

Consultation on the Advisory group report for the Horizon 2020 Societal Challenge on Health, Demographic Change and Well-being		
WHO YOU ARE:		
Pse describe in the box briefly the organisation replying to the consultation (Number and type of Members, Legal status, Sectors of activity...)	<p>The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is an independent non-profit organisation with its central office located in Brussels, Belgium. EFA is a European alliance of allergy, asthma and chronic obstructive pulmonary disease (COPD) patients' associations representing 30% of European citizens currently living with these diseases. Founded in 1991 in Stockholm, Sweden, EFA currently has 41 members in 25 European countries.</p> <p>As a European patient-led advocacy and action organisation, we strive to involve patients with asthma, allergy and COPD in all European decisions that influence their health. Through our members, we advocate and try to ensure that the right and access of people with asthma, allergy and COPD to best quality care, to participate in their care, have a safe environment and to live uncompromised lives is guaranteed by EU decision-makers.</p> <p>Our activities:</p> <ul style="list-style-type: none"> - EFA fosters dialogue, exchange and collaboration among its network of national patients' associations to help people with allergy, asthma and COPD understand, be informed about and continuously take part in the EU legislative process through news, briefings, educational tools, position papers, responses to consultations or advocacy materials - EFA represents patients with allergy, asthma and COPD at high-level fora, such as the European Medicines Agency Patients' and Consumers' Working Party - EFA regularly organizes high level events providing opportunities for stakeholders to come together with a patient-centred agenda on issues under discussion, raising awareness and giving visibility to topics that are crucial for people with allergy, asthma and COPD - EFA develops and promotes long term partnership with health professionals and scientists, industry and third sector organisations active in health, consumption and environment matters to ensure a holistic approach to policy changes affecting patients' health - EFA participates as partner in research projects funded the 7th Framework Programme and Horizon2020: in this context, EFA coordinates the active involvement of patients in research activities, ensuring that patient needs and expectations are met by the project outcomes, and disseminate the project findings to a broader audience and in patient-friendly language - EFA co-runs the secretariat of an Interest Group in the European Parliament composed of Members of the European Parliament committed to tackle asthma and allergy in Europe and to help patients relieve their symptoms. 	
Vertical Themes	YOUR OPINION (on the proposed theme)	YOUR RATIONALE (i.e. The expected impact of your proposed changes on Health, Demographic Change or the Well-being of European Citizens; the possible impact on businesses - in particular SMEs - on economic growth and job creation; the potential socio-economic outcome or contribution to the definition or the implementation of health policies...)
1. Personalised medicine	<p>Personalised Medicine is meant to drive the health research and innovation agenda for the years to come, but further progress is required in order for this approach to benefit the patients. Therefore, EFA agrees with the fact that implementation of personalised medicine is the main research question that should be addressed by 2020.</p> <p>Patient stratification is key, especially in non-communicable diseases (NCDs), such as chronic respiratory diseases, for which early and better diagnosis is crucial for slowing down disease progression and ensure better quality of life to patients. For ensuring successful implementation of personalised medicine, it is important to look at the latest developments in the field and to scale up innovation and technology produced in pilot actions or projects. Some EU-funded projects made outstanding progress in chronic diseases (asthma and COPD) and contributed significantly in bringing personalised medicine at higher level.</p> <p>Europe has the potential to be the global leader in personalised medicine Asthma, for example, as a complex, long-term condition affecting 30 million Europeans, is an ideal condition to exemplify the benefits of personalised medicine at scale. With up to 50% of people responding poorly to steroids, and 5-10% of people for whom no treatments exist, there is a substantial unmet need for asthma research, which can only be met through large-scale, public-private collaboration. By funding research on biological markers and new treatments for asthma, the Commission would also make significant steps towards its goals of advancing innovation in biomarker detection technologies and public trust in personalised medicine.</p> <p>MAIN CHALLENGES IN THE FIELD</p> <p>EFA welcomes the identification of early disease detection, prevention and self-management as main research orientations for addressing the challenge of accelerating medical research. Especially in diagnosis and prevention, the application of computational modelling and the validation of novel biomarkers have the potential to realize major improvements.