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Guidance to 2018 good practice: ARIA digitally-enabled, integrated, person-centred care for rhinitis and asthma


Abstract

Aims: Mobile Airways Sentinel NetworK (MASK) belongs to the Fondation Partenariale MACVIA-LR of Montpellier, France and aims to provide an active and healthy life to rhinitis sufferers and to those with asthma multimorbidity across the life cycle, whatever their gender or socio-economic status, in order to reduce health and social inequities incurred by the disease and to improve the digital transformation of health and care. The ultimate goal is to change the management strategy in chronic diseases.

Methods: MASK implements ICT technologies for individualized and predictive medicine to develop novel care pathways by a multi-disciplinary group centred around the patients.

Stakeholders: Include patients, health care professionals (pharmacists and physicians), authorities, patient’s associations, private and public sectors.

Results: MASK is deployed in 23 countries and 17 languages. 26,000 users have registered.
Introduction

In all societies, the burden and cost of allergic and chronic respiratory diseases (CRDs) is increasing rapidly. Most economies are struggling to deliver modern health care effectively. There is a need to support the transformation of the health care system for integrated care with organizational health literacy. MASK (Mobile Airways Sentinel Network) [1] is a new development of the ARIA (Allergic Rhinitis and its Impact on Asthma) initiative [2, 3]. It works closely with POLLAR (Impact of Air POLLution on Asthma and Rhinitis, EIT Health) [4], and collaborates with professional and patient organizations in the field of allergy and airway diseases. MASK proposes real-life care pathways (ICPs) centred around the patient with rhinitis and/or asthma multimorbidity. It uses mHealth monitoring of environmental exposure and considers biodiversity. With the help of three EU projects (DigitalHealthEurope, Euriphi and Vigour) recently accepted on the digital transformation of health, MASK proposes a second change management strategy. The first one was the ARIA change management associated with the recognition and wide acceptance by all stakeholders of the essential links between rhinitis and asthma. The second one deals with change management of care pathways for rhinitis and asthma [5].

In the context of implementing communication on the digital transformation of health and care, specifically in relation to chapter 5 of the document "Digital tools for citizen empowerment and for person-centred care" SG SANTE has taken steps towards supporting the scaling-up and wider implementation of good practices in the field of digitally-enabled, integrated, person-centred care. With the help of three EU projects (DigitalHealthEurope, Euriphi and Vigour) recently accepted on the digital transformation of health, MASK proposes a second change management strategy. The first one was the ARIA change management associated with the recognition and wide acceptance by all stakeholders of the essential links between rhinitis and asthma. The second one deals with change management of care pathways for rhinitis and asthma [5].

In the context of implementing communication on the digital transformation of health and care, specifically in relation to chapter 5 of the document "Digital tools for citizen empowerment and for person-centred care", DG SANTE has taken steps towards supporting the scaling-up and wider implementation of good practices in the field of digitally-enabled, integrated, person-centred care. This work was carried out in collaboration with the newly-established Commission Expert Group, the “Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases”.

For this purpose, DG SANTE—in collaboration with the Commission’s Joint Research Centre—organized a “marketplace” workshop with the Joint Research Centre in Ispra, the third biggest European Commission site after Brussels and Luxembourg. The aim of this workshop was for representatives from Member States and other countries participating in the 3rd Health Programme to learn more about the 10 good practices and key policy initiatives in the domain of digitally-enabled, integrated, person-centred care, with a view to possible transfer and replication of the presented practices.

The current paper reviews the questions raised during the workshop concerning the good practice on allergic rhinitis and asthma: ARIA digitally-enabled, integrated, person-centred care for rhinitis and asthma multimorbidity using real-world evidence [1]. This practice is a GARD (Global Alliance against Chronic Respiratory Diseases) demonstration project.

The practice

The practice includes the care pathways defined in 2014 [6–8] (Fig. 1) as well as ICT (Information and Communication Technology) solutions (cell phones for patients, inter-operable tablets for health care professionals and a web-based questionnaire for physicians) [1, 9] (Fig. 2). The aim is to develop a change management strategy for chronic diseases [5].

MASK is a patient-centred ICT system [8]. A mobile phone app (the Allergy Diary, now called MASK-air), central to MASK, is available in 23 countries. It has been validated [10] and found to be an easy and effective method of assessing the symptoms of allergic rhinitis (AR) and work productivity [10–13]. MASK follows the checklist for the evaluation of Good Practices developed by the European Union Joint Action JA-CHRODIS (Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle) [14]. One of the major aims of MASK is to provide care pathways [15] in rhinitis and asthma multimorbidity [16] including a sentinel network using the geolocation of users [17]. It can also inform the App users of the pollen and/or pollution risk level in their area, by means of geolocation (Table 1).

The practice has been developed for allergic rhinitis (and asthma multimorbidity), being the most common chronic disease globally [18, 19] and affecting all age groups from early childhood to old age. There are several unmet needs that should be addressed in an ICP. Moreover, the lessons learnt will benefit all chronic...
diseases since rhinitis is considered as a mild disease although it impairs social life, school and work productivity considerably [20]. It is estimated that, in the EU, work loss accounts for 30–100 b€ annually. Moreover, it is essential to consider mild chronic diseases and to establish health promotion and management strategies.
early in life in order to prevent a severe outcome and to promote healthy ageing [21].

Level of care integration

MASK is used for the integration of primary and specialist care, of primary-secondary-tertiary health care, as well as of health and social care for disease management.

Deployment

Many of the GPs that are developed in one region (country) take into account health systems, availability of treatments and legal considerations which makes it difficult to scale up the practice without customization. MASK has taken the opposite direction starting with a tool immediately available in 10 languages and 14 countries and regularly scaled up. Moreover, the tool is included in a generic ICP (Fig. 2) that can be customized easily in any country globally.

Geographical scope of the practice

MASK was developed in English and is currently available in 23 countries and 17 languages (Table 2).

New countries

Deployment is in process in Bolivia, Colombia, Japan and Peru. The involvement of developing countries is needed to offer a practice for middle- and low-income countries that will benefit poverty areas of developed countries and that will be in line with the mission of GARD. Deployment to the US is being discussed with the National Institute for Allergy and Infectious diseases (NIH).

Transfer of innovation of allergic rhinitis and asthma multimorbidity in the elderly (MASK Reference Site Twinning, EIP on AHA)

The EIP on AHA includes 74 Reference Sites. The aim of this TWINNING is to transfer innovation from the MASK App to other reference sites. The phenotypic characteristics of rhinitis and asthma multimorbidity in adults and the elderly have been compared using validated mHealth tools (i.e. the Allergy Diary and CARAT [22]) in 23 Reference Sites or regions across Europe, Argentina, Australia, Brazil and Mexico [23].

Individuals/institutions reached

ARIA has been implemented in over 70 countries globally [3], and several governments use the practice. Approximately 26,000 users have registered to the MASK database. 700 patients have been enrolled in the Twinning. Due to privacy, there is no possibility of assessing users who have reported data.

