



Rights and duties of patients with respiratory allergy

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Over the years, many documents on patients' rights have been published, most on the form of Charters. The WHO European Consultation on the Rights of Patients adopted in March 1994 “A Declaration on the Promotion of Patients' Rights in Europe”, focusing on information, consent, confidentiality and privacy, and on their application [1]. In 2002, the Active Citizenship Network, together with 12 citizen organizations from 15 EU countries, published the European Charter of Patients' Rights, where fourteen essential patients' rights were listed: Prevention, Access, Information, Consent, Free choice, Privacy, Respect, Quality services, Safety, Innovation, Avoid Unnecessary Pain, Personalized Treatment, Complain, Compensation [2]. The Charter was adopted to ensure a “high level of human health protection” (as stated in Article 35 of the Charter of Fundamental Rights of the European Union) in all national health services.

On April 18, 2024, WHO launched the first Charter to outline patients' rights in the context of safety [3]. The 10 fundamental safety rights were itemized: Timely, effective and appropriate care; Safe health care processes and practices; Qualified and competent health workers; Safe medical products and their safe and rational use; Safe and secure health care facilities; Dignity, respect, non-discrimination, privacy and confidentiality; Information, education and supported decision making; Access medical records; To be heard and fair resolution; Patient and family engagement.

More than half of the constitutions worldwide recognizes the right to health. However, despite the social interest in health rights and the relevant scientific progresses, the right to health is not guaranteed everywhere and for everyone [4–6]. Essentially, it is often difficult to make effective actions in response to the health rights, especially timely care, information and innovation [7].

For these reasons, documents on the rights of specific categories of particularly vulnerable patients (with cancer, diabetes, HIV, TB) have been progressively drawn up.

Patients with respiratory allergy have not been considered in this context, despite the extremely high number of people suffering from allergic rhinitis and asthma: more than 300 million people worldwide, with 455,000 annual deaths [8, 9]. Allergic rhinitis prevalence in Europe is 19.87% in children [10] and 18.1% in adults [11], that of asthma 8.2% in adults and 9.4% in children [12, 13]. In the USA the prevalence of respiratory allergy account for 15–30% [14]. The annual expenditure is extremely high: €159–554 as

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direct cost and €2,405 as indirect cost per patient in Europe and 3.4 billion USD per direct cost and 5.2 billion USD per indirect cost per year in the USA [12, 15]. Moreover, the disease has a dramatic impact on the quality of life and it is estimated that asthma induces the loss of 25 billion disability-adjusted life years every year, of this, 5.2 billion within the EU [16]. As far as Allergic Rhinitis, a recent study reports an impact on work productivity in EU for a cost of 30 to 50 billion € per year [17].

The remarkable progress of the science reached in the last decades, although highly effective, has not always led to parallel benefit for patients with respiratory allergy. Cross sectional studies [18–21] revealed poor perception of the severity of the disease, in particular asthma [22–26], one of the leading causes of a low adherence to treatments. Consequently, clinical charters to improve patient care in severe asthma were studied [27, 28]. Rhinitis patients were prone to self-manage the disease [29, 30] unaware of the possible evolution to asthma [31]. In addition, patients do not know the possibility to modify the course of the respiratory allergy, even up to reaching remission, with the allergen specific immunotherapy [32–34] despite the efforts of the scientific community [34]. Unfortunately, only a minority of family doctors in Europe have received allergy teaching as undergraduate, as reported by an EAACI task force [35]. On the other hand, allergy care should be delivered by well-trained specialists, but the number of doctors specialized in allergology is not sufficient to fulfill the necessity of the particularly great number of patients with allergy [36].

From all these observations comes the need to formulate a Manifesto on the rights of people with respiratory allergies.

The decision to produce the Manifesto was taken by the Italian Parliamentary Intergroup on Respiratory Allergies, which entrusted the task to its own technical-scientific committee (TSC) composed of representatives of the Italian allergology and environment scientific societies and of the associations of Italian allergy patients.

The Manifesto was written following the validated international practice on the drafting of documents on the right to health. In particular, inspiration was drawn from the documents of the WHO and the United Nations, the European Charter of Patients' Rights by Active Citizenship Network and, as a specific national document for the area, the Charter of Asthmatic and Allergic Citizens' Rights by Federasma Italia.

Furthermore, the Manifesto takes into account the Guideline Act of the Italian Ministry of Health which establishes the general rules for the participation of institutions and associations dedicated to health promotion in the decision-making processes of the Ministry itself [37].

In parallel, a survey on the topic was conducted among the subjects of the participating patient associations.

The Manifesto is composed of 12 points and each point has:

1. Title of the principle (right)
2. Statement describing the principle
3. What to do to make the principle come true

This allowed to have a complete form of the Manifesto from which to derive a charter with the title and statement of the principles.

Once the preliminary draft was completed, the TSC had an initial discussion with the representatives of patients. In a second phase clinicians were involved, representative of the Italian allergy societies.

The definitive document was finally subjected to a review phase for external validation by expert reviewers with extremely high competence and quality which guarantee an independent external evaluation process in line with international procedures.

The TSC decided to publish the Manifesto in the official Journal of the SIAAIC (Italian Society of Allergology, Asthma and Clinical Immunology), to promote a debate on the topic and to favor its adoption by international allergology societies with the appropriate modifications and additions in relation to the specific peculiarities of each country.

Abbreviations

TSC: technical-scientific committee

Declarations

Author contributions

MDG: Writing—original draft, Conceptualization, Supervision, Writing—review & editing. SB, SDG, GWC: Conceptualization, Supervision, Writing—review & editing. All authors read and approved the submitted version.

Conflicts of interest

Mario Di Gioacchino and Giorgio Walter Canonica are the Editors-in-Chief of *Exploration of Asthma & Allergy*. Sergio Bonini and Stefano Del Giacco declare that they have no conflicts of interest.

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