</p> <p>For what concerns self-management, the design of models for stratifying patients and for predicting the response to treatment, the validation of decision support tools, as well as the study of disease progression and co-morbidities need to be facilitated. For achieving this goal, collaboration among already established consortia and proposals built on the achievements and the knowledge from previous projects (e.g. AirPROM, U-BIOPRED) should be prioritized. Advancing in new technologies, big data and ICT is also crucial to the implementation of personalized medicine. In particular, the use of sensors for the collection of patients' physiological, behavioral as well as environmental data needs to be promoted in all proposals aimed at the developing of novel tools and devices for the self-management of chronic diseases.</p> <p>However, other challenges in the field need to be taken into account:</p> <ul style="list-style-type: none"> - developing awareness and empowerment among all stakeholders, patients and healthcare professionals in particular - bringing true innovation to the market, including regulatory aspects - improving infrastructures and shaping sustainable healthcare system - filling the lack of standardisation of existing diagnostic tests in non-communicable diseases - tailoring the treatment to the patients. <p>Especially in the case of asthma, areas essential for breakthroughs in diagnosis and the development of new treatments:</p>	<p>Examples of successful EU projects on personalized medicine are:</p> <ul style="list-style-type: none"> - AirPROM, funded by the FP7 programme, which contributed to a better understanding of asthma and COPD. The AirPROM project has developed models to predict airways diseases progression and response to treatment: it has been the first study to demonstrate the efficacy of anti-DP2 antibody when airways are inflamed. It also developed the first computational model of thermoplastic, a treatment suitable for some adults with severe asthma. Other models are still under development. The ultimate aims of AirPROM are: to decrease treatment costs by reducing the time spent on clinical trial stages for drug implementation; to develop better treatments for patients; to use newly developed patient screening tools to ensure that each patient receives the right treatment. - U-BIOPRED: funded by the IMI, the project used samples and medical information from hundreds of adults and children with severe asthma and compared them to samples from people with mild asthma, no asthma and COPD, for identifying different phenotypes of severe asthma. <p>These projects achieved outstanding results in computational modelling and in the validation of bio-markers. However, further research and studies need to be conducted to fully understand the complexities of asthma or COPD and to introduce project results in clinical practice. It is therefore necessary to build on this initiatives and to further invest in the research and development of new treatments and better screening tools to reduce the cost of treatment of chronic diseases.</p> <p>It is also important to guarantee continuity in research in Europe by facilitating the collaboration between projects funded by FP7 and existing or new projects under Horizon 2020. One example of this interaction is myAirCoach (funded by H2020), which is aiming at adapting the models developed in AirPROM for developing health support tools for asthma patients to control their disease: new monitoring approaches, combined with the development of novel sensors, will form a system that will address the needs of patients on a daily basis.</p> <p>Funding asthma research is an ideal opportunity to build on the three year, FP7 supported project, the European Asthma Research and Innovation Partnership (EARIP) that has worked to understand the current state-of-play in asthma research and care, looking at current developments and the areas of greatest unmet need for people with asthma. EARIP defines what is needed to reduce asthma deaths and hospitalisations in all EU member states.</p> <p>Following an extensive patient-led consensus, this consortium of the most expert European asthma scientists, industry and people with asthma has produced detailed roadmaps identifying the most promising areas for future asthma research. These roadmaps identified an overwhelming case for research into new biological markers of asthma (e.g. genomics, proteomics and metabolomics) as a tool for diagnosis and/or monitoring, and new treatments for people with severe asthma.</p> <p>The intellectual assets from EARIP, as well as the pan-European coordination it created, provides a once-in-a-generation opportunity to find new breakthroughs for tens of millions of Europeans with asthma – a lifelong, variable condition that affects people of all ages. Completing and following up on such initiatives will contribute to better understanding of disease etiologies and to improved self-management, which will lead to empower patients and enable them to be more involved in clinical trials, with the aims of making safer</p>
2. Rare diseases	NA	NA
3. Research and innovation for infectious diseases	NA	NA
