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PREPARING INTERNATIONAL CLASSIFICATION OF DISEASES (ICD)-11: MODEL OF ALLERGIC AND HYPERSENSITIVITY CONDITIONS

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** Joint Allergy Academies: American Academy of Allergy Asthma and Immunology (AAAAI), European Academy of Allergy and Clinical Immunology (EAACI), World Allergy Organization (WAO), American College of Allergy Asthma and Immunology (ACAAI), Asia Pacific Association of Allergy, Asthma and Clinical Immunology (APAAACI), Latin American Society of Allergy, Asthma and Immunology (SLAAI)

ABSTRACT

Originally considered rare disorders, allergic and hypersensitivity conditions (A/H) are among the fastest-growing conditions worldwide and are becoming a **major public health problem**. Efforts to record the impact of A/H in a structured and systematic way have so far been hampered by the absence at a conceptual and operational level of definitions of these conditions, which in turn has impeded comprehensive public health measures and investment. One recognized reason is the difficulty of coding A/H under the World Health Organization (WHO) ICD system (International Classification of Diseases: ICD-10). Taking the ICD-11 revision as a key window of opportunity, a detailed academic and evidence-based action plan was put in place under the *ALLERGY in ICD-11* initiative, with the aim of creating a more appropriate classification for allergic and hypersensitivity conditions in this new edition of ICD. This work consisted in strategic international actions acknowledged by the Joint Allergy Academies** and the WHO ICD representatives. These efforts resulted in the creation of a new “Allergic and hypersensitivity conditions” section in the chapter on “Disorders of the Immune system”. We were also able to introduce changes in the WHO mortality coding rules to include anaphylaxis as an underlying cause of death in official death certificates. In recognition of the work done and with the aim of formalizing collaboration with the WHO Family on International Classifications (WHO-FIC), a **WHO Collaborating Center (WHO CC) for the Scientific Classification of Allergic and Hypersensitivity Diseases** was established in June 2018 at the University Hospital of Montpellier, with Luciana Kase Tanno being appointed to the 20-member **Medical and Scientific Advisory Board to support the WHO ICD and other international classifications**. ICD-11 was presented and fully endorsed during the last World Health Assembly (May 2019) and this new classification is currently being introduced worldwide, with full global implementation anticipated by 2022. The creation of a new classification of A/H disorders in ICD-11 may be considered a timely and much-needed milestone in the history of the allergy specialty. More reliable, accurate, comprehensive and comparable A/H epidemiological data will provide a far clearer global picture of these conditions and will underpin improved management of allergic disorders worldwide.

Key words: allergy, classification, epidemiology, hypersensitivity, International Classification of Diseases, World Health Organization

RÉSUMÉ:

À l'origine perçue comme maladies rares, les maladies allergiques et d'hypersensibilité (A/H) font partie des affections croissant le plus au monde, devenant **un problème de santé publique majeur**. Jusqu'à présent, les efforts visant mesurer l'impact des A/H de manière structurée et systématique ont été bloqués par l'échec au niveau conceptuel et opérationnel de ces affections, empêchant des interventions de santé publique et des investissements conséquents. Une raison reconnue est la difficulté de coder les A/H dans le cadre du système l'Organisation mondiale de la santé OMS CIM (Classification internationale des maladies CIM). Considérant la révision de la CIM-11 comme une fenêtre d'opportunité clé, un plan d'action détaillé a été mis en place dans le cadre de l'initiative ALLERGIE dans la CIM-11, avec le but de créer une classification plus appropriée des affections A/H dans cette nouvelle édition de l'ICD. Ce travail a consisté en des actions stratégiques internationales, reconnues par les Joint Allergy Academies ** et les représentants de la CIM à l'OMS. Ces efforts ont abouti à la construction de la nouvelle section « Conditions allergiques et d'hypersensibilité » sous le chapitre « Maladies du système immunitaire ». Nous avons également été en mesure de promouvoir des changements dans les règles de codification de la mortalité de l'OMS en incluant l'anaphylaxie comme cause sous-jacente de décès dans les certificats de décès officiels. En reconnaissance du travail accompli et avec le but d'officialiser la collaboration avec la famille de classifications internationales (FIC) de l'OMS, le Centre collaborateur de l'OMS (CC de l'OMS) pour la classification scientifique des maladies A/H a été créé en juin 2018 au CHU de Montpellier, et l'intégration parmi les 20 membres du Conseil consultatif médical et scientifique pour soutenir la CIM de l'OMS et d'autres classifications internationales. La CIM-11 a été présentée et approuvée lors de la dernière Assemblée mondiale de la santé en mai 2019 et l'implémentation de cette nouvelle classification est en cours dans le monde entier. Elle sera complète en 2022. La construction de la nouvelle classification des maladies A/H dans la CIM-11 peut être considérée comme une étape opportune et bien nécessaire dans l'histoire de la spécialité allergologie. Des données épidémiologiques A/H plus fiables, précises, complètes et comparables fourniront une bien meilleure image globale de ces affections et soutiendront des améliorations dans leur gestion dans le monde entier.

