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citizen engagement and mHealth

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myAirCoach - Analysis, modelling and sensing of both physiological and environmental factors for the customized and predictive self-management of Asthma"

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Executive Summary

The present document constitutes the deliverable “D6.1. Assembly of the Consultative Patient Forum” and is connected to Task 6.1 Creation of the myAirCoach Consultative Patient Forum-CPF. This report details all procedures and actions that were undertaken in the context of the establishment of a “myAirCoach Consultative Patient Forum”. All activities have been implemented by EFA as the leader of Task 6.1, in collaboration with project partner Asthma UK.

The Consultative Patient Forum will ensure the provision of patient input throughout the whole project span, as the patient forum will serve to provide feedback on myAirCoach research activities and will contribute to the achievement of the WP’s objectives, from the patient perspective.

Actions put in place included the production of the Terms of Reference of the Patient Forum, the recruitment process and the kick-off meeting.

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List of abbreviations and acronyms

(In alphabetic order)

APF	Advisory Patient Forum
AUK	Asthma UK
CPF	Consultative Patient Forum
D	Deliverable
EFA	The European Federation of Allergy and Airways Diseases Patients Associations
EU	European Union
WP	Work Package
T	Task

1 Introduction

myAirCoach is a European project funded by the EU Horizon 2020 Research and Innovation framework programme that is aiming to develop user-friendly mHealth tools for people with asthma and support them in the self-management of their disease. Therefore, it is of fundamental importance that asthma patients are actively involved in the main phases of the project development, in order to ensure that the final outcomes will address the needs of the asthma community.

For this reason, the project consortium decided to establish a Consultative Patient Forum (CPF) in the context of Work Package WP6. The CPF will include a group of patient experts who will volunteer their time to (1) provide their input throughout the lifespan of the project, (2) assure inclusion of patients' perspective across all project WPs, by commenting on important documents and providing meaningful insights to researchers from the patients' point of view and finally (3) ensure the disease management models will address users' specific needs and will be user-oriented.

Both patient organisations EFA (Leader of Task 6.1) and Asthma UK, thanks to their expertise in patient involvement and to their previous experience in the establishment of the U-BIOPRED¹ Patient Input Platform, worked on the assembly of the Patient Forum, from the elaboration of participants' requirements to the recruitment process, and succeeded to form a group of 22 motivated asthma patients. The first teleconference meeting of the CPF was held on the 9th of June 2015, in accordance with the schedule of the project' description of work.

EFA will coordinate all activities of the Patient Forum for the entire project duration with the support of project partner Asthma UK.

¹ U-BIOPRED (Unbiased BIOMarkers in PREdiction of respiratory disease outcomes) is a research project using information and samples from adults and children to learn more about different types of asthma to ensure better diagnosis and treatment for each person.

2 Terms of Reference of the Consultative Patient Forum

The activities towards the establishment of the Consultative Patient Forum, followed immediately after the myAirCoach Kick-off meeting in Thessaloniki in January 2015 (Month 1). EFA and AUK worked on the production of a document which defines the terms of reference of the Consultative Patient Forum, detailing the objectives, activities, structure and distribution of roles, and lastly the participant requirements. The document was finalised at the end of February 2015 (Month 2), when it was agreed between EFA and AUK to rename the “Consultative Patient Forum” to “Advisory Patient Forum” (APF), to stress more on the patients’ role as ‘Advisor’ providing insights to the partners from a patient perspective, throughout the entire project life-cycle. Finally Appendix 1 “APF Terms of Reference” outlines the next steps and a timeline towards the establishment of the APF.

2.1 Objectives

The objectives were defined according to what was established in myAirCoach Description of Work and are as follows:

- To provide continuous feedback from patient experts to the members of the consortium
- To assure inclusion of the patients’ perspective across all Work Packages (WPs) and throughout the timeline of the project.
- To ensure that the proposed asthma management approaches will address the specific needs of patients, will be understandable for the lay target group and will have adequate adherence for all user groups.

2.2 Activities

The Advisory Patient Forum was established to support the efforts of the project towards the achievement of the above objectives by reviewing and/or providing feedback on relevant project documents and by exploring ideas for new activities or documents. The Advisory Patient Forum will give feedback, on a voluntary basis from the patient perspective on a wide range of issues, for the entire project lifespan and across all Work Packages (WP). The APF will input into the design of the project and advise on issues which are important to patients; including ethics, privacy, usefulness and acceptableness of the proposed measurements and any concerns about the proposed systems.

Moreover, the members of the Advisory Patient Forum will contribute to the promotion of myAirCoach in the translation of research outcomes in patient-friendly language and in disseminating project material through a broader audience (patient organisations, other European projects, stakeholders at national level and their own networks). This work will be strongly connected with WP7 “Dissemination and Exploitation”, which is also led by EFA,

The foreseen means of communication will be teleconferences and e-mail. On the one hand, teleconferences will be held regularly every 6 weeks and will form the main

communication channel to inform the Advisory Patient Forum for the ongoing activities of myAirCoach, discuss sensitive patients' issues, exchange opinions and plan upcoming activities. On the other hand, e-mail will form the main channel for the exchange of documents and necessary internal communication materials.

The activities of the Advisory Patient Forum will be focused in particular on 4 work packages:

- WP1: "User needs, system requirements, architecture"

The key objective of this WP is to define the overall user needs, the architecture, and the system specifications of the myAirCoach infrastructure that will be able to fulfil existing and future users' demands. The APF will contribute to the definition of patients' and users' needs, including their incentives, interests and potential concerns for using technology for the self-management of asthma.

