

POSITION PAPER

# Constructing a classification of hypersensitivity/allergic diseases for ICD-11 by crowdsourcing the allergist community

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## Abstract

The global allergy community strongly believes that the 11th revision of the International Classification of Diseases (ICD-11) offers a unique opportunity to improve the classification and coding of hypersensitivity/allergic diseases via inclusion of a specific chapter dedicated to this disease area to facilitate epidemiological studies, as well as to evaluate the true size of the allergy epidemic. In this context, an international collaboration has decided to revise the classification of hypersensitivity/allergic diseases and to validate it for ICD-11 by crowdsourcing the allergist community. After careful comparison between ICD-10 and 11 beta phase linearization codes, we identified gaps and trade-offs allowing us to construct a classification proposal, which was sent to the European Academy of Allergy and Clinical Immunology (EAACI) sections, interest groups, executive committee as well as the World Allergy Organization (WAO), and American Academy of Allergy Asthma and Immunology (AAAAI) leaderships. The crowdsourcing process produced comments from 50 of 171 members contacted by e-mail. The classification proposal has also been discussed at face-to-face meetings with experts of EAACI sections and interest groups and presented in a number of business meetings during the 2014 EAACI annual congress in Copenhagen. As a result, a high-level complex structure of classification for hypersensitivity/allergic diseases has been constructed. The model proposed has been presented to the WHO groups in charge of the ICD revision. The international collaboration of allergy experts appreciates bilateral discussion and aims to get endorsement of their proposals for the final ICD-11.

## Classification/coding of hypersensitivity/allergic diseases claims for updates in ICD-11

### The need for a classification of hypersensitivity/allergic diseases

More than 150 million Europeans and over 25–30% of the world's population are affected by hypersensitivity/allergic diseases (1), and allergic disorders account for more than 17 million outpatient office visits per year in the United States of America alone (2). The estimated annual direct cost of airway allergies itself in the United States is about \$20 billion (2, 3). Hypersensitivity/allergic diseases are linked to a host of chronic diseases (*e.g.*, rhinitis, asthma, eczema) and serious illnesses (*e.g.*, anaphylaxis, severe cutaneous drug hypersensitivity reactions, severe asthma).

The International Classification of Diseases (ICD), maintained by the World Health Organization (WHO), provides a common language for use worldwide as a diagnostic and classification tool for epidemiology, clinical purposes and health management. It enables the analysis of the general health situation of different population/disorder groups and provides data on the key problems to be managed. It is used to classify disease registries for many types of health and administrative purposes including death certificates and healthcare records. In addition to enabling the storage and retrieval of diagnostic information for clinical, epidemiological, and quality purposes, these reported data also provide the basis for compilation of national mortality and morbidity statistics by WHO Member States. Finally, it is used for reimbursement and resource allocation decision-making by some countries (4).

Currently, however, there is no universal standard platform in which hypersensitivity/allergic diseases and their impact on functioning or socio-economics are integrated into a health information system. The outcomes of the misclassification and/or under-notification of these diseases in the ICD are well known, having a direct and huge detrimental impact on hypersensitivity/allergic diseases data and therefore resulting in calls for changes (5, 6). This deficiency has led to low visibility of these conditions, low accuracy of epidemiological data, and decreased opportunities to monitor and evaluate research, treatment, and prevention, or to influence their formal diagnosis and appropriate management. This in turn has affected the allocation of resources and, *de facto*, means that allergy and clinical immunology is not recognized as a specialty by the WHO.

Efforts to capture the impact of hypersensitivity/allergic diseases in a structured and systematic way have been hampered by failure at both a conceptual and an operational level, as is exemplified by anaphylaxis death data. WHO rules highlight some diseases and conditions as underlying causes of death in detriment of others, and anaphylaxis has never been considered as underlying cause of death in the death certificates, resulting in under-notification (6). A key disadvantage of the ICD-10 is that it derives from a classification designed for tabulating and reporting diseases and therefore has some inherent limitations, which have forced artificial categorization that is not clinically meaningful. The ICD-10 framework was based on the sites or systems commitment,

meaning that complex disorders, such as anaphylaxis and drug allergies, cannot be classified appropriately (7, 8).