Mot clés: allergie, classification, épidémiologie, hypersensibilité, Classification internationale des maladies, Organisation mondiale de la santé

SCOPE OF THE PROBLEM

Allergic and hypersensitivity conditions

Allergic and hypersensitivity conditions (A/H) are multidimensional problems that may occur in numerous organs and in all age groups, and which significantly impact the quality of life of patients and their families. **"Hypersensitivity"** is defined as a group of *"conditions clinically resembling allergy that cause objectively reproducible symptoms or signs, initiated by exposure to a defined stimulus at a dose tolerated by normal subjects"*, and **"allergy"** as *"a hypersensitivity reaction initiated by proven immunologic mechanisms"*(1). A/H are *harmful immune responses that produce tissue injury and may cause serious diseases"*. Allergic reactions are classified into four types by Coombs and Gell. The clinical picture of A/H is complex and covers myriad entities, which means that all health professionals are likely to encounter both mild and severe A/H, and it is believed that the world is currently dealing with a real allergy epidemic, resulting in considerable consequences for patients around the world and in significant costs for societies (1).

Originally perceived as rare disorders, A/H are one of the fastest-growing conditions worldwide, and they pose a **major public health problem**. It is estimated that more than 150 million Europeans and over 25% to 30% of the global population are affected by these conditions (2,3). A/H accounts for more than 17 million outpatient visits annually in the USA alone (4).

The complexity and severity of these conditions continue to increase, especially in children and young adults, who are bearing the greatest burden. Allergies are now the fourth most extensive chronic disease in the world. The WHO predicts that in 2050, 1 in 2 people worldwide will present allergies, with this figure rising steadily, particularly in the industrialized countries. In France, the number of people suffering from an allergy has doubled in the last 20 years, especially among children and adolescents (2-4). Yet allergy, even as it relates to asthma, is often trivialized, with clinical services to help patients having such diseases being either limited or non-existent, and in any case lacking in cost-effective solutions.

A/H include life-threatening anaphylaxis, food allergies, certain forms of asthma, rhinitis, conjunctivitis, angioedema, urticaria and eczema, as well as a variety of eosinophilic disorders and drug and insect allergies. These allergic conditions commonly occur together in the same individual, which calls for greater awareness of these disorders and their underlying causes, particularly among primary care physicians, and underscores the importance of specialist diagnosis and treatment. For instance, all definitions of anaphylaxis

for clinical use by healthcare professionals set out the concepts of a serious, generalized A/H reaction that may be life-threatening and even fatal (7-13). This multi-faceted condition can present at any age, with multiple triggers, and may be encountered by any health professional. Consequently, all health professionals must be prepared on how to deal with mild to severe anaphylactic reactions. Treatment of anaphylaxis comprises medications at the acute phase (mainly adrenaline) as well as preventive measures. Despite its pivotal role, the auto-injectable form of adrenaline (AAI) is *not* readily available in the majority of countries (14), thus preventing optimal management of patients with anaphylaxis. The incidence of hospital admissions for A/H is rising (15,16). Additionally, no regular and systematic methods of data collection or dissemination of statistics on diagnosis-based morbidity exist at global level. Due to the lack of accurate A/H mortality information, it is impossible to obtain a comprehensive picture of public health and health measures and investments, such as the availability of AAI.

Coding the multiple facets of allergies is necessary

The need to record morbidity and mortality data, and to understand the progression of these disorders and map areas of interest/investments in the health system, drew attention to the need for accepted classification and coding systems suitable for extensive use to allow worldwide alignment. Many different systems of classification and terminology have emerged so far, such as the International Classification of Diseases (ICD). ICD is the global health information standard used to record morbidity and mortality statistics (MMS); it is maintained by the WHO and periodically updated. ICD is currently used by more than 75% of world countries as a public health tool to aggregate epidemiological statistics in order to substantiate decision-making and to allocate resources for both management and research. Work on the 11th edition were initiated by the Director of the Department of Health Statistics and Information Systems at the WHO in 2011 (17).