Timeframe

The project was initiated in 1999 during a World Health Organization (WHO) workshop (ARIA) and undergoes continuous developments. The ARIA initiative, commenced during a WHO workshop in 1999 [2], has been further developed by the WHO Collaborating Center

Table 1 The ICT solution

<table>
<thead>
<tr>
<th>App (MASK-air) deployed in 23 countries: TRL9 (Technology Readiness level), Electronic clinical decision support system (ARIA e-CDSS): TRL 7, e-physician questionnaire deployed in 16 countries: TRL9</th>
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<tr>
<td>MASK-air good practice [1, 14]</td>
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<td>5-year work</td>
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<td>App: 26,000 users, 23 countries, 17 languages</td>
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<td>GDPR including geolocation [105]</td>
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<td>GP of the EIP on AHA, follows CHRODIS [14]</td>
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<td>Based on 11 EU grants (MeDALL [106], GA2LEN [107]) including—in 2018—POLLAR [4], VIGOUR, DigitalHealthEurope and Euriphi</td>
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<td>From a validated “research” tool (2004-2018) to large scale deployment (2019-)</td>
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<td>Validation with COSMIN guidelines [40]</td>
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<td>Baseline characteristics [12]</td>
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<tr>
<td>Work productivity [41, 42]</td>
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<td>EQ-SD [43]</td>
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<td>Novel phenotypes of allergic diseases [44]</td>
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<td>Adherence to treatment and novel approaches to inform the efficacy of treatment [45].</td>
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<td>Patient’s organizations and scientific societies involved</td>
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<td>Next-generation care pathways meeting (Dec 3, 2018) with the EIP on AHA, POLLAR (EIT Health) and GARD</td>
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<td>47 MASK papers in 12 languages [99, 108, 109]</td>
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<td>Dissemination according to the EIP on AHA [26]</td>
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<td>Transfer of innovation (TWINNING [110])</td>
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<td>Interoperable platform with MASK</td>
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<tr>
<td>25 RS plus Argentina, Australia, Brazil, Canada, Mexico [99, 108, 109]</td>
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<tr>
<td>700 patients enrolled</td>
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<td>GDPR solutions being solved</td>
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<td>ARIA e-CDSS [9, 111]</td>
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<td>Interoperable platform with MASK</td>
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<td>Based on an expert meeting</td>
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<td>Electronic version available</td>
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<td>GDPR solutions being solved</td>
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<td>Developments</td>
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<td>App for home services</td>
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<td>App for sleep</td>
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<td>App for COPD</td>
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<td>App for other chronic diseases</td>
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</table>

Interoperable platform with MASK
25 RS plus Argentina, Australia, Brazil, Canada, Mexico [99, 108, 109] 700 patients enrolled GDPR solutions being solved
ARIA e-CDSS [9, 111] Interoperable platform with MASK Based on an expert meeting Electronic version available GDPR solutions being solved

Developments
App for home services
App for sleep
App for COPD
App for other chronic diseases
for Asthma and Rhinitis (2002–2013). The initial goals (Phase 1) were (1) to propose a new AR classification, (2) to promote the concept of multimorbidity in asthma and rhinitis and (3) to develop guidelines with all stakeholders that could be used globally for all countries and all populations. ARIA has been disseminated and implemented in over 70 countries [3, 19, 24–32]. It was developed as a guideline [19] using the GRADE approach [33–39].

MASK, the Phase 3 ARIA initiative, is focusing on (1) the implementation of multi-sectoral care pathways (2) using emerging technologies (3) with real world data (4) for individualized and predictive medicine (5) in rhinitis and asthma multimorbidity (6) by a multi-disciplinary group or by patients themselves (self-care) using the AIRWAYS ICPs algorithm (7) across the life cycle [8, 17]. It will be scaled up using the EU EIP on AHA strategy [26].


Developments for 2019 include a multimorbidity App and the deployment of an app for home services. The MASK project is intended to be sustainable and a business plan has been initiated.

The medium-term future is to develop care pathways for the prevention and control of chronic diseases to sustain planetary health. A symposium during the Finnish Presidency of the EU Council is planned for October 2019.

Scientific evidence and conceptual framework for configuring the practice

The scientific evidence is based on a validated “research” tool (The Allergy Diary, –2018) that has led to large scale deployment (MASK-air, 2019–):

- Validation of the app using COSMIN guidelines [40].
- Baseline characteristics informed [12].
- Work productivity associated with the control of allergic diseases [41, 42].
- EQ-5D is available and has been found to correlate to baseline characteristics [43].
- Novel phenotypes of allergic diseases have been discovered [44].
Adherence to treatment is extremely low and novel approaches to inform the efficacy of treatment have been proposed [45] leading to novel studies for a better understanding of guidelines [46, 47].

**Evidence of impact**

MASK has identified novel phenotypes of allergic diseases [44] that have been confirmed in classical epidemiologic studies by re-analyzing them [48–51]. One of the studies used the MASK baseline characteristics [49]. These phenotypes allowed the re-classification of allergic multimorbidity and the discovery of a new extreme phenotype of allergic diseases that need to be considered in the stratification of patients.

MASK has shown real-life mHealth data for the first time in allergy treatment in 9,950 users [1, 45]. This led to next-generation care pathways for allergic diseases (meeting co-organized by POLLAR, a member of EIT Health, EIP on AHA and GARD (WHO alliance): 3-12-2018) and proposed a change management strategy [5].

MASK is involved in an EIT Health project (POLLAR) which assesses the interactions between air pollution, asthma and rhinitis [4].

With the EIP on AHA, MASK is involved in 3 EU projects on the digital transformation of health and care (DigiHealthEurope, Euriphi and Vigour).

MASK is also involved in a large project on Planetary Health in a side event which will take place during the Presidency of the EU council (Finland). This event will gather researchers, academic leaders and other experts from European institutions as well as other stakeholders and will discuss Planetary Health global challenges and their scientific solutions. Experts on human health as well as on effects of climate change, urbanization and food production will be invited to prepare a European initiative to promote effective and sustainable research on planetary health issues. The event similarly aims at raising political awareness about the need for multidisciplinary and systemic approaches to Planetary Health issues globally and in the EU. The multimorbid App developed by MASK may be used in the project.

**Contextual relevance**

**The practice addresses a public health priority**

Chronic respiratory diseases (CRDs) are major non-communicable diseases (NCDs) [18]. Rhinitis and asthma multimorbidity is common and the two diseases should be considered jointly [19]. Asthma is the most common NCD in children and rhinitis is the most common chronic disease in Europe. They often start early in life, persist across the life cycle and cause a high disease burden in all age groups [19]. By 2020, rhinitis will affect at least 20% of the old age population [52–56]. These diseases represent an enormous burden associated to medical and social costs and they impact health and social inequalities.

The practice is based on a local/regional/national strategic action plan

The Polish Presidency of the EU Council (3051st Council Conclusions) made the prevention, early diagnosis and treatment of asthma and allergic diseases a priority to reduce health inequalities [57, 58]. The 3206th Cyprus Council Conclusions [59] recommended that the diagnosis and treatment of chronic diseases should be initiated as early as possible to improve AHA. Debates at the European Parliament recommended the early diagnosis and management of CRDs in order to promote active and healthy ageing (AHA) [60–62].