4. Non-communicable diseases	<p>Intervention studies for reducing the morbidity and mortality in non-communicable diseases (NCDs) are indeed necessary: preventive strategies and tailored therapeutic approach should include behavioural interventions but should also examine psychological factors that affect adherence to treatment, especially in specific age-groups. Synergies can be generated with the Personalized Medicine Theme but also with the Big Data Theme.</p> <p>In understanding the role of co-morbidities in NCDs, socio-economic and psychological factors should also be taken into account for reducing the risk of exacerbations.</p> <p>Early diagnosis should also be listed among the research priorities in non-communicable diseases: developing tools for quick, accurate and low cost diagnosis is key to slow down the disease progression and reduce mortality. COPD is a classic example.</p> <p>Other questions to be addressed include:</p> <ul style="list-style-type: none"> - optimizing disease self-management and adherence to treatment; - identify, understand and better classify the different forms of NCDs, their progression, and effect on the immune system; - understand the still unknown causes of some of the most common chronic diseases, such as asthma and allergy. <p>MAIN CHALLENGES</p> <p>Personalized Medicine approaches should be further promoted for tackling NCDs: new proposals should build on the results of previous EU projects that brought innovation in the field and should aim at implementing personalized medicine in clinical practices to the benefit of patients with NDCs. However, we should also be clear that personalised medicine is also to serve in existing treatments, and the goal should not be always new treatments. EFA emphasizes the need for performing prevention trials and screening programmes targeting risk factors that have an impact on chronic respiratory diseases; multimorbidity and its effect on exacerbation of disease should be studied also in COPD. Such programmes and studies should include vulnerable populations (including migrants, ethnic minorities, people who are socially excluded) and address issues such as lifestyle interventions and health literacy. Registries of population with specific chronic diseases should also be promoted as a way to better understand, and thus tackle NCDs.</p> <p>Broader programmes, e.g., European Innovation Partnership, targeting several common aspects in NCDs could also be promoted. Ageing population is one of the main challenges in Europe and therefore it is fundamental to maintain healthy workforce: in this respect, EFA promotes the provision of effective rehabilitation therapies (either hospitalized or ambulant) with any required multidisciplinary intervention to keep people in the working process for as long as possible. At the same time, another challenge is represented by elderly patients with NCDs who, for different reasons, cannot benefit from homecare: it would be interesting to promote further and tailored developments in homecare services for NCDs patients, with the use of eHealth, health and home automation technologies. A common comprehensive approach to tackle NCDs in Europe should be put forward and it should include disease specific best practices, as the Finnish Asthma and Allergy Programmes, the latter being the first and unique in Europe, which have the potential of reducing costs, incidence of diseases and improve health and quality of life of affected patients.</p>	<p>NCDs impose a growing burden on individuals and on the society in Europe. Approximately 10% of all adults in European countries live with COPD, which is the 6th cause of death in the world and, according to the World Health Organisation, it will be the third by 2030, after ischemic heart disease and stroke. Asthma affects 30 million of children and adults under 45 live in Europe: 6 million of them suffer from severe symptoms and 15,000 people die each year from an asthma attack. Respiratory allergy affects 30% of all Europeans; between 10% and 20% of adolescents aged 13 and 14 suffer from severe allergic rhinitis. By 2025, it is estimated that 1 out of 2 Europeans will be affected by a form of allergy. Diagnosis is a main issue in respiratory allergy: 45% of the patients have never received a diagnosis.</p> <p>The economic burden of COPD accounts for 141.4 billion EUR, almost half of the total annual financial burden of lung disease in Europe.</p> <p>Moreover, COPD accounts for more time off at work than any other illness and every year 32.8 billion EUR are lost due to reduced productivity of COPD patients in Europe. The total cost of asthma in Europe is 72 billion EUR per year. Productivity loss due to patients' poor control of their asthma is estimated at 9.8 billion EUR per year. Untreated allergy entails indirect costs between 55 and 151 billion Euros per year. Asthma and allergic rhinitis are responsible for 100 million lost workdays and missed school days in Europe per year.</p> <p>Prevention, early diagnosis and tailored therapies have the potential to reduce consistently these costs and to improve patients' quality of life: for example, it was estimated that with proper diagnosis and treatment of respiratory allergies, 142 billion Euros could be saved every year.