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Making allergic and hypersensitivity conditions visible in the International Classification of Diseases-11

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Understanding that the International Classification of Diseases (ICD)-11 revision would be an opportunity to standardize the code definitions for all allergic and hypersensitivity conditions, an international collaboration of Allergy Academies, including first the World Allergy Organization, the American Academy of Allergy Asthma and Immunology and the European Academy of Allergy and Clinical Immunology, has been coordinating tremendous efforts since 2013 to provide a better classification of these disorders in the new ICD-11. During this process, a strategic action plan has been constructed to keep bilateral dialog with representatives of the ICD revision by providing them scientific and technical evidences for the need of changes in the ICD framework. As a major achievement of this process, was the construction of the "allergic and hypersensitivity conditions" parented subchapter guided by the World Health Organization ICD representatives and further supported by three more regional allergy societies: the Latin American Society of Allergy, Asthma and Immunology, the American College of Allergy Asthma and Immunology, and the Asia Pacific Association of Allergy, Asthma and Clinical Immunology. Believing that the outcomes of all past and future actions will impact positively to the Allergy specialty, we expect for the full approval by the United Nations in 2017.

Key words: Allergy; Allergic Diseases; Hypersensitivity; Classification; International Classification of Diseases; World Health Organization

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WHY UPDATES OF THE ALLERGIC AND HYPERSENSITIVITY CONDITIONS' CLASSIFICATION AND CODING SYSTEMS ARE NEEDED

Allergy and hypersensitivity, originally perceived as rare disorders, are one of the fastest growing conditions worldwide becoming a major public health problem and the numerous reports over the last 20 years have been indicating that the world is dealing with an allergy epidemic. The allergic and hypersensitivity conditions are complex, covering a myriad of clinical presentations, some able to be overlapped with other specialties, such as Dermatology, Pulmonology, Otorhinolaryngology, Ophthalmology, Pediatrics and Gastroenterology among others. The current concepts used in the daily basis in the clinical practice by allergists are not widely known by the "sister-specialties" resulting in misclassification and/ or under-representation of these entities in health classification and coding systems so far, with a tremendous negative impact to the Allergy specialty at many different levels. Since these systems are the basis of collecting primary and secondary data related to healthcare, stakeholders have been delineating actions, support and investments according to the data generated by these registries. Therefore, the weak identity of our specialty in the international health classification and coding systems, such as the International Classification of Diseases (ICD), contributes to the lack of ascertainment and recognition of their importance for healthcare planning and resource allocation, and prevents clinical research from being performed.

A better classification of allergic and hypersensitivity conditions in international health classification and coding systems can provide a real-world scenario of our specialty based on reliable data able to support education, clinical practice and research. The implementations can in fact advocate in favor of the identity, visibility and recognition of Allergy as a specialty.

The World Health Organization International Classification of Diseases

The International Classification of Diseases (ICD), also known as International Statistical Classification of Diseases and Related Health Problems, is the global health information standard to capture mortality and morbidity statistics maintained by the World Health Organization (WHO). This system helps to monitor death and diseases rates worldwide and measure progress towards the United Nations Millennium Development Goals. Since its first edi-

tion in 1900, the ICD has been increasingly used in clinical care and research to define diseases and study disease patterns, manage health care, epidemiological data assessment, monitor outcomes and allocate resources. This classification system is in use by more than 100 countries, translated in more than 47 languages and periodically revised about each 10 years [1].

The majority of countries all around the world currently use the ICD 10th edition (ICD-10), except for some countries utilizing the 9th revision such as United States and Australia. The ICD-10 came into use by WHO Member Sates in 1994 composed by 3 volumes with mono-hierarchical structure. The level of detail provided by the ICD-10 is limited to four levels: chapter, block of codes, three-character codes and four-character codes. Any additional detail can be added only in clinical modifications used at the national level.

The ICD-11 revision process was initiated in April 2007 and came up with a different strategy with the aim of aligning ICD with scientific advances, to continue to serve as an international standard in multiple languages and settings to allow for comparable data and to link with computerized health information systems. For the first time, WHO opens the discussion of the current ICD-11 revision for the public opinion, inviting experts and stakeholders to make comments and submit proposals. The WHO stresses the need of following an established content model and providing robust scientific basis of all the comments and proposals to ensure comparability and consistency [1, 2].

The status of allergic and hypersensitivity conditions in the ICD

The allergic and hypersensitivity conditions are not adequately classified and coded in the ICD-10 as first demonstrated for the anaphylaxis deaths [3] and following publications drew attention to the inadequacy of the ICD-10 and ICD-11 frameworks for recording all allergic and hypersensitivity conditions [4]. The fact of having misclassifications of all allergic diseases codes in a recognized international classification system impacts directly the diagnosis of allergic patients and their diagnosis and management. Besides, the discrepancies in the classification of the conditions covered by our specialty in daily basis mean that *Allergy is not recognized as a specialty by the WHO* and *very badly known by other specialties*.

