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PORTUGUESE NATIONAL PROGRAMME for RESPIRATORY DISEASES

2012 - 2016



PORTUGUESE NACIONAL PROGRAMME for RESPIRATORY DISEASES (PNDR)

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PORTUGUESE NACIONAL PROGRAMME for RESPIRATORY DISEASES

1. Foreword

In Portugal, respiratory diseases are a major cause of morbidity and mortality, in particular chronic respiratory diseases (CRD), whose prevalence is about 40 %, with a tendency to increase.

The huge impact and human suffering resulting from CRD was recognized by the 53th World Health Assembly (resolution WHA 53.17, May 2000), which led the WHO, in 2000, to give priority to the prevention and control of non-communicable diseases, pressing member states to implement measures aimed at this goal, with special emphasis on developing countries and other underserved populations.

The WHO report, "Preventing Chronic Diseases, a vital investment"¹ (2005) and the publication, "Global Surveillance, Prevention and Control of Chronic Respiratory Diseases: a Comprehensive Approach"² (2007), warn again about the enormous impact of CRD and its risk factors and means of prevention and treatment.

The 60th General Assembly of Health encouraged member states to implement and increase support for global initiatives that contribute to achieving the goal of reducing mortality due to non-communicable diseases by 2%/year, over the next 10 years (Resolution WHA 60.23, May 2007).

Resolution WHA 61.14 of May 2008 endorsed the "Action Plan for the Global Strategy for Prevention and Control of Non-communicable Diseases" which includes the CRD in its scope of action.

¹ Preventing chronic diseases, a vital investment. Geneva, World Health Organization, 2005.
(http://www.who.int/chp/chronic_disease_report/en/index.html)

² Global surveillance, prevention and control of chronic respiratory diseases: a comprehensive approach. Geneva, World Health Organization, 2007.
(http://www.who.int/gard/publications/GARD_Manual/en/index.html)

The Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, signed by United Nations member states at the meeting held on 19-20 September 2011, recognized the significant impact of non-communicable diseases, including chronic respiratory diseases as a global and urgent problem. The consensus reached calls the attention to the need of adopting concrete actions based on public policies to combat such diseases.

In addition, the Official Journal of the European Union, 2nd of December 2011, relates the conclusions of the Council of Europe, regarding chronic respiratory diseases in children these diseases are the most common non-communicable diseases in this age group, thus requiring adapted health care. The member states recommendation prescribes an integrated prevention, early diagnosis and treatment, through cooperation with relevant stakeholders, especially organizations of patients and health professionals.

Within this broad movement, there is the action plan of the Global Alliance against chronic Respiratory Diseases (GARD), an alliance that receives sponsorship, technical and administrative support of the World Health Organization (WHO), which allies financial and human resources of partners to support the work of WHO in the effort of developing and implementing the component of CRD, as part of action plans to combat non-communicable diseases.

The approach of this health problem proposed by GARD have been subsequently adopted by a number of countries, mainly medium or low income and also by more than a dozen of high-income countries, including Portugal.

In this context the Portuguese National Programme for Respiratory Diseases was created by the Ministry of Health in 2012, by the Decision N° 404/2012, *Diário da República* N° 10, 2nd series of 13th January 2012, from which was removed the scope of the Portuguese National Programme Against Tuberculosis (Decision No. 5422/2012, of 20th of April).

The Portuguese National Programme for Respiratory Diseases (PNDR), systematizes the vision, mission, values, goals and overall strategy of the Directorate-General of Health (DGS) and its partners in order to conduct an action plan, from 2012 to 2016, in line with the WHO Action Plan for the Global Strategy for Prevention and Control of Non-communicable Diseases.

2. Global and National Framework

Among the most important chronic respiratory diseases, from the point of view of the Programme and due to their high prevalence, the diseases highlighted are the following:

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD)
- Sleep Apnea Syndrome

There is also a set of health conditions that are as well of programmatic importance, not only for the need of an extensive differentiation, and individualization on their approach, but also by the specificity of the treatment. This group of conditions includes:

- Pulmonary Hypertension
- Interstitial Lung Diseases
- Cystic Fibrosis

Worldwide, within hundreds of millions of people suffering from these diseases, 300 million suffer from asthma, 210 million suffer from COPD and 3 million have other chronic respiratory diseases. In 2005, 250,000 people died of asthma and 3 million of COPD. It is estimated that in 2030, COPD will become the 3rd leading cause of death worldwide³.

In Portugal, respiratory diseases remain a major cause of morbidity and mortality, with a clear trend towards an increasing prevalence, unlike what happens with other diseases, especially with cardiovascular diseases.

The current scenario of global economic crisis is also promoting an increase in chronic respiratory diseases. Indeed, in almost all countries, people with fewer financial resources are the most at risk of developing chronic respiratory diseases. Moreover, they are also the group most at risk of premature mortality due to these diseases.