- WP2: "Test campaigns, measurements, clinical analysis"

In the first half of the project, test campaigns will help to ground the foreseen patient models with experimental data. In the second half of the project, test campaigns will involve pilot execution in three pilot sites and will serve both model optimization and validation purposes. The APF will contribute to the achievement of WP's objectives and will facilitate an optimal coordination of WP's activities, including advising on recruitment plans and patient information leaflets for the test campaigns.

- WP6: "Evaluation"

The main objective of this WP is to test the myAirCoach integrated system in validation scenarios, by ensuring compliance with ethics standards. The APF is established in the context of this WP and will contribute to the achievement of its objectives through the optimal coordination of WP's activities, including advising on recruitment plans and patient information leaflets for the pilot campaigns.

- WP8: "Management & Ethics"

The objective of this work package is to guarantee the efficient functioning of the project in order to resolve possible conflicts that may arise and to complete in time deliverables and milestones. In the context of this WP the Ethics Advisory Board will be established to monitor the clinical trials pilot and to deal with ethical issues that may arise in the overall work plan, including: a) privacy and confidentiality protection, b) informed consent, c) incidental findings, d) transparency in the management of the collected data, e) information security, f) Risk assessment and g) delegation of control and incentives. Finally, up to two members of the Advisory Patient Forum will be appointed as member of the Ethics Advisory Board.

The members of the Advisory Patient Forum are expected to invest 4 hours per month in the implementation of the above mentioned activities within myAirCoach. The involvement of the patients will be on a voluntary basis and therefore the members of the APF cannot expect reimbursement from myAirCoach grant for the time invested. On the other hand, when opportunities arise for the APF to promote the project and the patients' involvement in relevant external conferences and events, project partners

EFA and AUK will explore the possibility to reimburse their attendance, and always in agreement with the rest of the consortium members.

2.3 Structure and distribution of roles

Taking into account the previous experience of EFA and AUK with patients' involvement in EU projects, it was agreed that the APF should be composed of up to 15 patients: as this size will guarantee the provision of various points of view and opinions, which will be transformed into profitable discussions and produce meaningful inputs from patient experts. Furthermore, collaborating with a restricted group of 15 patients will facilitate effective coordination and internal communication. Among the members of the APF, one patient will be nominated as chair to facilitate internal communication between the patients and the project partners EFA and AUK.

EFA and AUK are the only project partners involved in Task 6.1. EFA, as leader of the task, will act as Secretariat and will ensure the involvement of the APF in the project by constantly communicating with all WP leaders and with the Ethics Board. EFA will also act as liaison between APF members and be in constant communication with the APF Chair.

EFA will deal with the provision of documents from the project partners to the APF and vice versa: documents from project partners will be translated by EFA in patient-friendly language, will be accompanied by background information, if needed, and will be sent to the APF with sufficient time for review and feedback.

EFA will collect and review all feedback produced by the APF before submitting a consolidated review to the project partners. EFA will ensure internal communication, through e-mails and the provision of teleconferences services, as well as facilitate external communications with other patient platforms established in the context of relevant EU projects and with the general public. EFA Project Manager, Giuseppe De Carlo will be the coordinator and main reference person for the APF.

AUK will act as collaborative partner and will support EFA in all coordination activities. Moreover, AUK will inform of relevant events, training activities and new EU projects of interest to APF Members. AUK Senior Research and Involvement Officer, Courtney Coleman, will be the main AUK's contact person for the APF.

2.4 Participant requirement

As part of the establishment of the Advisory Patient Forum, EFA and AUK developed a role profile for myAirCoach Advisory Patient Forum members to ensure that members of the APF would be able to bring a wide range of experiences to the table, which would lead into meaningful and highly interesting discussions in terms of user needs and their relation to the project's tasks and objectives.

Some of the characteristics were considered essential for involvement:

- Since the project is focused on self-management of asthma, members of the APF must be **patients with asthma**; and therefore, parents of children with asthma or partners of asthma patients are excluded. At the same time, in order to avoid potential conflicts with national legislations on the involvement of

minors, EFA and AUK decided to restrict the recruitment to adults (aged 18 and above);

- The myAirCoach consortium language is English, therefore, to guarantee the full comprehension of and participation in the project, APF members must have a reasonable level of literacy and be able to communicate in English;
- As mentioned in section 2.2, the APF members will communicate by means of teleconferences and e-mails; taking into account that teleconferences can be attended also on-line, it is necessary that APF members have easy access to a computer with internet connection and are able to send and receive e-mails;
- The involvement in myAirCoach will require a time investment of what is estimated to be 4 hours per month (section 2.2): candidates to the APF must ensure their availability.

Other features were considered desirable and were meant to be taken into account if a selection process was required. These features are:

- Have an interest in research and clinical studies, and contemporary changes and trends in the field of healthcare;
- Be willing to familiarise themselves with scientific and medical language;
- Be willing to listen to the views and ideas of others and be able to express their own opinions in discussion;
- Prior experience as a patient representative in EU projects.