The practice is also a WHO-associated project: Initial workshop (1999), WHO Collaborating Center for rhinitis and asthma (2004–2014), Global Alliance against Chronic Respiratory Diseases (GARD) [63, 64] demonstration project (2015–).

**Unmet needs**

Several unmet needs have been identified in allergic diseases. They include (1) suboptimal rhinitis and asthma control due to medical, cultural and social barriers [65, 66], (2) better understanding of endotypes [67], phenotypes and multimorbidities, (3) assessment of allergen and pollutants as risk factors to promote sentinel networks in care pathways, (4) stratification of patients for optimized care pathways [68] and (5) promotion of multidisciplinary teams within integrated care pathways, endorsing innovation in clinical trials and encouraging patient empowerment [17, 69].

**Overall goal**

The general objective of AIRWAYS-ICPs [6–8] is to develop multi-sectoral ICPs for CRDs used across European countries and regions in order to (1) reduce the burden of the diseases in a patient-centred approach, (2) promote AHA, (3) create a care pathways simulator tool which can be applied across the life cycle and in older adults, (4) reduce health and social inequalities, (5) reduce gender inequalities, (6) use the lessons learned in CRDs for chronic diseases and (7) promote SDG3 (more specifically 3.4) (https://www.who.int/sdg/targets/en/). In September 2015, the UN General Assembly established the Sustainable Development Goals (SDGs), a set of global goals for fair and sustainable health at every level from planetary biosphere to...
local community [70, 71], essential for sustainable development. SDG 3 prioritizes health and well-being for all ages.

The aim of AIRWAYS-ICPs is also to generalise the approach of the uniform definition of severity, control and risk of severe asthma presented to WHO [66] and allergic diseases [72] in order to develop a uniform risk stratification usable for chronic diseases in most situations.

MASK further refined AIRWAYS ICPs using mobile technology to promote the digital transformation of health and care in developed and developing countries for all age groups.

Target population
In the initial phase, the target population included all patients with allergic rhinitis and asthma multimorbidity. Rhinitis and asthma are considered as a model for all chronic diseases and the project is being extended to chronic diseases.

All patients able to use a smartphone (≥12 years) represent the target population. A special effort is being placed in underserved populations from developing countries as the practice is a GARD (Global Alliance against Chronic Respiratory Diseases, WHO alliance) demonstration project.

Stakeholders involved
Involvement in the design, implementation (including the creation of ownership), evaluation, continuity/sustainability

As from the very first workshop in 1999, the ARIA initiative has included all stakeholders required to develop a WHO programme on CRDs (GARD). In particular, patient's organizations were involved. All health care professionals were also involved (physicians, primary care, pharmacists, other health care professionals). Another important component of ARIA was the deployment to developing countries [73]. Moreover, policy makers were also actively involved.

ARIA has grown regularly over the past 20 years and an ARIA chapter is ongoing in over 70 countries in all continents with a very active scaling up strategy [26]. MASK has used the ARIA working group to scale up the practice.

All stakeholders were highly receptive
The ARIA and now the MASK community is very cohesive and all members are extremely reactive. They have been particularly active in deploying MASK in the 23 countries and we have received requests from many other countries in which MASK-air is not yet available.

Resistance or conflict of interest: None

Implementation methodology/strategy
We used the scaling up strategy of the European Innovation Partnership on Active and Healthy Ageing and proposed a 5-step framework for developing an individual: (1) what to scale up: (1-a) databases of good practices, (1-b) assessment of viability of the scaling up of good practices, (1-c) classification of good practices for local replication and (2) how to scale up: (2-a) facilitating partnerships for scaling up, (2-b) implementation of key success factors and lessons learnt, including emerging technologies for individualized and predictive medicine.

This strategy has already been applied to the chronic respiratory disease action plan of the European Innovation Partnership on Active and Healthy Ageing [26].

Consistency in the pace of delivery
For the past 20 years, ARIA has been a success story in over 72 countries [3, 8, 19, 24, 25, 27, 28, 30–32, 38, 46, 74–100]. A Pocket Guide has been translated into 52 languages. MASK is following ARIA with the same group and the same strategy.

Main outcomes and evaluation of the practice
The ARIA strategy was to change management in the treatment of asthma and rhinitis since nasal symptoms—often the most troublesome—were not considered in most asthmatics. Over 85% of asthma in children and adolescents is associated with rhinitis, suggesting common pathways, whereas only 20–30% of rhinitis patients have asthma, suggesting rhinitis-specific genes. There is a link between asthma severity and rhinitis multimorbidity. Asthma is more severe in patients with rhinitis [101]. The strategy at all levels of care indicates that it is essential to consider multimorbidity in the management of asthma for the benefit of the patient and the satisfaction of the treatment as shown in many surveys (Fig. 3). Some studies have found that the ARIA strategy is more effective than free treatment choice [102]. Moreover, EMA has used the ARIA recommendations for the approval of a house dust mite immunotherapy tablet including asthma and rhinitis multimorbidity [103].

The change management strategy of MASK has not yet been evaluated. However, the results of the first studies indicate that the vast majority of patients are not adherent to treatment [45] and that next-generation care pathways are needed (Figs. 4 and 5).
Next-generation care pathways were initiated in Paris, December 3, 2018, as part of POLLAR, MASK and GARD.

Additional (secondary) outcomes assessed
Work productivity and school performance are measured. When rhinitis and/or asthma are not well controlled, work productivity is impaired [1, 41, 43].

**Sustainability of the practice**
The MASK App, The Allergy Diary, was used to demonstrate the scientific value of the project [1]. It has been replaced by the commercial App, MASK-air, which is version 3.0 and which includes questionnaires (e.g. tobacco and allergens) and sleep (VAS and Epworth questionnaire [104]) (Fig. 6). A business plan is in place for the sustainability of the practice.

Communication about the practice and dissemination of results
A communication strategy has been set up [1] and includes a website (mask-air.com), media coverage, leaflets and newsletters, publications in scientific journals and lay press, partners’ networks and events. The MASK community includes over 300 members in all countries in which MASK is deployed.

Goals
1. Embedding environmental data
2. Prevention of symptoms and asthma (self-care)
3. Assess if severity of symptoms is associated with allergens or pollution
4. Predict emergency care visits
5. Develop machine learning to optimize ICPs

Budget required to implement the practice
The budget required to implement the MASK strategy is around 1.5 M€. It will be provided by the private sector (1 M€) and from EU grants, in particular a Structural and Development Fund. POLLAR has an additive budget of 2 M€ to embed outdoor air pollution and aerobiology data in the ICP using artificial intelligence.

It is difficult to estimate human resources since many physicians worked in the 23 countries for the translation,
adaptation of the practice and its implementation. It can be proposed that 50–100 h have been spent working in each country.

