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## Anaphylaxis in France: Rate, characteristics and unmet needs

*Anaphylaxie en France : fréquence, caractéristiques et besoins non satisfaits*

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### Abstract

**Background.** – Ascertaining how anaphylaxis is diagnosed, and treated nationally and globally is an important preliminary step towards the development of worldwide strategic action plans in order to identify and solve key issues. In order to estimate the degree of awareness of anaphylaxis and evaluate the standards of care for the management of anaphylaxis, in this study we sought to assess the lifetime prevalence of anaphylaxis in France from general adult population as well as to gather on the characteristics of the reactions and its impact in quality of life and management.

**Methods.** – A prospective web-based survey was launched via Internet to a non-randomized, cross-sectional, convenience sample of French adult general population. The questions were related to the awareness regarding anaphylaxis and its management. Only fully completed questionnaires have been considered eligible for analysis.

**Results.** – From a total of 8003 responses, 56% of the French population surveyed mentioned being aware of the term “anaphylaxis” and 8% reported history of anaphylaxis. Respiratory manifestations associated with angioedema have been described by 34%, gastrointestinal symptoms by 17% and cognitive manifestations by 14%. However, the majority of cases (69%) have been treated in outpatients’ settings and only 43% have been referred to an allergist for further investigations. From those 130 patients (1.6%) who received auto-injectable adrenaline medical prescription, only 15% keep this device available for immediate use.

**Conclusion.** – The results of this pioneer study defining the rate of anaphylaxis, characteristics, and attitudes regarding anaphylaxis among a representative portion of the French population flag an urgent and pressing need for improved public health initiatives regarding anaphylaxis recognition and treatment, which may be managed in the forthcoming years due to implementation of national and international actions.

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**Keywords:** Anaphylaxis; Epinephrine auto-injectors; Survey; International Classification of Diseases; World Health Organization

### Résumé

**Contexte.** – L’analyse de la façon dont l’anaphylaxie est diagnostiquée et traitée au niveau national et mondial est une étape préliminaire importante vers le développement de plans d’action stratégiques afin d’identifier et de résoudre les questions clés. Avec l’objectif d’estimer le degré de connaissance de l’anaphylaxie et d’évaluer les normes de soins pour sa prise en charge, nous avons cherché, dans cette étude, la prévalence vie-entière de l’anaphylaxie en France de la population générale adulte, les caractéristiques des réactions, son impact sur la qualité de vie et sa gestion.

**Méthodes.** – Un sondage prospectif a été lancé par Internet sur un échantillon non segmenté et transversal de la population générale adulte en France. Les questions portaient sur la connaissance de l’anaphylaxie et sa prise en charge. Seuls les questionnaires remplis complètement ont été jugés admissibles à l’analyse.

**Résultats.** – Sur un total de 8003 réponses, 56 % de la population française interrogée mentionne connaître le terme « anaphylaxie » et 8 % rapportent des antécédents d’anaphylaxie. Les manifestations respiratoires associées à l’angio-œdème ont été décrites par 34 %, les symptômes

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gastro-intestinaux par 17 % et les manifestations cognitives par 14 %. Cependant, la majorité des cas (69 %) ont été traités en ambulatoire et seulement 43 % ont été référés à un allergologue pour investigations. Parmi les 130 patients (1,6 %) qui ont reçu une prescription médicale d'adrénaline auto-injectable, seulement 15 % conservaient ce dispositif avec eux pour une utilisation immédiate. **Conclusion**

Les résultats de cette étude pionnière qui définit le taux d'anaphylaxie, les caractéristiques et les attitudes à l'égard de l'anaphylaxie chez une partie représentative de la population française montrent un besoin urgent et pressant d'amélioration des initiatives de santé publique concernant la reconnaissance et le traitement de l'anaphylaxie en France.

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*Mots clés* : Anaphylaxie ; Adrénaline auto-injectable ; Enquête ; Classification internationale des maladies ; Organisation mondiale de la santé

## 1. Abbreviations

ICD	International Classification of Diseases
POFI	Public Opinion French Institute
PARSG	Perioperative Anaphylactic Reactions Study Group
AVN	Allergo-Vigilance Network
WHO	World Health Organization

## 2. Introduction

Anaphylaxis is an acute, life-threatening systemic reaction associated with different mechanisms, triggers, clinical presentations and severity [1]. This multi-faceted condition can manifest at any age and any health professional may have to face it during his/her carrier. All anaphylaxis guidelines [1–6] consistently highlight the severity of the anaphylactic episode and the need of rapid recognition and management of this condition, by applying adrenaline as the first line treatment. Most of national and international guidelines have been targeting the health professionals' community. Limited education programs have been addressed to the laymen population to increase awareness regarding allergic and hypersensitivity conditions, including anaphylaxis. Although this condition has been pointed as a high priority public health issue in the allergy world community, it has never been considered a priority by the Orphanet nor well addressed by a single section in the World Health Organization (WHO) International Classification of Diseases (ICD) frame, resulting in its misclassification and under-notification regarding both morbidity and mortality.

Although considered a high public health priority by the allergy community, anaphylaxis has never been regarded as a significant health worldwide problem in the World Health Organization (WHO) strategies, exemplified by the misclassification of anaphylaxis morbidity [8] and mortality [9] under the International Classification of diseases (ICD), what obviously lead to under-notification? The paucity of epidemiological data contributes to lack of recognition of the importance of anaphylaxis as well as allergic and hypersensitivity conditions, which in turn certainly impact health care planning, and hamper decision-making at many levels of the health care system.

In all countries, epidemiological and health research can serve as a baseline for quality improvement, prioritization of anaphylaxis management and prevention programs, and eventual reduction in morbidity and mortality. The French National

Health System is currently operating with the ICD-10. Taking the opportunity presented by the ongoing ICD-11 revision, a strategic international action plan supported by the Joint Allergy Academies and the ICD WHO governance [8–25] took place to update the classifications of allergic conditions for the new ICD edition. These efforts have resulted in the construction of the new "Allergic and hypersensitivity conditions" section in the ICD-11 [15,26], with a subsection addressed exclusively to anaphylaxis, which will support better morbidity and mortality statistics.

Over the last years, there have been an increasing number of publications to address anaphylaxis epidemiological data and management guidelines, but the incidence of this condition varies widely. The different estimates might be due to differences in the population studies, variability of study designs, studies focused in specific populations or in triggers.

Regional epidemiological data cite anaphylaxis incidence rates ranging from 1.5 to 7.9 per 100 000 person-years in European countries [27]. Although recent local French epidemiological data indicates an incidence of 32 per 100,000 person-years in hospitalized patients [23], there are currently only a limited number of epidemiological anaphylaxis morbidity studies in France.

Ascertaining how anaphylaxis is diagnosed, and treated nationally and globally is an important preliminary step towards the development of worldwide strategic action plans in order to identify and solve key issues. In order to estimate the degree of awareness of anaphylaxis and evaluate the standards of care for the management of anaphylaxis, in this study we sought to assess the lifetime prevalence of anaphylaxis in France from general adult population as well as to gather on the characteristics of the reactions and its impact in quality of life and management.

## 3. Methods

A web-based survey, in French, was launched via Internet. The questionnaire, which generated the web-based survey, counted with 15 multiple choice questions related to the awareness regarding anaphylaxis and its management. Eleven questions have been addressed to subjects who experienced anaphylaxis themselves or individuals who had a collateral familiar who manifested the reaction. We considered as collateral familiar those who had direct kinship, parents, brother or sister, and/or children. The questionnaire has been independently validated by two allergists before being translated to the digital version. The audience of this process included nonrandomized,

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