3 Recruitment process

The recruitment process started in April 2015 (Month 4). EFA and AUK produced 4 documents in support of this process:

- Official Invitation letter signed by EFA and AUK representatives Giuseppe De Carlo and Courtney Coleman as presented in Appendix 2.
- Role Profile of the APF Members, based on the APF Terms of Reference, presented in Appendix 3.
- The five minutes guide to myAirCoach (Appendix 4), which gives an insight to the project in a lay language and provides potential candidates with the following information:
 - What is myAirCoach?
 - What will myAirCoach do?
 - Why do we need personalized monitoring?
 - What will the myAirCoach personalized asthma monitoring system offer?
 - Who is involved in the project?
 - How will people with asthma be involved in myAirCoach? (Advisory patient forum, Focus groups, Clinical trials)
- The Application Form to assess whether a candidate fulfils all the requirements is listed in the Role Profile. Information requested in the application form includes:
 - Contact details
 - Personal information (Asthma severity; Employment status; English literacy; Access to computer; Availability and special requirements
 - Motivation

The filled Application Forms will be treated according to national regulations on data protection: for this reason, two versions of the application form were produced: one for dissemination and collection for EFA, which refers to the amended 1992 Belgian Data Protection Act (Appendix 5); one for dissemination and collection for AUK, which refers to the 1998 UK Data Protection Act (Appendix 6).

These documents were sent to all potential candidates to the APF among EFA and AUK members and partners, the myAirCoach consortium for further dissemination at national level and other relevant European projects consortium and Patient Platforms involved in research projects on respiratory diseases (e.g. U-BIOPRED Patient Input Platform). The deadline for the submission of candidacies was set at May 5th 2015 (Month 5).

3.1 Results of the Recruitment Process

In total EFA and AUK received 22 candidatures of people with differing levels of asthma severity, varying from mild to severe asthma (7 Mild; 2 Mild to Moderate; 6 Moderate;

1 Moderate to Severe; 6 Severe), from 4 different EU countries: Ireland (6), Portugal (2), the Netherlands (2) and the United Kingdom (12).

Three out of 22 applications raised concerns on the ground of the applicant's profession:

- One applicant is working as Marketing Co-ordinator for medical devices. However, the role of the applicant doesn't deal with product development and the company that the applicant works for is not active in the field of asthma management. Therefore, after consulting the project coordinator CERTH, it was agreed that the applicant's position doesn't represent a conflict of interest and that the applicant is eligible as member of the APF.
- Two applicants are working in the healthcare sector, one as a physician and the other as a respiratory physiologist. On the one hand their profession was considered as an added value because of their expertise and their understanding of clinical issues; on the other hand, their knowledge could influence the other members of the APF who could rely too much on their advice. However, EFA and AUK are certain that the applicants will act in the APF from the patients' perspective and decided to consider them eligible as members of the APF. Where their involvement may affect the activities of the APF, EFA and AUK will take the necessary actions to resolve the situation.

The number of applications (22) is above the target number fixed in the APF Terms of Reference (15). However, EFA's and AUK's previous experience in patients' involvement in EU projects, suggest that during the lifecycle of the project some members could decide to withdraw from the APF, while others could lose interest and motivation, which would limit their active participation to APF activities. For these reasons, EFA and AUK decided to accept all applicants as members of the APF. A personal communication was sent to each APF member on the 14th of May 2015 (Month 5) by the APF Coordinator, Giuseppe De Carlo.

Table 1: myAirCoach APF Members*

Name	Country	Level of English	EU Project Experience
BF	Ireland	native	HIGH - U-BIOPRED
RL	Ireland	native	None
MP	Netherlands	advanced	HIGH - U-BIOPRED / EARIP
UR	Ireland	native	None
MMA	Portugal	advanced	None
EOR	Ireland	native	None
LP	Portugal	intermediate	None
AR	UK	native	HIGH - U-BIOPRED / EARIP
CJ	Ireland	native	None
DG	Ireland	native	None

DH	Netherlands	advanced	HIGH - U-BIOPRED / EARIP
JN	United Kingdom	native	HIGH - U-BIOPRED
KLH	United Kingdom	native	None
AW	United Kingdom	native	Prior professional experience as EU Funding Manager.
TS	United Kingdom	native	None
LS	United Kingdom	native	HIGH - U-BIOPRED
DS	United Kingdom	native	Prior involvement in AUK research projects
DR	United Kingdom	native	None
CF	United Kingdom	native	None
PD	United Kingdom	native	HIGH - EARIP
LB	United Kingdom	native	None
VMG	United Kingdom	native	Prior involvement in 2 AUK research projects
* The current table indicates only the initials of participants in order to protect their privacy			

4 APF Kick-off meeting

Well in time with the proposed timeframe for the assembly of the Advisory Patient Forum (APF), on Thursday the 14th of May (Month 5), the 22 APF Candidate Members were officially welcomed as members of myAirCoach APF and were invited to indicate their availability, through means of a doodle poll, to determine the most suitable date for a kick-off meeting to be held by the first half of June 2015 (Month 6).

Given the short notice, it was decided that the kick-off meeting was going to be held by means of teleconference. The agenda proposed for the APF kick-off meeting was as follow:

- Brief introduction to myAirCoach and the APF
- Updates from WPs (especially those where the APF will input)
- APF Communication tools
- Working methods
- Upcoming activities and deliverables
- Scheduling of the following teleconference

On Tuesday the 9th of June 2015 (Month 6), EFA hosted the first APF teleconference and, together with AUK, introduced the selected candidates to the project and their expected involvement. After a round of introductions, EFA and AUK representatives gave a brief overview of the different myAirCoach work packages, especially those relevant to the APF, where they will give insight from the patients' perspective, and the different communication tools that will be used during the project lifespan, i.e. six weekly (one-hour) teleconferences and e-mails. In addition, a platform dedicated to the APF will be set up on the myAirCoach website and will serve as a repository of myAirCoach documents for APF review.