</p> <p>In the last few years the European Union has put forward European Innovation Partnerships (EIPs) as initiatives to address societal challenges through public and public involvement in innovation, as well as to enhance Europe's growth and competitiveness. A series of flagship European Innovation Partnerships have achieved important results in other areas, such as the European Innovation Partnership for Active and Healthy Ageing (EIP-AHA), which has already delivered successful outcomes through linking up public and private stakeholders to bring about innovations in the area of ageing. An independent expert group assessed the progress of EIPs in 2014, confirming the soundness of the approach and putting forward recommendations for improvement. The EU-funded project EARIP advocates for the establishment of an EIP in Asthma as a solution for curving down asthma morbidity and mortality by 2020: such programme should be promoted and potentially broadened to other NCDs.</p> <p>Investment aimed at maintaining healthy workforce also have the potential to reduce costs and improve quality of life. According to a study conducted by EFA (Real World Burden of COPD, JHP, December 2013), exacerbations are higher in unemployed COPD patients than employed patients (1.47 x year vs 0.83). Among unemployed patients with exacerbations 16% required hospitalization (vs 8% for employed). Patients who visited emergency department at least once a year due to exacerbation had 11.7 days off work (vs 3.4 for those who did not visit emergency). Unemployed patients have also poorer quality of life indexes: 12.2% of unemployed patients do not have co-morbidities (vs 19.7% in employed) and have greater incidence of depression than those employed (16.3% vs 6.9%).</p>

5. Paediatrics	<p>EFA welcomes the recognition of the importance of early detection and prevention of non-communicable diseases and of the use of eHealth and mHealth solutions for ensuring continuity of care and adherence to treatment.</p> <p>As regards inflammatory diseases, it is important to understand the mechanism of development of fetal and infant diseases, especially asthma and allergy, and to identify lifestyle and environmental aspects that could increase the risk of developing the disease.</p> <p>Improving adherence to treatment in childhood and in particular among adolescents is key to ensure better control of chronic diseases and thus better quality of life in adulthood. Several aspects need to be taken into account and investigated further, including:</p> <ul style="list-style-type: none"> - Promoting multidisciplinary care coordination to better support adolescent patients and to identify those at risk; - Developing Health Information Technologies (ICTs) specifically addressed to young patients to stimulate self-management, medication tracking and immediate healthcare feedback; - Empowering young patients through shared decision-making and tailored health literacy materials to enable adolescents to take responsibility about their own health and medication; - Conducting additional research to picture the long-term consequences associated with poor adherence in adolescence and to curve down the progression of NCDs. <p>An improved system of clinical trials for young patients is also needed to tailor medicines to their needs.</p>	<p>The MeDALL project, funded by FP7, has investigated the underlying mechanisms of development of allergies. MeDALL researchers collected biological information from more than 44,000 children, to build a common database of children in different areas of Europe. Thanks to this unique health data, scientists discovered that an Inge (Immunoglobulin E – antibody) reactivity to several allergen molecules in early childhood is a predictor of developing asthma and/or allergic rhinitis up to the age of 16 and is a supporting factor of disease persistence. This finding has led the MeDALL consortium to develop an allergen chip covering over 175 allergen molecules from more than 40 allergen sources. The chip, which proved to be as sensitive as the best specific IgE test, will contribute to early and cost-effective diagnosis of allergy. Another novel diagnostic tool developed by MeDALL and that could be applied in a clinical setting is the Risk Predictive Test for children, which allows predicting of asthma at school age. MeDALL legacy is represented by the invaluable data that was collected by the consortium researchers: this data should be the basis for the development of future research through other EU-funded projects.</p> <p>Reasons for poor adherence to treatment of adolescents with chronic diseases were recently investigated by EFA through a study which involved 200 young patients with asthma in Europe. Low adherence increases morbidity and medical complications, contributes to poorer quality of life and to an overuse of the health care system. The study indicates two factors that could largely explain variety of adherence: attitude and the daily impact of asthma. Health literacy did not have a direct relation to adherence, but did correlate significantly with attitude, and may thus impact adherence indirectly. Therefore, to improve adherence, today's health literacy needs to be more efficacious. Adolescents' high trust in healthcare professionals indicates the need for them to take on a mentoring role, informing and advising young patients to make well-informed decisions regarding the management of their condition. As non-adherence of adolescents is often non-intentional (forgetfulness), eHealth innovations can provide solutions that can support adolescents to implement reminders and alarms into their daily routine.</p>	