It is estimated a prevalence of 10 % for asthma, being higher in the younger population and constituting a frequent cause of hospitalization. In fact, as it is a common chronic disease in children and adults, it is known that, in Portugal, the average prevalence of asthma reaches more than 11.0 % of the population in the age group of 6-7 years, 11.8% in the 13-14 years and 5.2% in the 20-44 years. It is estimated that the total number of patients with active asthma may exceed 600,000. For rhinitis, a prevalence of 25 % is estimated.

The prevalence of COPD is 14.2 % in people over 40 years and increases with age and with the level of smoking in both genders. It has a weak expression (2 %) in the age group from

¹ World Health Statistics. Geneva, World Health Organization, 2008.
(<http://www.who.int/whosis/whostat/2008/en/index.html>)

40 to 49 years and 10.2% in the group from 50 to 59 years, reaching the value of 30.8 % over 70 years. In the older age group and in males, the prevalence of COPD is very high, reaching 47.2%.

Regarding the prevalence of sleep apnea syndrome, although there are no epidemiological Portuguese studies, it is estimated that its prevalence in adults approaches 20%, defined by an apnea - hypopnea index (number of apneas and hypopneas per hour of sleep) greater than five events per hour.

Regarding the mortality rate in 2011, 102,848 Portuguese citizens died by all causes of death, and 11,917 of them, by respiratory diseases (11.6%).

Analyzing the evolution of mortality between 2005 and 2009, there seems to be a downward trend of deaths from asthma and COPD, and an increased mortality due to pneumonia and respiratory cancer. It is also noted an increase in the number of hospitalizations for lung fibrosis.

Several determinants lead to the increasing of Chronic Respiratory Diseases (CRD), and the direct or indirect exposure to tobacco smoke is the major risk factor for the development of CRD. Other important risk factors are exposure to indoor air pollution and other enclosed spaces, to outdoor pollution, occupational exposure, malnutrition, low birth weight and to recurrent respiratory infections at an early age.

In recent decades, there is the evidence that there is an increased incidence of atopy and sensitization to allergens. The prevalence is increasing, especially in children and in urban areas.

The CRD have been relegated to the background due to other priorities and for the main reason that a number of determinants of respiratory health are socio-economic and therefore difficult to combat. Poverty affects a wide range of the world population and may determine the existence of some of the most important risk factors. Therefore, the socio-economic factors have a heavy impact in increased prevalence and severity of CRD, mainly through the environmental factors on one hand, and on the other, because of the lack of access to the indicated health care.

3. Vision Mission and Values

The vision of the Portuguese National Programme for Respiratory Diseases (PNDR), in line with the GARD, is *a world where all people breathe freely*.

The mission is to promote and improve conditions for patients with respiratory disease and whose action is based on three fundamental pillars:

- Agents promoters of activism and social mobilization;
- Scientific knowledge, sharing and development;
- Technical and standardization mission and ensuring political commitment in the implementation of the technical components of the programme.

The values are:

- Respect for People with Respiratory Illnesses (their Families and Caregivers) and the needs of these patients, who are at the center of PNDR;
- Social solidarity and scientific support that PNDR may provide, with a view to minimize the suffering caused by respiratory diseases at different levels of health care.

4. PNDR strategic and scientific referential

The purpose of PNDR is to reactivate the programmatic approach to combating CRD, in line with major international scientific and strategic referential, in particular the GARD (Global Alliance against chronic and Respiratory Diseases).

The GARD (www.who.int/respiratory/gard), is a voluntary alliance of national and international organizations, created in 2006 under the auspices of the WHO, which aligns synergies to combat chronic respiratory diseases, and which Portugal joined in 2007.

It has the main objective of interconnectedness and knowledge of the various participants that are actively working in the national surveillance, prevention and control of the CRD, in order to reduce their severity and frequency, at each country's national level and globally.

Its main strategic goals of intervention are: 1 - information at the level of each country and internationally, enabling through a concerted strategy to combat the CRD most relevant risk factors; 2 - promote the dissemination of strategies to identify and reduce the impact of CRD; 3 - encourage countries to implement activities for the prevention of CRD; 4 - initiate and develop strategies for management and control of the CRD.

The PNDR, following the GARD model, establishes a network of partnerships and alliances at the national level under the leadership of the Directorate-General of Health in order to obtain data on the prevalence of CRD and its risk factors, to promote the involvement of sick and affected populations, to implement policies for the promotion of health and prevention of CRD and implement simple and not expensive strategies for the management of CRD.