As agreed during the first teleconference EFA invited APF members to appoint an APF chair and APF representative in the myAirCoach Ethics Advisory Board (Teleconference minutes available in Appendix 7). The APF members were also asked to provide a short biography, which will serve to introduce the APF members to the consortium and all interested in myAirCoach and myAirCoach APF.

Together with the kick off meeting minutes, detailing what was discussed and the next steps, a myAirCoach project briefing was sent to all APF members for their interest. Already a first deliverable would be submitted in the days following the teleconference for APF review. APF members were also proposed to have 2 APF members' testimonies on patient involvement in myAirCoach as a blog entry, in order to bring their expectations of their involvement, at the start of the project, to the fore. EFA, as the secretariat, will collect all their input and communicate this to the project partners.

Conclusion

Great efforts were put in place by the project partners EFA and AUK towards the establishment of the Advisory Patient Forum, and the finalisation of all the required documents, providing a clear framework for the APF, including objectives, activities and responsibilities, and ensured the submission of the Deliverable 6.1 in a timely manner.

The recruitment process was highly successful in terms of number of enrolled patients, their expertise and motivation and also their geographical distribution across 4 different European countries. The recruitment process was also designed to be highly transparent: EFA and AUK evaluated all applications and discussed the main points of concerns. When needed, EFA consulted project coordinator CERTH for advice.

The first Kick-off meeting of the APF was held successfully and laid out a roadmap for immediate actions to be taken by the APF within the forthcoming weeks. The previous experience of EFA and AUK gives them high confidence that the APF will be able to achieve its objectives and will provide meaningful feedback to the project consortium from the patients' perspective. Finally, an annual report is scheduled to collect all APF activities and distribute its outcomes within the consortium.

Appendix 1

MyAirCoach Advisory Patient Forum

Terms of reference

Introduction

MyAirCoach is a project funded by the EU Horizon 2020 programme, which aims to develop a holistic mobile health (*mHealth*) personalised asthma monitoring system. The myAirCoach system will empower patients to manage their own health by providing user friendly tools to increase their awareness of real-time environmental triggers, changes to their asthma symptoms and the effectiveness of their treatments. Feedback from the system will provide valuable advice to help people with asthma to better manage their condition.

Only by involving people affected by asthma we can ensure that myAirCoach addresses the needs of the asthma community – the ultimate beneficiary. The European Federation of Asthma and Allergy Airways Diseases Patients Associations together with Asthma UK, will ensure patient involvement in all aspects of the project through the establishment of an **Advisory Patient Forum (APF)**. This forum will guarantee the inclusion of the patient perspective on all questions and discussions which may impact the project outcomes and will help to ensure that patients' needs and requirements will be fully addressed.

The Advisory Patient Forum will be composed by June 2015 and will be active for the whole duration of the project. Two patient organization partners of the project, EFA (Leader of this specific Task 6.1) and Asthma UK, will coordinate the activities of the APF and will facilitate the regular flow of inputs to the several project work packages. The assembly of the Advisory Patient Forum represents deliverable (D6.1) of the myAirCoach project.

Objective

The Advisory Patient Forum's main objectives are:

- To provide continuous feedback from patient experts to other members of the consortium
- To assure inclusion of the patients' perspective across all project Work Packages (WPs)
- To ensure the asthma management models will address the specific needs of patients and will be understandable for the lay target group

Activities

The Advisory Patient Forum will play a key role in ensuring that our work remains patient-centred. Members of the group will provide **input on a voluntary basis from the patient perspective** on a wide range of issues, including:

- WP1: User needs, system requirements, architecture. The APF will contribute to the definition of patients' and users' needs, including their incentives, interests and potential concerns for using technology for the self-management of asthma
- WP2: Test campaigns, measurements, clinical analysis. The APF will contribute to the achievement of WP's objectives and will facilitate an optimal coordination of WP's activities, including advising on recruitment plans and patient information leaflets for the test campaigns. To ensure that the members of the APF are well prepared to partake in the discussion and provide meaningful contributions, specific training activities and/or information material will be provided by WP2 leader
- WP6: Evaluation. The APF will contribute to the achievement of WP's objectives and will facilitate an optimal coordination of WP's activities, including advising on recruitment plans and patient information leaflets for the pilot campaigns. To ensure that the members of the APF are well prepared to partake in the discussion and provide meaningful contributions, specific training activities and/or information material will be provided by WP6 leader
- WP8: Management & Ethics. The APF will provide up to 2 patient representatives as members to the Ethics Advisory Board in order to fully address any ethical issues

The inputs expected by the APF will consist of reviewing **or providing feedback on relevant project documents** and in **exploring ideas** for new activities or documents. It is expected also that the Members of the APF will **promote the activity of the APF and myAirCoach** project throughout their own channels (patient organizations, other EU projects, stakeholders at national level).

Members of the APF will communicate by means of **e-mail and/or telephone**. EFA will also arrange **teleconferences on a regular basis** (every 6 weeks) in order to keep APF members updated on myAirCoach outcomes and areas for APF involvement.