The practice has been presented to multiple national and international meetings.

Sustainability has been carefully evaluated and a business plan is in place.

Main lessons learned

• Adherence to treatment is the major problem of allergic disease.
• Self-management strategies should be considerably expanded (behavioural).
• Change management is essential in allergic diseases.
• Education strategies should be reconsidered using a patient-centred approach.
• Lessons learned for allergic diseases can be expanded to chronic diseases.

Improvement and expansion of the practice

An expert meeting took place at the Pasteur Institute in Paris, December 3, 2018, to discuss next-generation care pathways and lessons learnt (Fig. 7, Annex 1): (1) patient participation, health literacy and self-care through technology-assisted “patient activation”, (2) implementation of care pathways by pharmacists and (3) next-generation guidelines assessing the recommendations of GRADE guidelines in rhinitis and asthma using real-world evidence (RWE) assessed by mobile technology. The meeting was organized by POLLAR and MASK in collaboration with GARD, patient’s organizations and all European scientific societies in the field.

Abbreviations

AHA: active and healthy ageing; AIRWAYS ICPs: integrated care pathways for airway diseases; AR: allergic rhinitis; ARIA: allergic rhinitis and its impact on asthma; CDSS: clinical decision support system; CRD: chronic respiratory disease; DG CONNECT: directorate general for communications networks, content and technology; DG Santé: directorate general for health and food safety; EIP on AHA: European innovation partnership on AHA; EIP: European innovation partnership; EQ-5D: euroquol; Euforea: European forum for research and education in allergy and airways diseases; GARD: global alliance against chronic respiratory diseases (WHO Alliance); GINA: Global Initiative for Asthma; MACVIA: Fondation VIA-LR, SPLF: Société de Pneumologie de Langue Française, SFA: Société française d’Allergologie, WAO: World Allergy Organization.

Authors’ contributions

All authors are MASK members and have contributed to the design of the project. Many authors also included users and disseminated the project in their own country. All authors read and approved the final manuscript.

Author details

1 MACVIA-France, Fondation Partenariale FMC VIA-LR, CHU Arnaud de Villemeuvne, 371 Avenue du Doyen Gaston Giraud, 34295 Montpellier Cedex 5, France. 2 INSERM U 1168, VIMA: Ageing and Chronic Diseases Epidemiological
Institute of Health, Comprehensive Allergy Center, Department of Dermatology and Allergy, Global Allergy and Asthma European Network (GA2LEN), Berlin, Germany. 20Department of Respiratory Medicine, National Institute of Diseases of the Chest and Hospital, Dhaka, Bangladesh. 21Centre for Individualized Medicine, Department of Pediatrics, Faculty of Medicine, Linköping, Sweden. 22Department of Prevention of Environmental Hazards and Allergology, Medical University of Warsaw, Poland. 23BIBER Department of Dermatology and Allergy, Rheinische Friedrich-Wilhelms-Universität Bonn, Bonn, Germany. 24Dept of Biochemistry and Clinical Chemistry, University of Pharmacy with the Division of Laboratory Medicine, Warsaw Medical University, Warsaw, Poland. 25Department of Dermatology and Allergy, Odense University Hospital, Odense Research Center for Anaphylaxis (ORCA), Odense, Denmark. 26Department of Respiratory Medicine and Allergology, University Hospital, Lund, Sweden. 27Department of Geriatrics, Montpellier University Hospital, Montpellier, France. 28EA 2991, Euromov, University Montpellier, France. 29Department of Pathophysiology and Transplantation, University of Milan, IRCCS Fondazione CaGranda Ospedale Maggiore Policlinico, Milan, Italy. 30Argentine Association of Respiratory Medicine, Buenos Aires, Argentina. 31Division of Internal Medicine, Asthma and Allergy, Barlicki University Hospital, Medical University of Lodz, Poland. 32Pediatric Department, University of Verona Hospital, Verona, Italy. 33UOC Pneumologia, Istituto di Medicina Interna, F. Pollinici Gemelli IRCCS, Università Cattolica del Sacro Cuore, Rome, Italy, and National Heart and Lung Institute, Royal Brompton Hospital & Imperial College London, London, UK. 34Second University of Naples and IRCCS-Azienda Ospedaliera Universitaria San Martino, Genoa, Italy. 35Universidade Federal da Bahia, Escola de Enfermagem, Salvador, Brazil. 36Plateforme Transversale d’Allergologie, Institut du Thorax, CHU de Nantes, Nantes, France. 37ANUA International Healthcare Consultancy, Northern Ireland, UK. 38Innovación y nuevas tecnologías, Salud Sector sanitario de Barbastro, Barbastro, Spain. 39Novo Nordisk Research and Research Office of the Department of Health and Public Health Solidarity, Autonomous Province of Trento, Italy. 40Life and Health Sciences Research Institute (ICVS), School of Medicine, University of Minho, Braga, Portugal. 41ICVS/38, PT Government Associate Laboratory, Braga/Guimarães, Portugal. 42Servicio de Allergología, Hospital Angeles del Carmen, Guadalajara, Mexico. 43FIMMG (Federazione Italiana Medici di Medicina Generale), Milan, Italy. 44UCIBIO, REQUINTE, Faculty of Pharmacy and Competence Center on Active and Healthy Ageing of University of Porto (PortoAging), Porto, Portugal. 45Allergologo, Mexico City, Mexico. 46IMT Milnes Alés, Université Montpellier, Alés, France. 47Department of Medicine, Nova Southeastern University, Davie, University of Miami Dept of Medicine, Miami, Florida, USA. 48Regional Director Assafar Campania and Vice President of the Board of Directors of Cofaser, Salerno, Italy. 49PicAR – Nucleo de Excelencia em Arma, Federal University of Bahia, Ribeira Group and WHO GARD Group, Salvador, Brazil. 50Second University of Naples and Institute of Translational Medicine and Allergy, Institute of Inflammation and Repair, University of Manchester and University Hospital of South Manchester, Manchester, UK. 51Medical Consulting Czarelewski, Levallois, France. 52The Centre for Allergy Research, The Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden. 53Assoazienda provinciale per i Servizi sanitari di Trento (APSS-Trento), Italy. 54Department of Internal Medicine and Allergy Clinic of Professor Polidoro Ernani de São Thago University Hospital, Federal University of Santa Catarina (UFSC), Florianópolis, Santa Catarina, Brazil. 55Sleep Unit, Department of Neurology, Hôpital Gu-de-Chauliac Montpellier, Inserm U1061, France. 56Department of Dermatology and Allergy, Technische Universität München, Munich, Germany; ZAUM-Center for Allergy and Environment, Helmholtz Center Munich, Munich Technical University, Munich, Munich, Germany. 57Allergy Division, Chest Disease Department, University Hospital of Strasbourg, Strasbourg, France. 58IEFE European Federation of Allergy and Airways Diseases Patients’ Associations, Brussels, Belgium. 59AQAS, Barcelona, Spain & EUREGHA, European Regional and Local Health Association, Brussels, Belgium. 60Polyclinica Geral do Rio de Janeiro, Rio de Janeiro – Brazil. 61Department of Medicine, Surgery and Dentistry “Scuola Medica Salernitana”, University of Salerno, Salerno, Italy. 62Professor Polydoro Ernani de São Thiago University Hospital, Federal University of the State of Rio de Janeiro, School of Medicine and Surgery, Rio de Janeiro, Brazil. 63Allergy and Immunology Discipline, Uluu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania. 64Department of Medicine, Division of Clinical Immunology and Allergy, McMaster University, Hamilton, Ontario, Canada. 65Laboratoire de Pharmacie Respiratoire, UPRES EA220, Hôpital Foch, Suresnes, Université Versailles Saint-Quentin, Université Paris Saclay, France. 66FARMacia Dei Golfo Group, Massa Lubrense, Italy. 67Rangueil-Larrey Hospital, Respiratory Diseases Department, Toulouse, France. 68University Clinic of Pulmonology and Allergy, Medical Faculty Skopje, Republic of Macedonia. 69Allergologo, Mexico City, Mexico. 70Service de Pneumo-Allergologie, Centre Hospitalo-Universitaire de Béni-Messous, Algiers, Algeria. 71Clinical of infectious, chest diseases, dermatology and allergology, Vilnius University, Vilnius, Lithuania. 72Allergy and Clinical Immunology National Heart and Lung Institute, Imperial College London, UK. 73Guy’s and st Thomas’ NHS Trust, Kings College London, UK. 74Section of Allergy and Immunology, Saint Louis University School of Medicine, Saint Louis, Missouri, USA. 75Pediatric Allergy and Immunology Unit, Children's Hospital, Ain Shams University, Cairo, Egypt. 76Department of Computing Science, Umeå University, Sweden and Four Computing OY, Finland. 77Clinical of Children’s Diseases, Faculty of Medicine, Vilnius University, Vilnius, Lithuania. 78University of São Paulo Medical School, Sao Paulo, Brazil. 79Andalusian Agency for Healthcare Quality, Seville, Spain. 80Global Allergy and Asthma Platform GAAP, Vienna, Austria. 81Division of Allergy, Department of Pediatric Medicine - The Bambino Gesù Children’s Research Hospital, Rome, Italy. 82Department of Otorhinolaryngology, Academic Medical Centers, Amsterdam, the Netherlands. 83CINTESIS, Center for Research in Health Technologies and Information Systems, Faculdade de Medicina da
Universidade do Porto, Porto, Portugal and MEDIDA, Lda, Porto, Portugal.