6. Public health and prevention including migration	<p>Prevention is better than cure, therefore public health should look at all risk factors and promote well-being by 2020. Highest priority should be given to the interplay between the person and the environment: air pollution, indoor air quality and pollen concentration cause several health problems and trigger the health conditions of patients affected by chronic respiratory diseases. Stronger measures are needed in Europe for improving the environment; moreover, ICT tools should be developed with the aim of monitoring environmental factors and facilitating individuals' control over their diseases. Prevention should encompass research and actions to tackle all risk factors causing or exacerbating chronic diseases, including exposure to chemicals and second-hand smoke or smoking habits in our daily life.</p> <p>Several programmes have been implemented with success in Europe so far, focused on prevention and early interventions in specific disease areas or with a broader scope. It is important to assess the results of some best examples and promote the adaptation and transfer in other contexts in Europe.</p> <p>RESEARCH GAPS</p> <p>EFA agrees with the gaps identified at the levels of Science and Innovation, Innovation, Market, and Policy. In addition, EFA believes that a change of mindset is needed in order to rethink public health:</p> <ul style="list-style-type: none"> - as an overarching goal, public health should be driven by a patient-centered approach, prioritizing patient needs and rethinking how patients are treating and managing their conditions; - a multi-disciplinary and multi-stakeholder approach should be promoted in the development of public health programmes; - Continuous education should not be restricted to local health authorities, but should be guaranteed as well to healthcare professionals and patients. 	<p>Air pollution contributes to severe chronic disease across the lifespan including cardio-vascular and respiratory diseases, such as asthma, allergies, COPD, lung cancer, impaired prenatal and early childhood development, and other chronic conditions, such as diabetes, liver disease, mental health, obesity and childhood leukemia. The health-related economic costs of air pollution are estimated at between €330 - €940 billion for the EU annually, which is equivalent to 3 - 9% of the EU's GDP. Long-term effects of air pollution exposure include changes in mortality patterns and diseases incidence and prevalence. Short-term effects of air pollution are particularly affecting patients with respiratory diseases. Asthmatics suffer more on or after days with higher pollution levels as air pollution reduces lung function, irritates nose and throat, causes wheezing, coughing, pain when taking a deep breath and breathing difficulties and more in general, it aggravates the symptoms of patients already affected by these diseases.</p> <p>Clean air indoors is crucial for public health and particularly important for vulnerable groups, i.e. babies, children, the elderly, as well as people living with respiratory and allergic diseases. Indoor air quality (IAQ) can be modified today by addressing other variables, such as the building emissions -construction equipment, surfacing materials-, the indoor equipment -furnishing, heating, ventilating. Emissions from cleaning products, releases from cooking and other occupant actions, such as smoking, opening/closing of windows and even individual hobbies are also affecting the quality of the air we breathe indoors. Today, there is evidence showing that various indoor air pollutants are responsible for causing or exacerbating respiratory diseases, allergies, intoxication and certain types of cancer.</p> <p>Information on pollen concentration are fundamental for clinicians and allergic patients to manage allergy symptoms. Accurate knowledge of prevalent aeroallergens can improve the diagnosis and treatment of patients with pollen allergy. Pollen information is key as it enables a timely start of the preventive and symptomatic treatment of seasonal allergy problems.</p> <p>Smoking and exposure to second-hand smoke are major sources of nuisance and exacerbation for people with asthma, allergy and chronic obstructive pulmonary disease (COPD), leading to social, work exclusion and unnecessary illness. Smoking with asthma is associated with a higher degree of asthma severity, worsening of symptoms, increased hospital admissions, accelerated decline in lung function, limited short-term responses to medicines and poorer asthma control. Smoking and exposure to second-hand smoke is a major factor in provoking allergic responses for babies and young children. 40-50% of lifelong smokers will develop COPD, compared with 10% of people who have never smoked.</p> <p>In the context of the EARIP project, EFA assessed the impact of national and regional asthma programmes in Europe (European Respiratory Review 2015; 24). Most of the programmes showed good results towards the reduction of asthma morbidity and mortality.</p>	