EFA and Asthma UK will also provide opportunities for sharing experiences and best practices with other patient forums/groups involved in EU research projects (e.g. the **Patient Input Platform** established within the U-BIOPRED project).

The **investment** in terms of time for the Members of the APF is estimated at on average **4 hours per month**

Structure and distribution of roles

The APF will be composed by **10-15 asthma patients** or **parent/partner** of an asthma patient who will be involved in the project exclusively on a **voluntary basis**. The Members of APF will nominate among themselves a **Chair**, who will be the spokesperson of the APF and responsible for the communication with EFA and AUK.

EFA and AUK will respectively serve as **Secretariat** and as **Collaborative Partner** for the APF. Here below a detail of the duties and responsibility of the two bodies:

1. Secretariat (EFA; Coordinator: Giuseppe De Carlo):

- Ensuring APF involvement **across myAirCoach WPs**
- Maintaining communication with **WP1, WP2, WP6 and WP8 Leaders**
- Acting as **liaison between APF Members** and constantly communicating with the **Chair**
- Maintaining communication with the **Ethics Advisory Board**
- Ensuring that project material of interest of the APF is **forwarded with sufficient time for review and feedback** from APF Members
- **Reviewing APF material** produced
- Producing **background or lay documents** when needed
- Providing **teleconferences services** to APF Members
- Ensuring collaboration and communication between the **U-BIOPRED Patient Input Platform** (in view of the establishment of a European Patient Input Platform) and other **patient organizations** and **EU stakeholders**
- **Promoting the APF** towards EFA's members, patients, EU stakeholders and general public
- **Offering financial support** under myAirCoach grant for reimbursing participation in events and activities

2. Collaborative Partner (Asthma UK; Coordinator: Courtney Coleman):

- Collaborating with EFA in **ensuring APF involvement in WP1**
- Informing of **relevant events, training activities and new EU projects** of interest for APF Members
- Supporting EFA in ensuring that project material of interest of the APF is **forwarded with sufficient time for review and feedback** from APF Members
- Supporting EFA in **reviewing APF material** produced
- Participating in and helping to facilitate **teleconferences** with APF Members
- Supporting EFA in producing **background or lay documents** when needed
- **Promoting the APF** towards AUK's members, patients, EU stakeholders and general public

Participant Requirements

Ideal profile of patient representative for the myAirCoach Advisory Patient Forum:

- Members of the Advisory Patient Forum are people aged 18 and above with **asthma**.

- **Prior experience as a patient representative in EU projects** is desirable, but not a prerequisite of membership.
- Members of the Advisory Patient Forum need to have an **interest in the conduct of research and clinical studies**, and **contemporary (technological) changes and trends** in the field of healthcare e.g. mobile health.
- Members of the Advisory Patient Forum will receive specific training from WP leaders, but need to be **willing to familiarize themselves with scientific and medical language**.
- Members of the Advisory Patient Forum are expected to have **reasonable levels of literacy** and to be able to communicate in **English**.
- Members of the Advisory Patient Forum must be **willing to listen to the views or ideas of others** and be able to express their own opinions when appropriate.
- Members of the Advisory Patient Forum will need **easy access to a computer** and be able to send and receive e-mails.
- Members of the Advisory Patient Forum will need to be **available for approximately 4 hours per month**.

Next steps

- Discuss with Asthma UK on how to **involve the APF in WP1** (*March 2015*)
- Launch of the **call for interest** (*March 2015*)
- **Selection** of APF Members (*Early April 2015*)
- Draft **work plan** (*April/May 2015*)
- **Kick off meeting** – TC (*June 2015*)

Appendix 2

Invitation to join the Advisory Patient Forum

Dear asthma patients,

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA)² and Asthma UK³ are inviting asthma patients to join the **Advisory Patient Forum (APF)** of a European research project on self-management of asthma, called **myAirCoach**.

myAirCoach aims to develop a mobile health (mHealth) personalised asthma monitoring system. By giving people live access to information about their environment, their medicines and their body's response to their treatments, myAirCoach will help people with asthma to take the right steps at the right time to stay on top of their asthma and prevent attacks.

Only by involving people affected by asthma can we ensure that myAirCoach addresses the needs of the asthma community. The role of the Advisory Patient Forum is to provide feedback and insight from the perspective of patients to ensure that the myAirCoach self-management system is relevant to their needs and can be used in the real world.

That's why we're writing to you now. If you're interested in participating in the myAirCoach Advisory Patient Forum, please read through the attached role profile and information sheet - this sets out what we aim to achieve, what your responsibilities will be, and what type of experience we're looking for. Please note that you do not need to be an expert in research or medicine to take part.

If you would like to apply to join the Advisory Patient Forum, please complete an application form and send it to us using the contact details below. The deadline for applications is **Tuesday 5 May 2015**.

If you have any questions about joining the Advisory Patient Forum, please get in touch with us.

We look forward to receiving your application.

