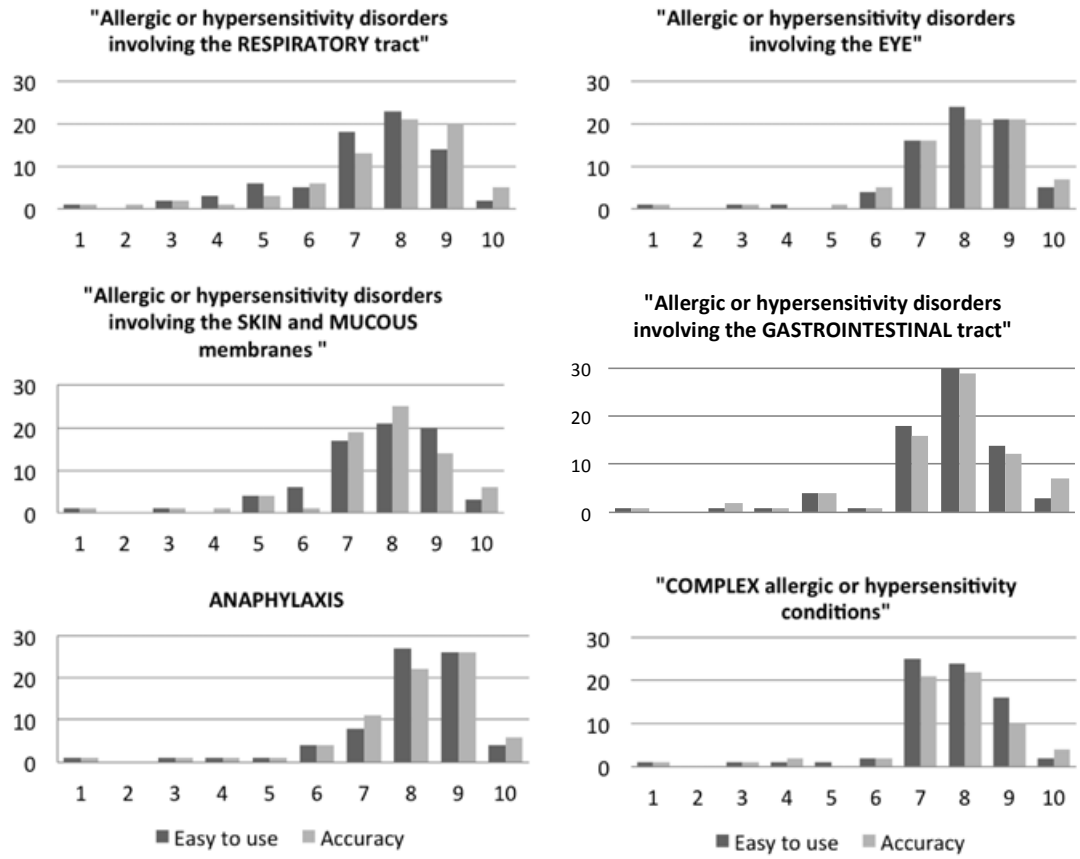


Figure 5: "Easy to use" and "accuracy scores given to the new ICD-11 "Allergic and hypersensitivity conditions" chapter sections

Table 1: Frequency of use of the International Classification of Diseases (ICD) and demographic data of the respondents

Frequency of use of International Classification of Diseases (ICD)	Always (N= 35) (%)	Often (N=15) (%)	Sometimes (N= 17) (%)	Never (N=6) (%)
Continent				
Europe (N= 39)	11 (31.5)	14 (93.4)	8 (47)	6 (100)
North America (N= 25)	23 (65.7)	0 (0.0)	2 (12)	0 (0.0)
South America (N= 5)	1 (2.8)	0 (0.0)	4 (23.5)	0 (0.0)
Africa/Middle East (N= 3)	0 (0.0)	1 (6.6)	2 (12)	0 (0.0)
Asia (N= 1)	0 (0.0)	0 (0.0)	1 (5.5)	0 (0.0)
Mean age (years)	54.0	54.0	55.6	56.8
Gender				
Male (N= 49)	19 (54.3)	13 (86.7)	13 (76.5)	4 (66.7)
Female (N= 24)	16 (45.7)	2 (13.3)	4 (23.5)	2 (33.3)
Years of professional experience				
10 to 20 (N= 13)	8 (22.8)	3 (20.0)	1 (5.9)	1 (16.6)
20 to 30 (N= 30)	16 (45.7)	4 (26.7)	8 (47.0)	2 (33.4)
30 to 40 (N= 24)	9 (25.7)	6 (40.0)	7 (41.2)	2 (33.4)
More than 40 (N= 6)	2 (5.8)	2 (13.3)	1 (5.9)	1 (16.6)