144Allergist, Reims, France. 145Hospital General Regional 1 “Dr Carlos Mc Gregor Sánchez Navarro” IMSS, Mexico City, Mexico. 146Regional hospital of ISSSTE, Puebla, Mexico. 147National Center for Disease Control and Public Health of Georgia, Tbilisi, Georgia. 148Allergology, Guadalajara, Mexico. 149Allergy Clinic, National Institute of Respiratory Diseases, Mexico City, Mexico. 150Department of Pulmonary Diseases, Istanbul University-Cerrahpaşa, Cerrahpaşa Faculty of Medicine, Istambul, Turkey. 151Allergology unit, UHATEM “NIPirogov”, Sofia, Bulgaria. 152Medical University, Faculty of Public Health, Sofia, Bulgaria. 153Allergy and Immunology Division, Clinica Ricardo Palma, Lima, Peru. 154Department of Medicine, University of Lodz, Poland. 155Institute of Social Medicine, Epidemiology and Health Economics, Charité – Universitätsmedizin Berlin, Berlin, and Institute for Health Economics, Experimental Respiratory Immunoallergy, IDIBAPS, CIBERES, University of Barcelona, Spain. 156Professor of Medicine University of Malta, Deputy Dean Faculty of Medicine, University of Malta, Valletta, Malta.