² EFA is European network of 38 allergy, asthma and chronic obstructive pulmonary disease patient associations in 24 countries. EFA aims to improve the care, participation and environment of people with asthma and prevention. www.efanet.org

³ Asthma UK's is the leading asthma charity in the UK. Asthma UK's mission is to stop asthma attacks and cure asthma. We do this by funding world leading research, campaigning for improved care and supporting people to reduce their risk of a potentially life threatening asthma attack. www.asthma.org.uk

With best wishes,

Giuseppe De Carlo

EFA Project Manager and Coordinator of the Advisory Patient Forum

And

Courtney Coleman

Asthma UK Senior Research and Involvement Officer and Support to the Advisory Patient Forum

For further information please email or call:

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Appendix 3

MyAirCoach Advisory Patient Forum

Role Profile

Introduction

MyAirCoach is a project funded by the EU Horizon 2020 programme which aims to develop a mobile Health (mHealth) personalised asthma monitoring system. By giving people live access to information about their environment, their medicines and their body's response to their treatments, myAirCoach will help people with asthma to take the right steps at the right time to stay on top of their asthma and prevent attacks.

Only by involving people affected by asthma can we ensure that myAirCoach addresses the needs of the asthma community – the ultimate beneficiary. We will ensure patient involvement in all aspects of the project by assembling an **Advisory Patient Forum (APF)**. This forum will guarantee the inclusion of the patient perspective on all questions and discussions, helping to shape the project outcomes and ensure that the myAirCoach self-management system is relevant to patients' needs and can be used in the real world.

The Advisory Patient Forum will be convened by June 2015 and will be active for the whole duration of the project. Two patient organization partners, EFA and Asthma UK, will coordinate the activities of the Advisory Patient Forum and will facilitate ongoing patient input into each area of work.

Objectives of the Advisory Patient Forum (APF)

The Advisory Patient Forum's main objectives are:

- To provide continuous feedback from patient experts to the academic and clinical teams
- To assure inclusion of the patients' perspective across all areas of the project which is divided into work packages (WPs)
- To ensure the asthma management models will be user-friendly and will address users' specific needs

Activities – what will I be expected to do?

The Advisory Patient Forum will play a key role in ensuring that our work remains patient-centered. Members of the group will provide **input on a voluntary basis from the patient perspective** on a wide range of issues, including:

- WP1: User needs, system requirements, architecture. The APF will contribute to the definition of patients' and users' needs, including their incentives, interests and potential concerns for using technology for the self-management of asthma
- WP2: Test campaigns, measurements, clinical analysis. The APF will contribute to the achievement of WP's objectives and will facilitate an optimal coordination of WP's activities. To ensure that the members of the APF are well prepared to partake in the discussion and provide meaningful contributions, specific training activities and/or information material will be provided by WP2 leader
- WP6: Evaluation. The APF will contribute to the achievement of WP's objectives and will facilitate an optimal coordination of WP's activities. To ensure that the members of the APF are well prepared to partake in the discussion and provide meaningful contributions, specific training activities and/or information material will be provided by WP6 leader
- WP8: Management & Ethics. The APF will provide up to 2 patient representatives as members to the Ethics Advisory Board in order to fully address any ethical issues

The inputs expected by the APF will consist of **reviewing or providing feedback on relevant project documents** and in **exploring ideas** for new activities or documents. It is expected also that Members of the APF will **promote the activity of the APF** and **myAirCoach** project throughout their own channels (patient organisations, other EU projects, stakeholders at national level).

Members of the APF will communicate by means of **e-mail and/or telephone**. EFA will arrange teleconferences **on a regular basis** (every 6 weeks), in order to keep APF members updated on myAirCoach outcomes and get feedback from members of the APF.

EFA and Asthma UK will also provide opportunities for sharing experiences and best practices with other patient forums/groups involved in EU research projects (e.g. the **Patient Input Platform** established within the U-BIOPRED project, and the Patient Advisory Group involved in the European Asthma Research and Innovation Partnership (EARIP)).

The **investment** in terms of time for Members of the APF is estimated at on average **4 hours per month**.

This is a voluntary role and we are unable to pay for your time. We are able to pay for reasonable costs, including travel and accommodation costs associated with attending any meetings and events. We'll provide more detail on what expenses you are eligible to claim if you are appointed to the Advisory Patient Forum.

Person Profile – who can get involved?

Members of the Advisory Patient Forum will be people who are affected by asthma. We want to make sure that a diverse range of experiences are represented, including people from different age groups and ethnic backgrounds, and people with mild, moderate and severe asthma.

As a Europe-wide project, we are recruiting patient representatives from across the continent.

We expect members of the forum to meet the following criteria:

- Be an adult (aged 18 and above) with **asthma**.
- Have an **interest in research and clinical studies**, and **contemporary (technological) changes and trends** in the field of healthcare e.g. mobile health.
- Members will receive specific training from academic and clinical partners, but need to be **willing to familiarize themselves with scientific and medical language**.
- Have **reasonable levels of literacy** and be able to communicate in **English**.
- **Willing to listen to the views and ideas of others** and be able to express their own opinions in discussion.
- Have **easy access to a computer** and be able to send and receive e-mails.
- Be **available for approximately 4 hours per month**.
- **Prior experience as a patient representative in EU projects** is desirable, but not a prerequisite of membership.

How to get involved

Before you apply

Please read through the invitation letter and this role description – this sets out what we aim to achieve, what your responsibilities will be, and what type of experience we are looking for.

Application

If you would like to apply to become a member of the Advisory Patient Forum, please complete an application form and send it to the contact details below

The deadline for applications is **Tuesday 5 May 2015**.

Interview

After reviewing all applications, we may invite shortlisted applicants to telephone interviews depending on the level of interest. These will take place on XXX and will last approximately 30 minutes. If there are any times on these days when you would be unavailable for an interview, please let us know when you apply.