The 11th revision of ICD, officially launched by WHO in 2007 and currently under revision, aims to reflect progress in health sciences and medical practice in the two decades since the release of ICD-10 (9). The global allergy community believes that the ongoing ICD-11 revision is a unique opportunity to improve the representation of hypersensitivity/allergic diseases and to create a specific chapter for classifying them in coding systems so that epidemiological studies can be carried out and the true burden of the allergy epidemic can be evaluated. The classification of hypersensitivity/allergic diseases would be aligned with the WHO's mission and would constitute a tool able to help WHO member nations, particularly low- and middle-income countries, to reduce the disease burden associated with hypersensitivity/allergic diseases. It would also raise public awareness of our specialty and what it can offer.

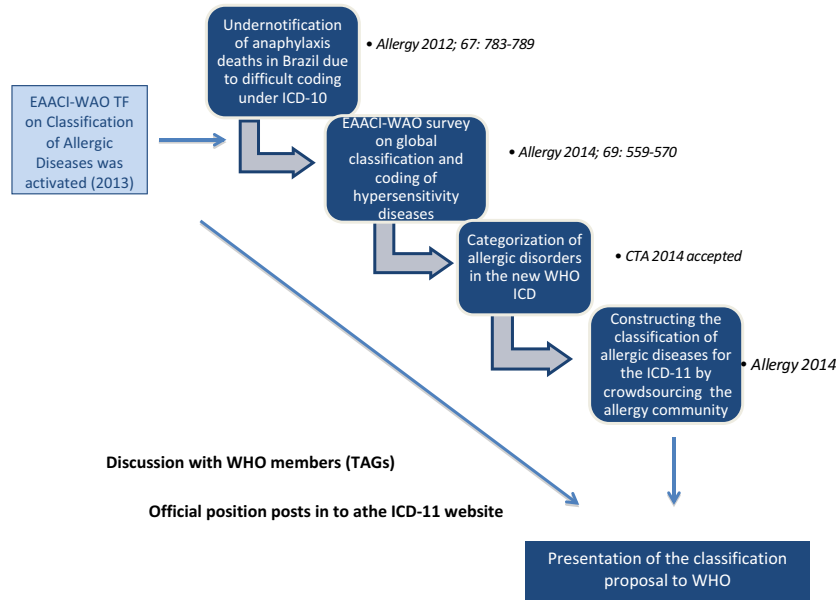
### Recent relevant actions and achievements

With the aim of actively contributing to and raising the profile of hypersensitivity/allergic diseases in an international coding system, a strategy has been developed by the European Academy of Allergy and Clinical Immunology (EAACI) (Fig. 1). Following publications that drew attention to the inadequacy of ICD-10 for recording anaphylaxis deaths (6) and, more generally, for recording all allergic conditions (10), an EAACI–World Allergy Organization (WAO) task force was set up to advocate at the highest level for a better classification of hypersensitivity/allergic diseases in the ongoing ICD-11 revision. Firstly, together with the WAO, the EAACI–WAO community survey on the global classification and coding of hypersensitivity/allergic diseases proved that ICD-10 is the most widely used classification worldwide (although the USA is still working with ICD-9); however, it was not considered appropriate in clinical practice by the majority of responders (11). They indicated that the EAACI–WAO classification (12) is easier to use and more accurate in daily practice. The global allergy community pointed out the need for a diagnostic system useful for nonallergists and endorsed the possibility of a global, cross-culturally applicable classification system of hypersensitivity/allergic diseases (11). Whereas the results of the EAACI–WAO survey provided data to support the arguments for changes in the current ICD-11 draft, some other actions have been implemented (Table 1) politically and technically, and in particular, we have performed a careful comparison between the relevant content in ICD-10 and its ICD-11 equivalent, the Joint Linearization for Mortality and Morbidity Statistics ('Joint Linearization'), which is still in a beta phase of development. We have identified gaps and areas of regression in allergy coding and have offered solutions (13).