157Center of Allergy and Immunology, Georgian Association of Allergology, and Clinical Immunology, Tbilisi, Georgia. 158Latvian Association of Allergists, Center of Tuberculosis and Lung Diseases, Riga, Latvia. 159Federal District Base Hospital Institute, Brasilia, Brazil. 160Institute of Health Policy and Management IBMG, Erasmus University, Rotterdam, The Netherlands. 161University Hospital Olomouc – National eHealth Centre, Czech Republic. 162Immunology and Allergy Division, Clinical Hospital, University of Chile, Santiago, Chile. 163Skin and Allergy Hospital, University of Helsinki, Helsinki, Finland. 164Cencht: centre d'expertise national des technologies de l'information et de la communication pour l'autonomie, Gérontopôle Centre d'expertise Partenariat Européen d'Innovation pour un vieillissement autonome longévité des Pays de la Loire, Conseil régional des Pays de la Loire, Centre d'expertise Partenariat Européen d'Innovation pour un vieillissement actif et en bonne santé, Nantes, France. 165Autonomous University of Baja California, Ensenada, Baja California, Mexico. 166Department of Paediatrics and Child Health, University College Cork, Cork, Ireland. 167Hospital General Regional 1 “Dr. Carlos MacGregor Sánchez Navarro” IMSS, Mexico City, Mexico. 168Université Paris-Sud; Service de Pneumologie, Hôpital Bicêtre, Inserm UMR_S999, Le Kremlin Bicêtre, France. 169Department of medical, chirurgie et odontoostomatia, università di salerno, Italy. 170Division for Health Innovation, Campania Region and Federico II University Hospital Naples (R&D and DISMET) Naples, Italy. 171Servicio de Alergia e Immunología, Clínica Santa Isabel, Buenos Aires, Argentina. 172President, Libra Foundation, Buenos Aires, Argentina. 173Medical University of Gdańsk, Department of Allergology, Gdańsk, Poland. 174Airway Disease Infection Section, National Heart and Lung Institute, Imperial College, MRC & Asthma UK Centre in Allergic Mechanisms of Asthma, London, UK. 175Dept of Respiratory Medicine, Ghent University Hospital, Ghent, Belgium. 176Halym University College of Medicine, Halym University Sacred Heart Hospital, Gyeonggi-do, South Korea. 177Department of Clinical Immunology, Wroclaw Medical University, Poland. 178Ukrainian Medical Stomatological Academy, Poltava, Ukraine. 179Pediatric Allergy and Asthma Unit, Hacettepe University School of Medicine, Ankara, Turkey. 180Hacettepe University, School of Medicine, Department of Chest Diseases, Immunology and Allergy Division, Ankara, Turkey. 181Allergy Centre, Tampere University Hospital, Tampere, Finland. 182First Department of Family Medicine, Medical University of Lodz, Poland. 183Institute of Social Medicine, Epidemiology and Health Economics, Charité – Universitätsmedizin Berlin, Berlin, and Institute for Health Economics, Experimental Respiratory Immunoallergy, IDIBAPS, CIBERES, University of Barcelona, Spain. 184Department of Medicine, McMaster University, Health Sciences Centre 3V47, West, Hamilton, Ontario, Canada. 185National Research Center, Institute of Immunology, Federal Medicobiological Agency, Laboratory of Molecular Immunology, Moscow, Russian Federation. 186GARD Chairman, Geneva, Switzerland. 187Allergy & Asthma Center Westend, Berlin, Germany. 188Center for Rhinology and Allergology, Wiesbaden, Germany. 189Department of Immunology and Allergy, Health Ageing Research Center, Medical University of Lodz, Lodz, Poland. 190Children’s Hospital and University of Helsinki, Finland. 191Department of Clinical Science and Education, Södersjukhuset, Karolinska Institutet, Stockholm and Sach’s Children and Young Hospital, Södersjukhuset, Stockholm, Sweden. 192Faculty of Medicine, Vilnius University, Vilnius, Lithuania. 193Department of Prevention of Environmental Hazards and Allergology, Medical University of Warsaw, Poland. 194Center of Excellence in Asthma and Allergy, Médica Sur Clinical Foundation and Hospital, México City, Mexico. 195President of MCAC, Milano, Italy. 196Department of Pedro de Elizalde Children’s Hospital, Buenos Aires, Argentina. 197University of Medicine and Pharmacy, Hochiminh City, Vietnam. 198Federal University of Bahia, Brazil. 199Sifmed, Milano, Italy. 200State Key Laboratory of Respiratory Diseases, Guangzhou Institute of Respiratory Disease, the First Affiliated Hospital of Guangzhou Medical University, Guangzhou, China. 201Departments of Internal Medicine and Pediatrics (Divisions of Allergy and Immunology), University of Tennessee College of Medicine, Germantown, TN, USA. 202Scotia, Centre for Respiratory Research, Cardiovascular & Diabetes Medicine, Medical Research Institute, Ninewells Hospital, University of Dundee, UK. 203Oslo University Hospital, Department of Paediatrics, Oslo, and University of Oslo, Faculty of Medicine, Institute of Clinical Medicine, Oslo, Norway. 204Department of Pulmonary Medicine, CHU Sart-Tilman, and GIGA I3 research group, Liege, Belgium. 205Faculty of Health Sciences and CICS – UBI, Health Sciences Research Centre, University of Beira Interior, Covilhã, Portugal. 206Department of Philosophical, Methodological and Instrumental Disciplines, CUCS, University of Guadalajara, Guadalajara, Mexico. 207Department of Pulmonary Medicine, Rashid Hospital, Dubai, UAE. 208Biomax Informatics AG, Munich, Germany. 209Director General for Health and Social Care, Scottish Government, Edinburgh, UK. 210Department of Respiratory Medicine, University of Bratislava, Bratislava, Slovakia. 211Coimbra Institute for Clinical and Biomedical Research (ICBR), Faculty of Medicine, University of Coimbra, Portugal, Ageing@Coimbra EIP-AHA Reference Site, Coimbra, Portugal. 212Medical center Iskar Ltd Sofia, Bulgaria. 213Department of Medicine (RCSI), Bon Secours Hospital, Glasnevin, Dublin, Ireland. 214Kronikogune, International Center of Excellence in Chronicity Research Barakaldo, Bizkaia, Spain. 215Division of Clinical Immunology and Allergy, Laboratory of Behavioral Immunology Research, The University of Mississippi Medical Center, Jackson, Mississippi, USA. 216Tobacco Control Research Centre,Iranian Anti Tobacco Association, Tehran, Iran. 217Argentine Association of Allergy and Clinical Immunology, Buenos Aires, Argentina. 218Hospital de Especialidades, Centro Médico Nacional Siglo XXI, Mexico City, Mexico. 219University of Southeast Bahia, Brazil. 220Allergy-Centrum-Chanté at the Department of Dermatology and Allergy, Chanté - Universitätsmedizin Berlin, Germany. 221Maputo Central Hospital, Department of Paediatrics, Maputo, Mozambique. 222Allergology, Veracruz, Mexico. 223Sachs’ Children and Youth Hospital, Södersjukhuset, Stockholm and Institute of Environmental Medicine, Karolinska Institutet, Stockholm, Sweden. 224Allergy and Asthma Medical Group and Research Center, San Diego, California, USA. 225CIRIFF, Federico II University, Naples, Italy. 226Department of Physiology, CHRU, University Montpellier; Vice President for Research, PhyMedExp, INSERM U1046, CNRS UMR 9214, France. 227Croatian Pulmonary Society. 228National Institute of Pneumology N Masta, Bucharest, Romania. 229Clinic for Pulmonary Diseases, Clinical Center of Serbia, Faculty of Medicine, University of Belgrade, Serbian Association for Asthma and COPD, Belgrade, Serbia. 230Regionie Piemonte, Torino, Italy. 231Col Jardines de Sta Monica, Taliaepantla, Mexico. 232Central Region for Research in Chronic Respiratory Diseases, Tirshreen University School of Medicine, Latakia, Syria. 