If you have any questions or concerns about joining the Advisory Patient Forum, please get in touch with us using the contact details below:

Giuseppe De Carlo: giuseppe.decarlo@efanet.org / +32 (0)2 227 2713

Courtney Coleman: ccoleman@asthma.org.uk / +44 (0)207 786 4940

Appendix 4

The five minute guide to myAirCoach

What is myAirCoach?

European researchers have been awarded over € 4.5 million to create a user-friendly tool to support people with asthma to monitor their condition, improve their asthma control and increase their quality of life.

Funded by the EU Horizon 2020 Research and Innovation framework programme, over the next three years patients, health professionals and researchers will work together to develop a patient-friendly, sensor-based tool to collect clinical, environmental and behavioural data relating a person's asthma, with the aim of improving asthma self-management.

What will myAirCoach do?

MyAirCoach will allow people with asthma to use their mobile phone to help them manage their condition. By incorporating sensors and taking measurements of your physical environment and your asthma symptoms, myAirCoach will be able to give you personalised advice based on your day to day activities and symptoms, straight to your mobile phone.

The sensors and measurements will include, for example, pollution and pollen levels, tracking when and where you take your medication, and lung function measurements which can help to indicate how well controlled your asthma is.

Why do we need personalised monitoring?

Asthma is one of the most common chronic diseases in Europe, affecting over 30 million people. However, we know that everyone's asthma is different and this can make it more difficult to manage. The place where a person lives and works, the weather and season, their age and their emotions (for example work-related stress) can all have an impact on their asthma symptoms and how best to treat them.

This makes every case unique and we know that many people with asthma struggle to manage their symptoms and their medication. Even for an individual patient, their symptoms can vary on a day to day basis which can make managing their asthma more difficult.

In Europe each year there are 500,000 people hospitalised because of their asthma, and 15,000 deaths from asthma. That's why we need to find ways to tailor asthma management and treatment to each patient's needs.

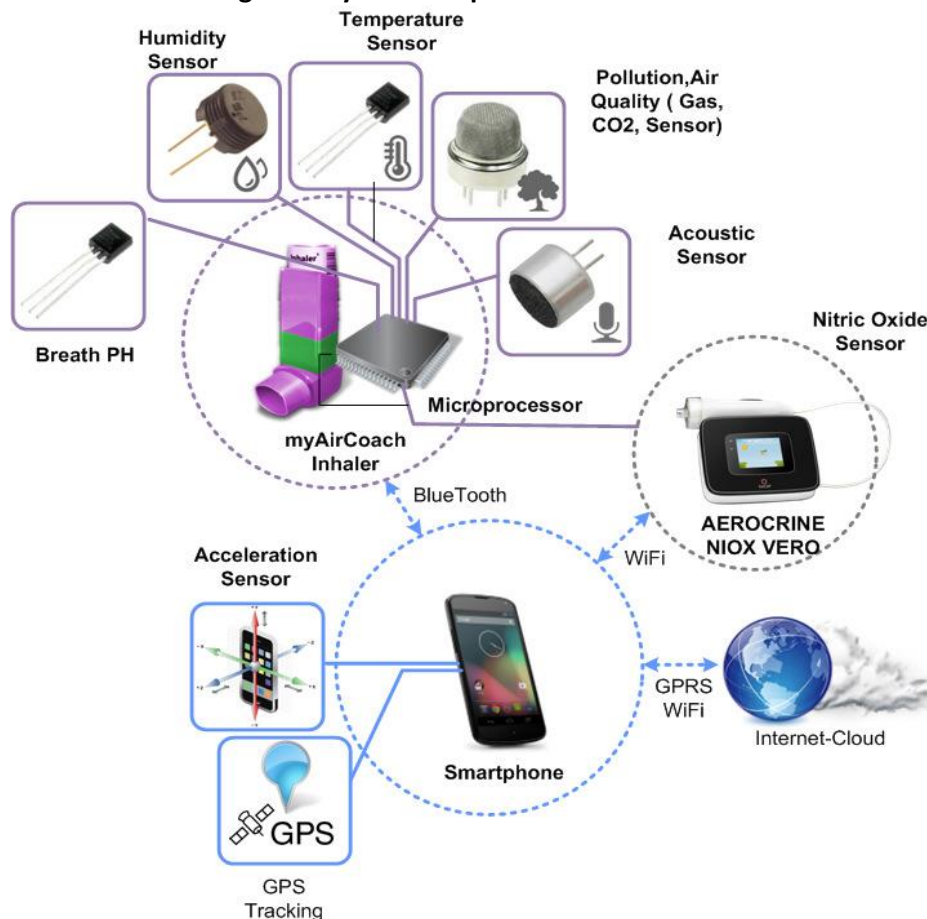
What will the myAirCoach personalised asthma monitoring system offer?

Today, mobile devices can support medical and health practice if the right apps are in place. Mobile or mHealth can contribute to patients' empowerment, enabling them to manage their health more actively and to live more independently. With access to real-time information about their asthma symptoms and treatment, patients will be able to take more informed decisions about their health, with support from health professionals.

With increased demand on healthcare budgets, mHealth can also support healthcare professionals in treating patients more efficiently, as mobile apps can provide information on adherence to treatment and encourage healthy lifestyles.