### The construction of the classification proposal

#### The new classification of hypersensitivity/allergic diseases

Believing that getting an appropriate ICD-coding framework for allergy accepted by our community is a crucial building block to best code hypersensitivity/allergic diseases of interest



**Figure 1** Historical prospective actions and strategies to increase the profile of hypersensitivity/allergic diseases in the ICD-11. TF: task force, ICD: International Classification of Diseases, WHO:

World Health Organization, TAG: topic advisory group, CTA: Clinical Translational Allergy Journal.

and to ensure the appropriate recognition of these conditions, we here propose the construction of the classification of hypersensitivity/allergic diseases for the ICD-11 by crowdsourcing the experts in the field of allergy. For that, we built a core module with 10 parental axis categories to cover respiratory, cutaneous, ocular, drug, food, and hymenoptera allergies and anaphylaxis (Appendix S1). The EAACI–WAO revised nomenclature publication (12) was the basis of the proposed categories, updated by the new knowledge generated since its publication (10, 14–42). To avoid conceptual misunderstandings among physicians not specializing in allergy, other health professionals and laypersons, the authors decided always to link the terms *hypersensitivity* and *allergy* across the current paper. For the purposes of the current article, this simplification is used; however, the authors are aware that hypersensitivity is not identical to allergy. In the same way, although we are aware of the importance of immunological diseases including immune deficiencies and autoimmune disorders, these conditions were not incorporated into the proposal as the ICD-11 has already dedicated a chapter for these disorders entitled ‘Immune System Disorders’ (9). The multiaxial and hierarchical structure was set up based on the content model of ICD-11 (Table 2) as well as ICD rules (43) and on the main international guidelines in the allergy field. We considered the need for a diagnostic system useful for physicians not specialized in allergy, other health professionals and laypersons and for a global, specialized cross-culturally applicable multiaxial classification of allergic disorders. Therefore, we considered the many different aspects of allergy, including mechanism of injury, objects/substances producing injury, topography of injury, and additional special topics (exercise-induced or exacerbated condi-

tions and occupational injuries). Appendix S1 was first drafted in February 2014, completed in May 2014, and fine-tuned in August 2014, respecting the ICD-11 timeline discussion (9).

Understanding that the construction of the classification proposal by a core group was necessary but not sufficient to represent the allergy community, we embraced a crowdsourcing process. The audience for this process included the leaderships of the major allergy societies across the world, experts in allergy, terminology leaders, and end-users. The content of the classification proposal was extensively discussed by exchange of e-mails and face-to-face meetings and presented in business meetings during the 2014 EAACI annual congress in Copenhagen. Obeying the ICD-11 revision timeline and advised by some members of ICD Topic Advisory Groups (TAGs), we shared the classification proposal document with representatives of the revision steering group (RSG), and all TAGs involved in the discussion of updates of hypersensitivity/allergic diseases into the ICD-11 revision. Aware of the intentions of aligning the ICD and Systematized Nomenclature of Medicine Clinical Terms (SNOMED-CT) ontology, the document has also been shared with a SNOMED-CT expert in terminologies. Responses were obtained within 150 days. The document was revised, and the potential inputs were harmonized with the ICD-11 content model and with the suggestions of TAG representatives. Comments were taken into account in the final draft, which was then approved by the governing boards of the participating organizations. The final document was then shared with representatives of ICD-11 TAGs and RSG with the aim of obtaining their endorsement.

**Table 1** Crucial past steps to increase the profile of hypersensitivity/allergic diseases in ICD-11

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Crucial steps to increase the profile of hypersensitivity/allergic diseases in ICD-11

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The WHO's groups in charge of the International Classification of Diseases (ICD) revision (TAGS—topic advisory groups) have been directly accessed aiming to improve the classification/coding of hypersensitivity/allergic diseases. The discussions are ongoing since June 2013. The postponement of ICD-11 discussion to 2017 has slowed down our exchanges dramatically