233Department of Public health and health products, Paris Descartes University-Sorbonne Paris Cité, EA 4064 and Paris Municipal Department of social action, childhood, and health, Paris, France. 234Paris municipal Department of social action, childhood, and health, Paris, France. 235Lead Respiratory Physician Mater Dei Hospital Malta, Academic Head of Dept and Professor of Medicine University of Malta, Deputy Dean Faculty of Medicine and Surgery University of Medicine, La Valette, Malta. 236Department of Medical Sciences, Allergy and Clinical Immunology Unit, University of Torino & Mauriziano Hospital, Torino, Italy. 237Instituto de Previsión Social IPS HC, Socia de la SPA, Tesorería de la SLAAI, Asuncion, Paraguay. 238Allergy Center, CUF Descobertas Hospital, Lisbon, Portugal. 239250Director of Center of Allergy, Immunology and Respiratory Diseases, Santa Maria, Italy. 240Professor of Medicine University of Malta, Deputy Dean Faculty of Medicine, University of Malta, Valletta, Malta. 241Allergy Centre, UHATEM “NIPirogov”, Sofia, Bulgaria. 242Denver Federal University of Bahia, Brazil. 243RhinoU Unit & Smell Clinic, ENT Department, Hospital Clinic; Clinical & Experimental Respiratory Immunology, IDIBAPS, CIBERES, University of Barcelona, Spain. 244Danish Committee for Health Education, Copenhagen East, Denmark. 245Food Allergy Referral Centre Veneto Region, Department of Women and Child Health, Padua General University Hospital, Padua, Italy. 246Director, Medical Communications Consultant, MedScript Ltd, Dundalk, Co Louth, Ireland and New Zealand, and Honorary Research Fellow, OPC, Cambridge, UK. 247Johns Hopkins School of Medicine, Baltimore, Maryland, USA. 248Director of the Allergy Service, Salmiak, Salorno, Italy. 249Scientific Centre of Children’s Health under the MoH, Moscow, Russian National Research Medical University named Pirogov, Moscow, Russia. 250Director of Center of Allergy, Immunology and Respiratory Diseases, Santa
Fe, Argentina Center for Allergy and Immunology, Santa Fe, Argentina. 251 Dept of Otorhinolaryngology, Medical University of Vienna, AKH, Vienna, Austria. 252 Hospital of the Hospitalier Brothers in Buda, Budapest, Hungary. 253 Die Hautambulanz und Rothaar study center, Berlin, Germany. 254 Neuroulogia y Alergia Infantil, Hospital La Fe, Valencia, Spain. 255 Center for Health Technology and Services Research - CINTESIS and Department of Internal Medicine, Centro Hospitalar Sao Joao, Porto, Portugal. 256 Caisse d'assurance retraite et de la santé au travail du Languedoc-Roussillon (CARSAT-LR), Montpellier, France. 257 Director of Department of Pharmacy of University of Naples Federico II, Naples, Italy. 258 ENT Department, University Hospital of King Saud, Kingdom of Saudi Arabia. 259 Department of Otorhinolaryngology, Respiratory Medicine, Alfred Hospital and Central Clinical School, Monash University, Melbourne, Victoria,Australia. Department of Immunology, Monash University, Melbourne, Victoria, Australia. 252 Medical center 'Research expert', Varna, Bulgaria. 253 National Hospital Organization, Tokyo National Hospital, Tokyo, Japan. 254 Dept of Otorhinolaryngology, Chiba University Hospital, Chiba, Japan. 255 Dept of Otorhinolaryngology, Nilsson Medical School, Tokyo, Japan. 256 Allergology, Jalisco, Guadalajara, Mexico. 257 Centre Hospitalier Universitaire Pédiatrique Charles de Gaulle, Ouagadougou, Burkina Faso. 258 Dept of Comparative Medicine, Messerli Research Institute of the University of Veterinary Medicine and Medical University, Vienna, Austria. 259 Department of Immunology and Allergology, Faculty of Medicine and Faculty Hospital in Pilsen, Charles University in Prague, Pilsen, Czech Republic. 260 Division of Infection, Immunology and Respiratory Medicine, University of Manchester's, Hospital, University of Manchester, Manchester, UK, and Allergy Department, 2nd Pediatric Clinic, Athens General Children's Hospital "P&A Kyriakou," University of Athens, Athens, Greece. 261 Department of Allergy and Clinical Immunology, Ajou University School of Medicine, Suwon, South Korea. 262 Respiratory Medicine, Department of Medical Sciences, University of Ferrara, Ferrara, Italy. 263 Allergy and Respiratory Diseases, Ospedale Policlinico San Martino - University of Genoa, Italy. 264 Farmacias Holon, Lisbon, Portugal. 265 Department of Pediatrics, Nippon Medical School, Tokyo, Japan. 266 University of Southern Denmark, Kolding, Denmark. 267 Université Grenoble Alpes, Laboratoire HP2, Grenoble, INSERM, U1042 and CHU de Grenoble, France. 268 Allergy Unit, CUF-Porto Hospital and Institute; Center for Research in Health Technologies and information systems CINTESIS, Universidade do Porto, Portugal. 269 Sociologist, municipality area n3, Sorrento, Italy. 270 Center for Rhinology and Allergology, Wiesbaden, Germany. 271 Department of Otorhinolaryngology, Head and Neck Surgery, Universitätsmedizin Mannheim, Medical Faculty Mannheim, Heidelberg University, Mannheim, Germany. 272 Centre for empowering people and communities, Dublin, UK. 273 Conseil Général de l’Economie Ministère de l’Economie, de l’Industrie et du Numérique, Paris, France. 274 Société de Pneumologie de Langue Française, Espace francophone de Pneumologie, Paris, France. 275 Département de pédiatrie, CHU de Grenoble, Grenoble France. 276 Medical School, University of Cyprus, Nicosa, Cyprus. 277 Children's Hospital Srebrnjak, Zagreb, School of Medicine, University J.J. Strossmayer, Osijek, Croatia. 278 Karl Landsteiner Hospital, Portugal. 279 Department of Otorhinolaryngology, Head and Neck Surgery, Universitätsklinikum Düsseldorf, Germany. 280 Centre of Pathophysiology, Infectiology and Immunology, Medical University of Vienna, Vienna, Austria. 281 Allergy Unit, Department of Dermatology, University Hospital of Zurich, Switzerland. 282 Société de Pneumologie de Langue Française, Paris, France. 283 Département de pneumologie et rhinologie, CHU de Reims, France. 284 Medical School, University of Manchester, Manchester, UK, and Allergy Department, 2nd Pediatric Clinic, Athens General Children's Hospital "P&A Kyriakou," University of Athens, Athens, Greece. 285 Department of Allergy and Clinical Immunology, Ajou University School of Medicine, Suwon, South Korea. 286 Respiratory Medicine, Department of Medical Sciences, University of Ferrara, Ferrara, Italy. 287 Allergy and Respiratory Diseases, Ospedale Policlinico San Martino - University of Genoa, Italy. 288 Farmacias Holon, Lisbon, Portugal. 289 Department of Pediatrics, Nippon Medical School, Tokyo, Japan. 290 Centre for Research in Health Technologies and information systems CINTESIS, Universidade do Porto, Portugal. 291 Department of Otorhinolaryngology, Plovdiv, Bulgaria. 292 European Forum University of Crete School of Medicine, Heraklion, Greece. 293 Department of Otorhinolaryngology, University Hospital of Coimbra, Portugal. 294 Allergy Unit, Centro Médico-Brasileiro, São Paulo, Brazil. 295 Centre of Pathophysiology, Infectiology and Immunology, Medical University of Vienna, Vienna, Austria. 296 Department of Nephrology and Endocrinology, Karolinska University Hospital, Stockholm, Sweden. 297 Centre of ENT, Medical University of Graz, Austria. 298 Campania Region, Division on Pharmacy and devices policy, Naples, Italy. 299 Department of Respiratory Medicine, Hvidovre Hospital & University of Copenhagen, Denmark. 300 Universidade Federal dos Pampas, Uruguaiana, Brazil. 301 Division of Immunopathology, Department of Pathophysiology and Allergy Research, Center for Pathophysiology, Infectology, and Immunology, Medical University of Vienna, Vienna, Austria. 