The first version of ICD was launched in 1893, and this was preceded in 1885 by the first International List of Causes of Death, which was drafted by Jacques Bertillon and colleagues in 1885 (18). ICD is regularly updated and at present most of the world is using the tenth edition of ICD (ICD-10) or national adaptations thereof.

In French public institutions, extensive alignment of individual diagnostic and procedural health expenses is based on ICD codes, currently those of ICD-10. Patients' medical data are routinely recorded and coded in institutional databases using ICD, under the coordination of Medical Information Departments and in keeping with national ethical

pronouncements., Like the vast majority of world countries, France uses ICD-10 for MMS and health economics.

Efforts to record the impact of A/H in a structured and systematic way have so far been hampered by the absence at a conceptual and operational level of definition of these conditions (19,20), which in turn has impeded comprehensive public health measures and investment. One recognized reason is the difficulty of coding A/H, as exemplified by anaphylaxis (19), under the WHO ICD system. The limited number of ICD-10 codes suitable for recording A/H data leads to difficulties in MMS collection based (chiefly) on administrative data similar to those already in existence regarding causes of death or healthcare data based on hospital discharges.

GIVING VOICE TO THE ALLERGY SPECIALTY IN ICD

The ALLERGY in ICD-11 initiative

Taking the ICD-11 revision process as a key window of opportunity, a detailed academic and evidence-based action plan was put in place under the *ALLERGY in ICD-11* initiative (led by LKT and PD) with the aim of creating a more relevant classification for A/H conditions in the new edition of ICD. We produced technical and scientific evidence demonstrating the need for changes to classification and coding and participated in an ongoing dialogue with the WHO ICD-11 Revision governance team. All these efforts have been documented in peer-reviewed publications (19-47) and have been acknowledged and supported by the Joint Allergy Academies comprising the American Academy of Allergy Asthma and Immunology (AAAAI), the European Academy of Allergy and Clinical Immunology (EAACI), the World Allergy Organization (WAO), the American College of Allergy Asthma and Immunology (ACAAI), the Asia Pacific Association of Allergy, Asthma and Clinical Immunology (APAAACI), and the Latin American Society of Allergy, Asthma and Immunology (SLAAI) (14).

The main outcome of this process has been the creation of a section on “Allergic and hypersensitivity conditions” under the new “Immune system disorders” chapter of ICD-11 (23,48) (Figure 1).

We were also able to introduce changes in the WHO mortality coding rules so as to include anaphylaxis as an underlying cause of death in official death certificates, which will ensure more accurate mortality data in the years to come.

The new framework addressing A/H conditions has undergone field testing (37) and quality assurance (31-33), and demonstrates a clear improvement in MMS through use of ICD-11. Furthermore, ICD-11 enables diagnoses to be linked to a range of different

parameters through the addition of one or more “extensions”, classified under the “Extension codes” chapter, via a process termed “post-coordination”. WHO has promoted this classification strategy under which a stem entity (e.g. *Anaphylaxis*) can be more fully defined by linking it to a range of different value sets that include severity, anatomical site and causal agent.

The Montpellier WHO Collaborating Centre for Classification Scientific Support

In recognition of the work done and with the aim of formalizing collaboration with the WHO-Family on International Classifications (WHO-FIC), the **WHO Collaborating Center (WHO CC) for the Scientific Classification of Allergic and Hypersensitivity Diseases** was established in June 2018 at the Pulmonology and Allergology Unit of the University Hospital of Montpellier under Luciana Kase Tanno and Pascal Demoly (49), with Luciana Kase Tanno being appointed to the 20-member **Medical and Scientific Advisory Board to support the WHO ICD and other international classifications** (50). The Montpellier CC is one of 25 WHO CCs in the field of international classifications and the only one working on A/H conditions. As part of the WHO-FIC network, our mission is to promote the implementation, use, maintenance and updating of the WHO reference health classifications. The WHO-FIC Network CC also assists the WHO in the revision and development of the reference classifications (45). The Montpellier WHO CC will be involved in national and international initiatives to ensure quality implementation of ICD-11 and other WHO international classifications, such as training modules to enhance the quality of classification and coding under the new framework, as well as collaborative work with other institutions, including the French Technical Agency for Hospital Information and the French Epidemiology Centre on Medical Causes of Death.

GET READY FOR ICD-11!

ICD-11 was presented and fully endorsed at the last World Health Assembly (May 2019) and this new classification is currently being rolled out worldwide, with full implementation anticipated in 2022 (6).