PNDR has GARD as its main strategic referential, which is the more comprehensive and integrative for chronic respiratory diseases in strategic terms, but also considers other strategic and scientific referential, namely:

- GINA - Global Initiative for Asthma
- GOLD - the Global initiative for chronic Obstructive Lung Disease
- ARIA - Allergic Rhinitis and its Impact on Asthma

GINA was implemented in 1993 to develop a network between organizations and public institutions to disclose information and research related to asthma, in order to reduce their prevalence, morbidity and mortality.

The GOLD is an international initiative born in 1997, with WHO support, for the prevention and control of COPD.

ARIA is a non-governmental organization, officially established in 2001, that collaborates with WHO in order to disclose and implement evidence-based knowledge on allergic rhinitis and its association with asthma.

5. Structure of PNDR

The structure of PNDR consists of a directorate, which articulates at each Regional Health Administration, with the respective Regional Coordinator, and at the national level with the Scientific Coordinators for the different strategic areas of intervention. The Autonomous Regions of the Azores and Madeira have appointed their respective Regional Coordinators.

The strategic areas of intervention are distinguished by the main diseases and other strategic areas crossing the entire programme.

The strategic areas of intervention by the main respiratory diseases include the most prevalent diseases, which are asthma, chronic obstructive pulmonary disease (COPD), syndrome of obstructive sleep apnea, and other diseases with lower prevalence, such as interstitial lung disease, pulmonary hypertension and cystic fibrosis.

The strategic intervention areas across all programme, include allergies (which includes rhinitis), smoking, environment, pediatrics, equipment and respiratory care at home, respiratory infections, research, epidemiological surveillance, quality, and an area of activism, communication and social mobilization.

Also as part of the open structure and dynamics of the PNDR, are the Scientific Committee, established by a panel of experts, and the Consultative Committee, which includes representatives of Professional Associations, Health Institutions, Academia, Scientific Societies and Patient Associations.

6. Strategy for the Prevention and Control of Respiratory Diseases

A strategy will be developed by the scientific coordination of each scientific or social intervention area covered by PNDR, whose components are framed in the priority areas of intervention. It has the political support of the Ministry of Health as well as the support of the scientific and professional Regional Coordinators, its main implementing agents, and which are, namely, the following:

- Involvement of patients and civil society and partnerships;
- Evaluation and monitoring;
- Control of the aggravation factors;
- Use of medical devices, drugs and other therapies, according to best practices and clinical guidelines.

7. PNDR Objectives

7.1. General Objective

The overall goal of PNDR, until 2016, is to reduce the burden of respiratory diseases at national level, and expressed as follows:

- a) Promoting primary prevention, in particular secondary and tertiary prevention, through the development of specific plans for 100 % of health regions;
- b) Improving the accessibility of respiratory patients to health care delivery, through the development and implementation of a referral network for CRD;
- c) Contributing to the early diagnosis, in particular increasing the accessibility to spirometry in primary health care;
- d) Optimizing the use of therapeutic devices, in particular reducing the aerosol prescription;
- e) Improving the efficiency of prescribing, namely, extending the electronic prescription for respiratory home care;
- f) Reducing the hospitalizations for CRD by 10 %;
- g) Reducing morbidity from chronic respiratory disease and mortality by 2 %.

7.2. Strategic Objectives

To achieve its purpose, the PNDR provides two axes of intervention, each of them with two strategic objectives.

The first axis concerns the establishment of partnerships in terms of activism and awareness, creating discussion platforms at national and regional levels. The second axis relates to the technical support that the PNDR could give, and receive, from regional action plans and epidemiological surveillance.

AXES OF INTERVENTION	STRATEGIC OBJECTIVES
Activism, communication and social mobilization	Activism and communication with the aim of increasing awareness of the importance of CRD to be integrated in the policies of the health system at all levels.
	Social mobilization and partnerships to promote partnerships for the prevention and control of CRD.
Strategic and scientific intervention	Action Plans (National and Regional) to strengthen the health system for the prevention and control of respiratory diseases.
	Epidemiological surveillance to support PNDR monitoring of respiratory diseases and their determinants and evaluate progress at national and regional levels.

8. Activism and Communication

It is a strategic objective of the PNDR to promote the recognition of the importance of respiratory diseases at the global, national and regional level, and defend the involvement of all sectors of health in its combat, including the public and private sectors.

8.1. Nuclear Activities

- a) Formulation of communication messages and awareness, with and to civil society, for dissemination and collaboration in the implementation of PNDR;
- b) Promoting the recognition of the importance of the CRD and the involvement of all sectors of health in its combat;
- c) Development and availability of awareness material (eg newsletter, brochures and other means of communication);
- d) Creation and maintenance of a micro website PNDR for information and dissemination of the Programme;
- e) Disclosure and ensuring the access to the original version of the official publication of the GARD WHO Global Surveillance, Prevention and Control of Chronic Respiratory Diseases, a Comprehensive approach;
- f) Support the organization of events to draw attention to the importance and awareness of the health problems that respiratory diseases represent, at the national and regional level;
- g) Supporting organizations of the World Days related to Respiratory Diseases;
- h) Support for the mobilization of patients, families and communities affected;
- i) Identification of Goodwill Ambassadors for CRD.