302 Medical University of Graz, Department of Internal Medicine, Centro Hospitalar Sao Joao, Porto, Portugal. 303 Honorary Clinical Research Fellow, Allergy and Respiratory Research Group, University of Edinburgh, Edinburgh, UK. 304 Department of Immunology and Allergology, Medical University of Tokyo, Tokyo, Japan. 305 Association of Finnish Pharmacies, Helsinki, Finland. 306 Allergy and Clinical Immunology Department, Centro Médico-Docente la, Trinidad and Clinica El Avila, Caracas, Venezuela. 307 Faculty of Medicine, Autonomous University of Madrid, Spain. 308 The Royal National TNE Hospital, University College London, UK. 309 DIBIMIS, University of Palermo, Italy. 310 Allergy Unit, Department of Dermatology, University Hospital of Zurich, Zurich, Switzerland. 311 Asthma Reference Center, Escola Superior de Ciencias da Santa Casa de Misericórdia de Vitoria – Esperito Santo, Brazil. 312 The Usher Institute of Population Health Sciences and Informatics, The University of Edinburgh, Edinburgh, UK. 313 Department of Pediatrics & Child Health, Department of Immunology, Faculty of Medicine, University of Manitoba, Winnipeg, Manitoba, Canada. 314 INSERM, Université Grenoble Alpes, IAB, U 1134, Team of Environmental applied to Medical Manchester of Environment and Respiratory Health, Université Joseph Fourier, Grenoble, France. 315 Société Paraguay de Alergia Arma e Imunologia`a, Paraguay. 316 Division of Allergy, Clinical Immunology and Rheumatology, Department of Pediatrics, Federal University of São Paulo, São Paulo, Brazil. 317 European Health Futures Forum (EHFF), Dromahair, Ireland. 318 AENT, Aachen, Germany. 319 Kyrgyzstan National Centre of Cardiology and Internal medicine, Euro-Asian respiratory Society, Bishkek, Kyrgyzstan. 320 University Hospital Olomouc, Czech Republic. 321 Department of Paediatric and Adolescent medicine, University Hospital of North Norway, Tromsø, Paediatric Research Group, Department of Clinical Medicine, Faculty of Health Sciences, UiT The Arctic University of Norway, Tromsø, Norway. 322 Presidente, IMLI (Lombardy Medical Initiative), Bergamo, Italy. 323 Pulmonary Division, Heart Institute (InCor), Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, São Paulo, Brazil. 324 Public Health Institute of Vlunius University, Vlunius, Lithuania. 325 Universidade Federal do Estado do Rio de Janeiro, Rio de Janeiro, Brazil. 326 RNA (Réseau National de Surveillance Aérobiologique), Brussel, France. 327 The Hospital for Sick Children, Dalla Lana School of Public Health, University of Toronto, Canada. 328 Immunology, Centro Hospitalar Universitario de Coimbra and Faculty of Medicine, University of Coimbra, Portugal. 329 Department of ENT, Medical University of Graz, Austria. 330 Campania Region, Division on Pharmacy and devices policy, Naples, Italy. 331 Department of Respiratory Medicine, Hvidovre Hospital & University of Copenhagen, Denmark. 332 Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil. 333 Primary Care Respiratory Research Unit Institute Investigaçao Sanitaria de Palma IdS, Palma de Mallorca, Spain. 334 Allergy Unit, Presidio Columbus, Rome, Catholic University of Sacred Heart, Rome and IRCCS Oasi Maria SS, Trona, Italy. 335 Hospital General, Mexico City, Mexico. 336 Regionie Piemonte, Torino, Italy. 337 Medical University of Graz, Department of Internal Medicine, Graz, Austria. 338 Servizio di Immunologia Epatologia Hospital da Luz, Lisboa, Portugal. 339 Hospital de Clinicas, University of Parana, Brazil. 340 Division of Allergy Asthma and Clinical Immunology, Emek Medical Center, Afula, Israel. 341 Honorary Clinical Research Fellow, Allergy and Respiratory Research Group, Institute of Pathophysiology, Laboratory of Endocrinology, Medical University of Vienna, Vienna, Austria. 342 Asthma UK, Mansell street, London, UK. 343 Primary Care Respiratory Research Unit Institute Investigaçao Sanitaria de Palma IdS, Palma de Mallorca, Spain. 344 Medical University of Vienna, AKH, Vienna, Austria. 345 University Hospital of Coimbra, Portugal. 346 Allergy Unit, Department of Dermatology, University Hospital of Zurich, Zurich, Switzerland. 347 University of São Paulo, São Paulo, Brazil. 348 Department of Lung Diseases and Clinical Immunology, University of Turku and Terveystalo allergy clinic, Turku, Finland. 349 Pulmonary Environmental Epidemiology Unit, CNR Institute of Clinical Physiology, Pisa, Italy; and CNR Institute of Biomedicine and Molecular Immunology "A Monnoy", Palermo, Italy. 350 Medical University, Plovdiv, Bulgaria, Department of Otorhinolaryngology, Department of Otorhinolaryngology, University Hospital of Coimbra, Portugal. 351 Division of Otorhinolaryngology, University of Athens, Athens, Greece. 352 Dept of Otorhinolaryngology, Universitätsklinikum Düsseldorf, Germany. 353 Asthma UK, Mansell street, London, UK. 354 Nova Southeastern University, Fort Lauderdale, Florida, USA. 355 Department of
Otaryngology, Yong Loo Lin School of Medicine, National University of Singapore, Singapore. 363Department of Medicine, Clinical Immunology and Allergy, McMaster University, Hamilton, Ontario, Canada. 364Division of Immunodermatology and Allergy Research, Department of Dermatology and Allergy, Hannover Medical School, Hannover, Germany. 365Department of Medicine Solna, Immunology and Allergy Unit, Karolinska Institutet and Department of ENT diseases, Karolinska University Hospital, Stockholm, Sweden. 366Eshelman School of Pharmacy, University of North Carolina, Chapel Hill, NC, USA. 367International Primary Care Respiratory Group IPCRG, Aberdeen, Scotland. 368Bradford Institute for Health Research, Bradford Royal Infirmary, Bradford, UK. 369Allergologyst - Medical College of Medical Faculty, Thracian University, Stara Zagora, Bulgaria. 370Department of Research, Omslo Medical Center, Rochester, Minnesota, USA. 371Cyprian International Institute for Environmental & Public Health in Association with Harvard School of Public Health, Cyprus University of Technology, Limassol, Cyprus; Department of Pediatrics, Hospital 'Archbishop Makarios III', Nicosia, Cyprus. 372Celal Bayar University Department of Pulmonology, Manisa, Turkey. 373The Allergy and Asthma Institute, Islamabad, Pakistan. 374Department of Paediatrics and Child Health, Red Cross Children’s Hospital, and MRC Unit on Child & Adolescent Health, University of Cape Town, Cape Town, South Africa. 375Department of Otologyngology Head and Neck Surgery, Beijing TongRen Hospital and Beijing Institute of OtoInology, Beijing, China. 376Universidad Católica de Córdoba, Córdoba, Argentina. 377University Clinic of Respiratory and Allergic Diseases, Gelnik homes, Slovenia. 378Geriatricsregion Kassel · HRCB Projekt GmbH, Kohl, Germany. 379Akershus University Hospital, Department of Otorhinolaryngology, Akershus, Norway. 380Chief of Staff, the Northern Immunology of the Kazakh National Medical University, Kazakhstan.

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Dr. Zuberbier reports and Organizational affiliations: Committee member: WHO-Initiative “Allergic Rhinitis and Its Impact on Asthma” (ARIA). Member of the Board: German Society for Allergy and Clinical Immunology (DGAKI). Head: European Centre for Allergy Research Foundation (ECARF) Secretary General: Global Allergy and Asthma European Network (GAA4LEN). Member: Committee on Allergy Diagnosis and Molecular Allergology, World Allergy Organization (WAO).

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