A/H MMS may now gain new perspectives through the implementation of ICD-11 in the next few years since A/H are now adequately classified and coded in ICD-11. By consolidating all A/H conditions within a single section of ICD-11 rather than distributing them over numerous chapters, as in ICD-10, and by allowing use of all the relevant codes for

mortality and morbidity outcomes, our aim was to simplify the location and description of allergic disorders for end-users, data custodians and other relevant personnel. Consolidation of the new section dealing with A/H means that the latter will now be recognized as clinical conditions requiring specific documentation and management. By allowing the inclusion in ICD-11 of all the relevant diagnostic terms for these conditions, the WHO has recognized their importance not only for clinicians but also for epidemiologists, statisticians, healthcare planners and other stakeholders.

Since knowledge derived from populations constitutes key information for more realistic decision-making, the creation of a new section of ICD-11 focusing on A/H conditions will facilitate the collection of more accurate epidemiological data, which will in turn ensure higher quality patient management. Ultimately, this will result in better health care planning for the implementation of public health measures aimed at preventing and reducing morbidity and mortality attributable to these conditions.

The creation of a new classification of A/H disorders in ICD-11 may be considered a timely and much-needed milestone in the history of the allergy specialty. More reliable, accurate, comprehensive and comparable A/H epidemiological data will provide a far clearer global picture of these conditions and will underpin improved management of A/H disorders worldwide.

ABBREVIATIONS

AAI: adrenaline auto-injector

AAAAI: American Academy of Allergy Asthma and Immunology

ACAAI: American College of Allergy Asthma and Immunology

APAAACI: Asia Pacific Association of Allergy, Asthma and Clinical Immunology

EAACI: European Academy of Allergy and Clinical Immunology

WHO-FIC: World Health Organization - Family of International Classifications

ICD: International Classification of Diseases

SLAAI: Latin American Society of Allergy, Asthma and Immunology

WAO: World Allergy Organization

WHA: World Health Assembly

WHO: World Health Organization

WHO CC: World Health Organization Collaborating Centre

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CONFLICT OF INTERESTS

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

CONTRIBUTIONS

The above authors contributed to creation of the document (study design, data analysis and interpretation, and drafting of the manuscript).

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LIST OF FIGURES

Figure 1: Generic representation of the new "Allergic and hypersensitivity conditions" section of the International Classification of Diseases (ICD)-11

ICD-11 Beta Draft (Foundation) Signed in as: LUCIANAKASE TANNU | Manage Account | Log off
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- ▼ ICD-11 Beta Draft
 - ▶ Infectious diseases
 - ▶ Neoplasms
 - ▶ Diseases of the blood and blood-forming organs
 - ▼ Disorders of the immune system
 - ▶ Immune system disorders by clinical syndrome
 - ▶ Immune system disorders by white cell lineage
 - ▶ Symptoms, findings and clinical forms of blood, forming organs and the immune system
 - ▶ Non-organ specific systemic autoimmune disorder
 - ▶ Autoinflammatory syndromes
 - ▼ Allergic and hypersensitivity conditions
 - ▶ Allergic or hypersensitivity disorders involving the respiratory tract
 - ▶ Allergic or hypersensitivity disorders involving the eye
 - ▶ Allergic or hypersensitivity disorders involving skin and mucous membranes
 - ▶ Allergic or hypersensitivity disorders involving the gastrointestinal tract
 - ▶ Anaphylaxis
 - ▶ Complex allergic or hypersensitivity conditions
 - ▶ Allergy and allergic reactions of unspecified nature
 - ▶ Hypersensitivity reactions of unspecified nature
 - ▶ Endocrine, nutritional and metabolic diseases
 - ▶ Conditions related to sexual health
 - ▶ Mental and behavioural disorders
 - ▶ Sleep-wake disorders
 - ▶ Diseases of the nervous system
 - ▶ Diseases of the eye and adnexa

Allergic and hypersensitivity conditions

- ▼ Allergic and hypersensitivity conditions
 - ▶ Allergic or hypersensitivity disorders involving the respiratory tract (78 entities)
 - ▶ Allergic or hypersensitivity disorders involving the eye (8 entities)
 - ▶ Allergic or hypersensitivity disorders involving skin and mucous membranes (233 entities)
 - ▶ Allergic or hypersensitivity disorders involving the gastrointestinal tract (14 entities)
 - ▶ Anaphylaxis (11 entities)
 - ▶ Complex allergic or hypersensitivity conditions (68 entities)
 - ▶ Allergy and allergic reactions of unspecified nature
 - ▶ Hypersensitivity reactions of unspecified nature

⚠ Please read the Caveats

Figure 1: Generic representation of the new "Allergic and hypersensitivity conditions" section of the International Classification of Diseases (ICD)-11