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The position of the EAACI–WAO task force has been formally posted several times into the online beta-phase ICD-11 revision (September 2013, October 2013, January 2014, May 2014). As a result, the 'Disorders of Immune System' chapter has been identified for the first time in the online linearization; in addition, 'Allergy and allergic reactions' has been included as a subchapter of the External Causes Chapter. Although we consider this as positive moves, we still believe that it is not appropriate

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A careful comparison between ICD-10 and ICD-11 beta-phase codes was prepared to identify the areas of regression in allergy coding. The findings from this analysis helped us to support more comments and suggestions into the online ICD-11 revision and gave substrate for the new classification proposal for hypersensitivity/allergic diseases

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A classification proposal for hypersensitivity/allergic diseases has then been constructed based on previous work, main international guidelines, and ICD rules, in a view that it has to be reasonable for a global use, covering different specialties, general practitioners, and nonphysicians

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Examples of different terminology systems have been considered such as The Systematized Nomenclature of Medicine–Clinical Terms (SNOMED-CT) that enables information input into electronic health record system. However, so far, the system looks too complex and is not globally used

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### Crowdsourcing the classification of hypersensitivity/allergic diseases

To undertake the crowdsourcing process, the working committee first addressed the proposal draft by e-mail to EAACI sections and interest groups and EAACI, WAO, American Academy of Allergy Asthma and Immunology (AAAAI), and European Union of Medical Specialties (UEMS) Allergy Section executive committees and leaderships (June 2014). Three reminders have been sent out (June, August, and October 2014). The draft proposal was launched by e-mail to 195 members of EAACI sections and interest groups and EAACI, WAO, AAAAI and UEMS Allergy Section & Board executive committees and leaderships. Twenty-four (13%) of these messages were returned by the server, and 50 (29%) responses were received. The classification proposal has been discussed by face-to-face meetings with 13 experts from EAACI sections and interest groups and presented in three business meetings during the 2014 EAACI annual congress in Copenhagen.

**Table 2** The International Classification of Diseases (ICD)-11 content model

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Any category in ICD is represented by TITLE of ENTITY: name of disease, disorder, or syndrome

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1. Content title	8. Temporal properties
1.1 Fully specific name	8.1 Age of occurrence and occurrence frequency
	8.2 Development course/stage
2. Classification properties	9. Severity of subtype properties
2.1 Parent	
2.2 Type	
2.3 Use and linearization	
3. Textual definition(s)	10. Functioning properties
	10.1 Impact on activities
	10.2 Contextual factors
	10.3 Body function
4. Terms	11. Specific condition properties
4.1 Base index terms	11.1 Biological sex
4.2 Inclusion terms	11.2 Life cycle properties
4.3 Exclusion terms	
5. Body structure description	12. Treatment properties
5.1 Body system	
5.2 Body part(s)	
5.3 Histopathology	
6. Manifestation properties	13. Diagnostic criteria
6.1 Signs and symptoms	
6.2 Investigation findings	
7. Causal properties	14. External causes
7.1 Etiology type	
7.2 Causal Property Agents	
7.3 Causal Properties—mechanisms	
7.4 Genomic linkage/risk factors	

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The initial proposal comprised 192 key words related to 10 main categories of hypersensitivity/allergic diseases covering respiratory (asthma and rhinitis), skin (dermatitis, urticaria, and angioedema), ocular (conjunctivitis), drug, food, and hymenoptera allergies and anaphylaxis. It has been updated according to the suggestions of the crowdsourcing participants and has been fine-tuned with advice from the Dermatology TAG chair, who suggested developing a higher level structure reorganizing the previous draft into five domains: (i) allergic disorders involving the eyes and respiratory tract, (ii) allergic disorders involving the skin and mucous membranes, (iii) allergic disorders involving the digestive tract, (iv) anaphylaxis, and (v) complex allergic disorders (drug, food, and hymenoptera hypersensitivity) (Appendix S1).