9. Social Mobilization and Partnerships

It is a strategic objective of the PNDR to promote the participation of stakeholders in the prevention and control of respiratory diseases, forming alliances with partner entities somehow linked to respiratory diseases, at the national and international level, in order to achieve the aims of the GARD, and also partnerships with other national Portuguese programmes.

The entities with which the PNDR intends to establish partnerships are Health Organizations, Networks, Departments and Health Institutions, Academia, Professional

Associations, Scientific Societies and Patient Organizations involved in respiratory diseases.

9.1. Nuclear Activities

- a) Drawing up of national and international partnerships;
- b) Participation in the WHO GARD Annual General Meeting;
- c) International disclosure of PNDR.

10. Nacional and Regional Action Plans

The Action Plans are communication platforms ruled between the Directorate-General of Health, the Ministry of Health and the Regional Health Administrations to establish, support and strengthen national and regional policies on prevention and control of CRD, in line with the approaches and methods endorsed by WHO.

10.1. Nuclear Activities

- a) Implementation of initiatives in the area of prevention (avoidance of smoking, reduction of interior spaces pollution, reducing occupational exposure), particularly in conjunction with other national programmes and strengthening the control of the CRD;
- b) Definition and publication of guidelines for the main CRD, in line with the Action Plan for the Global Strategy for the Prevention and Control of Non-communicable Diseases, in particular addressed to Primary Health Care ;
- c) Support for research projects in the field of respiratory diseases;
- d) Support to regional initiatives and projects that aim at the prevention and control of respiratory diseases.

11. Epidemiological Surveillance

The PNDR has the strategic objective of monitoring respiratory diseases and their determinants, as a support for evaluating the implementation of PNDR, at national and regional level.

The PNDR has the support of external and internal structures, including the Directorate of Analysis and Information of the Directorate-General of Health, the Central Administration of Health Services and the health data platform from the Ministry of Health.

The PNDR undertakes to publish annually, in collaboration with the Directorate of Analysis and Information, the report "Portugal - Respiratory Diseases in Numbers".

11.1. Nuclear Activities

- a) Collection, organization and systematization of recent epidemiological information, at national and international level, through the integration of different sources. Integration and disclosure of information in order to support strategic reviews of action plans;
- b) Promotion of the inventory of national and international data on the prevalence and severity of CRD and promote research, particularly in morbidity and mortality, mainly through operational research;
- c) Preparing and disclosing information and the most recent evidences regarding the key determinants of CRD, as well as the impact of interventions for prevention and control of CRD in terms of cost / effectiveness, through the analysis of the results and consultation of experts panels, according to the "State of the Art";
- d) Providing recommendations based on health indicators, including the IQar indicators (Air Quality Index) and listing and prioritizing interventions cost / benefit for CRD.

12. Quality

Quality is a strategic area of intervention across the entire PNDR in order to standardize practices and disseminate knowledge about respiratory diseases in terms of quality and safety, for professionals, patients and caregivers, and also for technical equipment, based on the evidence of best practices and scientific knowledge, with the ultimate goal of providing better healthcare to patients with respiratory diseases, that will lead to an increase in health.

12.1. Nuclear Activities

- a) Collection and organization of information in the context of quality and safety to provide health care to patients with respiratory diseases;

- b)* Development and disclosure of written documents for professionals and patients, in terms of quality and safety of health care delivery to patients with respiratory diseases, by carrying out working groups consisting of expert panels;
- c)* Definition, standardization and disclosure of scientific or organizational criteria for major pathologies of PNDR ;
- d)* Preparation of flowcharts processes for health care providing and for the interconnection between different levels of care (primary health care, hospital, home care and long-term care), for major respiratory diseases, indicating the scheduled recommended care;
- e)* Definition of quality and safety requirements for infrastructure, environment, equipment and processes, in the context of respiratory diseases;
- f)* Disclosure of procedures and technical guidelines of good practice in the field of respiratory diseases;
- g)* Identification of risks and proposals for error minimization;
- h)* Definition of objectives to achieve a better quality of life for patients with chronic respiratory diseases;
- i)* Definition of professional skills, education and training needed for interventions in the provision of healthcare to patients with respiratory diseases;
- j)* Contribution to the education of patients and caregivers, through the dissemination of information and tools to support patient decisions;
- k)* Developing indicators for each disease, in relation to the structure, processes and outcomes for each level of health care;
- l)* Definition of indicators for monitoring the PNDR.



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