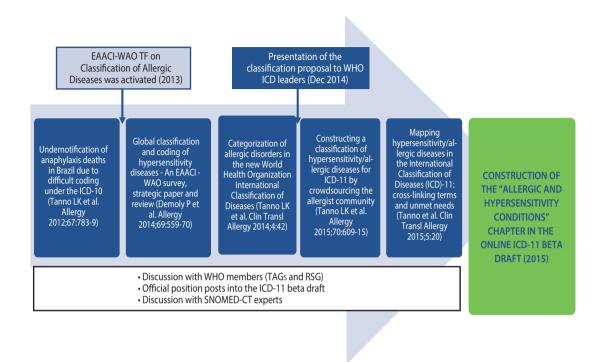


Fig. 1. Historic-prospective action plan for the construction of the "allergic and hypersensitivity conditions" chapter in the ICD-11. ICD, International Classification of Diseases; EAACI, European Academy of Allergy and Clinical Immunology; WAO, World Allergy Organization; TF, task force; WHO, World Health Organization; TAG, pediatric topic advisory group; RSG, revising steering group; SNOMED-CT, systematized nomenclature of medicine-clinical terms.

THE ALLERGY ACADEMIES ENGAGEMENT FOR THE BETTER REPRESENTATION OF ALLERGIC AND HYPERSENSITIVITY CONDITIONS

Understanding that the ICD-11 revision would be an opportunity to standardize the code definitions for all allergic and hypersensitivity conditions, an international collaboration of Allergy Academies, including World Allergy Organization, American Academy of Allergy Asthma and Immunology and European Academy of Allergy and Clinical Immunology, has been coordinating efforts since 2013 to provide a better classification of these disorders in the new ICD-11.

To call attention to the inadequacy of the ICD-10 to allergic and hypersensitivity conditions and to contribute to improvements to be made in the ICD-11 revision, we firstly proposed a global survey of healthcare professionals' attitudes toward allergic disorders classification [5]. Meanwhile, we entered on bilateral discussion with representatives of the WHO ICD-11 revision. Following a careful

comparison of ICD-10 and 11 beta phase linearization, we could identify gaps, trade-offs and areas of regression in allergy coding [4]. This process was the building block for the construction of an allergic and hypersensitivity classification proposal following the ICD/WHO rules in particular with the aim to be used by allergists, nonallergists and nonphysicians. The classification proposal was validated by crowdsourcing the allergy academies' leadership community. As a result, a high level complex structure of classification for allergic and hypersensitivity conditions has been constructed and offered to the WHO groups in charge of the ICD revision for endorsement [6]. To facilitate the acceptance of the proposed classification model, we aligned the constructed classification to the ICD-11 beta draft by a cross-linking terms process. We could underline the need for a chapter in ICD-11 addressed to the disorders covered by our specialty [7].

During the WHO meeting in December 2014, we could present details of the historic-prospective strategic actions (Fig. 1) to the revising steering group (RSG) WHO responsible for the revision of the ICD and the pediatric topic advisory group and discuss feasible



ways of having a better classification of allergic and hypersensitivity conditions into the ICD-11 structure. All the actions and the support of the academies were fully appreciated by the WHO representatives, who advised us to perform a simplification process to fit our classification proposal to the ICD-11 framework [8]. Following the meeting, we carried on intensive dialog with the RSG WHO representatives and with their guidance; the "allergic and hypersensitivity conditions" parented subchapter has been constructed under the "immune system disorders" chapter in early 2015. The building process was a detailed technical/scientific labor-intensive construction in which we had to reach a consensus with all the "sister-specialties" with whom we have overlapping conditions. As a result, the "allergic and hypersensitivity conditions" parented subchapter counts with more than 300 entities classified under 6 headings [2].

READY FOR NEW HORIZONS

The ICD-11 beta phase is not finished and receives frequent inputs and, therefore, has to be constantly reviewed. The "allergic and hypersensitivity conditions" parented subchapter is a major achievement to the recognition and visibility of our specialty and can be considered as a milestone in the history of our specialty. However, we are aware that its development is not set. We carry on working in the dissemination and validation process with the WHO guidance and the support of the allergy academies. In this regard, we are most grateful to recently have had the support of three more regional allergy societies: the Latin American Society of Allergy, Asthma and Immunology, the American College of Allergy Asthma and Immunology, and the Asia Pacific Association of Allergy, Asthma and Clinical Immunology. Believing that the outcomes of all past and future actions will impact positively to the Allergy specialty, we expect for the full approval by the United Nations in 2017

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