7. Active and healthy ageing	<p>Preventing and managing age-related conditions is crucial for facing ageing population. However, EFA stresses the fact that active and healthy ageing starts in childhood, therefore the Active and healthy ageing theme should also focus on strategies for preventing the development of diseases, on early diagnosis and on supporting the self-management and the adherence to treatment among young patients.</p> <p>EFA welcomes:</p> <ul style="list-style-type: none"> - the recognition of the rise of the burden of chronic diseases in view of the ageing population; - the need for patients' and citizens' involvement and empowerment: in this respect, patients' associations can play a crucial role in providing education and in ensuring a support network for all patients, elderly in particular, and should therefore be supported by local, national and European authorities; - the importance of improving patients' involvement in research; - the need for workplace intervention models to prolong active living; - the recognition of the potential of telemedicine, eHealth and other ICT tools for ensuring access to healthcare for all and enabling independent living. <p>However, it has to be noted that many investments have been dedicated so far by the European Union in Active and healthy ageing. A dedicated European Innovation Partnership was established in 2014; specific calls for proposals were dedicated to this theme in various EU-funded programmes (e.g. in 3rd Public Health Work Programme 2015); many best practices have been implemented at regional and national level in Europe thanks to different EU programmes (e.g. INTERREG IVC). For this reason, EFA suggests to address active and healthy ageing as a cross-cutting issues rather than as Vertical Theme.</p>	<p>See above in Pediatrics theme about the adherence to treatment among adolescents</p> <p>See above in Personalized Medicine theme the good example of patient involvement from U-BIOPRED</p> <p>See above in NCD theme about maintaining people in workforce</p>	
Horizontal Themes	YOUR OPINION (on the proposed theme)	YOUR RATIONALE (i.e. The expected impact of your proposed changes on Health, Demographic Change or the Well-being of European Citizens; the possible impact on businesses - in particular SMEs - on economic growth and job creation; the potential socio-economic outcome or contribution to the definition or the implementation of health policies...)	
I. Big data	<p>EFA agrees with the fact that the focus should shift from data generation to data integration and interpretation. More attention should be given to the integration of big data and ICT solutions, computational modelling, nutritional, lifestyle and environmental exposure data.</p> <p>On the other hand, other fundamental research aspects must not be neglected, namely data security and ownership, privacy, ethical and social challenges and needs, patient's benefit, transparency as well as the practicability for the doctors, other providers and patients. Efforts are needed in empowering the patients (and more in general the citizens) and enabling them to store, manage and actively share data.</p>	<p>Research in Europe has generated extensive datasets (see above examples from projects AirPROM, U-BIOPRED, MeDALL). The integration of this data with ICT solutions (e.g. myAirCoach) and other technologies such as computational modelling (AirPROM) will improve disease stratification and pave the way for more personalized medicines, thus resulting in more effective and tailored treatments.</p> <p>Currently, most of the data are owned by companies. Citizens' co-ownership of data and a non-for-profit organisational structure will contribute to overcome the existing lack of trust and enable the active participation of citizens and patients, which is essential for ensuring exploitation of big data.</p>	
II. eHealth, mHealth, ICT	<p>EFA welcomes the recognition of the following main challenges in the field:</p> <ol style="list-style-type: none"> 1. Governance and privacy protection; 2. Quality and interoperability of health data; 3. Adoption and scaling up of innovation and the related research orientations; <p>1. the development of best practices in information governance and in privacy enhancing techniques;</p> <ol style="list-style-type: none"> 2. The participatory design and promotion of interoperability assets; 3. guidelines for assessing the quality and reliability of data generated by ICT tools should be developed and put into practice; 4. developing and integrating evidence of outcomes and value from better integrated and reused health data. <p>EFA strongly recommends to include these aspects as mandatory in all calls for proposals in this field.</p> <p>However, from a patient perspective the main challenge related to the use of eHealth, mHealth and ICT, is the identification of the best tools for managing their conditions, especially the mobile applications market has experienced a great development recently and too many products are available for free or at a very little price. Patients need to be guided in selecting the best tool which must respect the data privacy, needs to be developed according to evidence-based science and MUST be designed with the participation of the patients.