### The next steps for the new classification of hypersensitivity/allergic diseases

The revision of the classification of hypersensitivity/allergic diseases suitable for the ICD-11 has been a stepwise approach. The first step was to address inconsistencies

between standard definitions for allergy and hypersensitivity with the aim of reaching an acceptable definition for hypersensitivity/allergic diseases. The field of allergy has developed rapidly over the last decades, and knowledge of underlying mechanisms has improved the diagnosis and management of many allergic conditions, but without parallel progress in creating more rigorous definitions. Our definitions clearly differentiate immune hypersensitivity diseases from allergic diseases, but the risk of future incorrect classification still remains. With the recent published results of the EAACI-WAO survey (11), which reported that the allergy community considered the EAACI-WAO revised nomenclature (12) easier and more accurate than existing terminologies for use in daily practice, we took it as the reference for standard definitions for our proposal, which has, however, been updated with the recent specific task force reports (14–42).

In the EAACI-WAO revised nomenclature, the hypersensitivity concept has been introduced for clinical entities resembling allergy for which the mechanism is unclear and allergy only when the mechanism is immune mediated (12). However, this distinction is still not used by nonallergists and nonphysicians for whom everything resembling allergy is allergy; consequently, the solution used here was always to link the terms *hypersensitivity* and *allergic* across the paper. In this way, the endorsement of the current classification proposal by WHO may help our specialty to disseminate concepts recognized and used by allergists and nonallergists worldwide. Currently, there is no alignment between hypersensitivity/allergic diseases between the ICD-11 beta draft and SNOMED-CT, but this article may bring up the need for reviewing some concepts to achieve a much cleaner structure for this link.

After identifying and correcting the gaps and trade-offs of the current ICD-11 Joint Linearization (9), the new classification was submitted to the leaderships of major allergy academies. In the development of the new modular classification, which has 10 core axis categories, we looked for a technical solution which could provide a realistic and reliable platform for use not only in research but also in routine information systems.

EAACI favors the crowdsourcing approach (44). This method was applied in the current article to the allergy leadership community and not to all allergists. Further extensions are relevant by the acceptance of allergists not belonging to the leaderships and nonallergists, for example. Crowdsourcing is the process of obtaining requisite services, ideas, or content by soliciting contributions from a large group of people. It is driven by principles of openness, user innovation, and collective intelligence. Projects can be divided into specific tasks, with groups of contributors working together to evaluate, share, and develop solutions for specific problems. The technique has been used since 2005, mainly in the business field but also in research. It has much in common with community engagement and community-based participatory research approaches in that the core of the endeavor is a strong belief that community members can contribute to finding solutions for complex problems. The major benefit of crowdsourcing is that the questions are often highly relevant

to the intended audience, because its members are usually directly involved in ideation and working out solutions for the identified problems.

As a result, a high-level complex structure of classification for hypersensitivity/allergic diseases has been constructed (Appendix S1). The proposal has been well accepted by the ICD-11 TAGs and RSG, and changes have been noticed in the online ICD-11 beta draft according to our suggestions. However, hypersensitivity/allergic disorders need to be made more visible at chapter level or at a high level in the new immunology chapter if the new classification is to succeed in ensuring that these disorders are coded more easily, appropriately and accurately.

Some limitations are well known in online-based studies, such as the number of bounced messages. Even with the good levels of participation by professionals which we achieved, the study may be hampered by the short time frame in which responses had to be made in order for us to be able to follow the ICD-11 revision timeline. While we have been able to engage core members of the allergy specialty, dissemination and validation of the current proposals are obviously needed.

With the mission of producing an international classification for global use that is up to the contemporary challenges of its suitability for use in electronic health records, as a standard for scientific comparability and for facilitating communication among all those interested in allergy, the proposed model should be approved by coding experts from all around the world. It has thus been presented to the WHO groups in charge of the ICD revision. The international collaboration of allergy experts formed by the EAACI, the WAO, and the AAAAI would appreciate bilateral discussion with those groups with the aim of obtaining endorsement of its proposals for the final ICD-11.

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This document has been reviewed and endorsed by the Executive Committees of the European Academy of Allergy and Clinical Immunology (EAACI).

### 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). Nikolaos G. Papadopoulos, Moises A Calderon, Bruce J. Gold-

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### Conflicts of interest

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

### Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Classification proposal of hypersensitivity/allergic diseases.

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