</p> <p>Asthma, in particular, is a large, complex and growing global health challenge. It is an episodic condition where severity and risk of a potentially life-threatening attack can vary day by day, season by season and across someone's lifetime. Asthma medication also needs to be delivered variably to manage an individual's asthma "pattern". The sheer variety of inhalers, with their own</p>	<p>The quality and reliability of data generated by ICT tools is an unsolved issue, particular relevant for those tools such as well-being apps that do not fall under the medical devices directive. The European Commission has put in place a working group for developing guidelines on the assessment of this data. However, the application of these guidelines will be voluntary; EFA encourages the European Commission to make further progress in promoting the adoption of the guidelines in view of the development of better applications that will benefit patients and citizens in Europe.</p> <p>Patient involvement in the development of ICT solutions is key for ensuring that future tools developed will meet the real needs of the patients, and will respect privacy and ethical issues. Within the context of the H2020 myAirCoach project, EFA in collaboration with Asthma UK established a group of patients (22 from 6 European countries) who are providing feedback and comments to the research activities. The projects aims at developing a support system for the self-management of asthma that will take into account physiological, behavioral and environmental aspects around the patient. The involvement of the patient in the design of the system, starting from the user needs and requirements, will guarantee meaningful outcomes for the patients. Such approach and methodologies needs to be promoted in all future projects in the field.</p> <p>A focus on asthma allows for the development of consumer ICT technologies such as smart, connected medical devices such as inhalers that will be used by millions. Unlike many other conditions most people with asthma are likely to carry an additional device along with their smartphone at all times - their asthma inhaler. The combination of these factors makes asthma a strong candidate for value demonstration that ICT investments will generate quantifiable organisational and outcome benefits. The complexity of asthma - exemplified by the wide range of triggers opens up a considerable opportunity for the development of smart connected medical</p>	
III. Integration of care	NA	NA	

IV. Environment and health, green solutions and sustainability including climate change	EFA welcomes the recognition of the need of increasing investments in air quality, both outdoor and indoor spaces. Especially in chronic respiratory diseases, asthma, allergy, COPD, poor air quality is a major trigger factor that contributes to the progression and exacerbation of the diseases. Moreover, progress is needed in monitoring pollen concentration: climate change and air pollution make pollen grains suspend in the air more aggressive to human health. People living with asthma, allergy and COPD are the first citizens harmed by dirty air. The symptoms of their diseases may worsen as a result of air pollution.	See above in Public Health Theme about air pollution	
Cross-cutting Issues	YOUR OPINION (on the proposed theme)	YOUR RATIONALE (i.e. The expected impact of your proposed changes on Health, Demographic Change or the Well-being of European Citizens; the possible impact on businesses - in particular SMEs - on economic growth and job creation; the potential socio-economic outcome or contribution to the definition or the implementation of health policies...)	
A. Social Sciences and Humanities, integration, inequalities, migration and ethics	EFA recognizes the importance of: 1. Accelerating genetics, research and SSH (insuring privacy protection in handling/sharing personal data; understanding the interaction between environment/exosome and genes/their expression); 2. Advancing risk research for understanding developmental changes across the lifespan (algorithms to predict risk factors and disorders based on environmental, psychosocial, genetic and behavioural risk factors).	NA	
B. Sex and gender differences in medicine	NA	NA	
C. Commercialisation within "Health, Demographic Change and Well-being"	NA	NA	
D. Encouraging stronger and successful involvement of EU-13*	EFA welcomes the provision of encouraging participation of EU-13. Moreover, EFA strongly encourage the participation to EU research projects of patient organisations from the EU-13 countries. One of EFA main objectives is to reduce health inequalities for people with asthma, allergy and COPD in Europe and this is in line with our goal. Also patient organisations in EU-13 have often less resources than those in EU-15. We also need to recognise that for many patients, the problem is access to treatments that already exist, and therefore the participation and relevant issues for EU-13 in our consultation	Patients in Europe have different needs and different opportunities, including possibilities for accessing care. Therefore EU research should not be restricted to EU-15 but should involve more and more countries that recently joined the EU and that face different challenges. EFA already makes efforts in this field by building capacities of its members and, when possible, by involving them in EU project proposals as partners or third parties. The Patient Access Partnership PACT has been established to address inequalities in access to good quality care in the EU that persist: www.patient+access.eu and is developing work in this field.	
* Countries which have joined the EU in this millennium, i.e. Bulgaria, Croatia, Cyprus, Czechia, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Romania, Slovakia and Slovenia.			