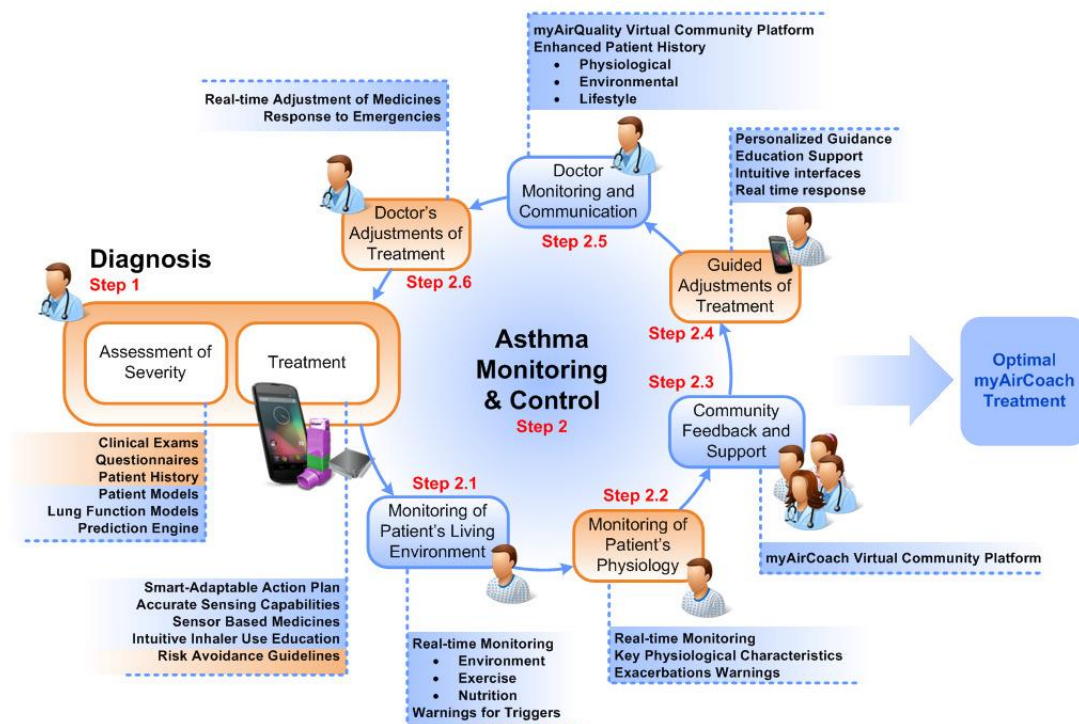
The clinical, environmental and behavioural data provided via the myAirCoach sensors (see image 1 below) will serve as the basis for a digital model that will enable the medical and research community to make accurate predictions of the patient's condition. This might include, for example whether they are at high risk of an asthma attack.

Image 1 – myAirCoach possible sensor network



Patients will receive immediate feedback on how to manage their condition, enabling them to manage their health, reduce asthma symptoms and improve their quality of life (see image 2 below).

Image 2: myAirCoach role in asthma management



Who is involved in the project?

MyAirCoach will run for three years and involves collaborators from research centres, academic organisations, patient organisations, pharmaceutical companies and private medical companies from across Europe.

How will people with asthma be involved in myAirCoach?

Only by involving people affected by asthma can we ensure that myAirCoach addresses the needs of the asthma community. People with asthma will be involved in several different ways, helping to ensure the end product is relevant to patients:

- The **Advisory Patient Forum** will input into the design of the project and advise on issues which are important to patients, including ethics, privacy, how acceptable some of the proposed measurements are and if they have any concerns about the proposed system.
- In the early stages of the project we will hold **focus groups** and conduct a **survey** with people with asthma, to get their feedback on using mobile technology to manage their asthma, how acceptable some of the proposed measurements are, their preferences for managing their asthma, their preferences about what the myAirCoach system should look and feel like, and if they have any concerns about the proposed system.
- Later in the project, people with asthma will be recruited to take part in a small **clinical trial**. This will allow us to test whether myAirCoach is effective in helping people to manage their asthma.

How can I find out more about the project?

To find out more about the project, please visit the [myAirCoach website](#).

Appendix 5

MyAirCoach Advisory Patient Forum

Application Form

Contact details	
Name:	
Address:	
Postcode:	
Country:	
Email:	
Telephone:	
Mobile:	

Information about you	
<p>Please tick</p> <p>*To tick the boxes in the table below:</p> <ol style="list-style-type: none"> 1. Double click on the box or right click and select 'Properties' 2. In the pop-out box under 'Default values', select 'checked' 3. Click 'OK' at the bottom of the pop-out box 	
<p>At what level of severity is your asthma?</p> <p>Please tick</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p>	
<p>Additional information (optional):</p>	
Current profession/position:	
<p>Are you in ...</p> <p>Please tick</p> <p><input type="checkbox"/> Full-time employment</p> <p><input type="checkbox"/> Part-time employment</p>	

☐ Not currently working

At what level is your spoken and written English?

Please tick

Spoken

☐ Native speaker

☐ Advanced

☐ Intermediate

☐ Beginner

Written

☐ Native speaker

☐ Advanced

☐ Intermediate

☐ Beginner

What other languages do you speak?

Do you have access to a computer and/or the internet?

Please tick

☐ Computers

☐ Internet

When do you have access to a computer and/or internet?

☐ All the time

☐ several days a week

☐ Several hours a day

Are there any days or times when it would not be convenient for you to take part in the Advisory Patient Forum?

Do you have any special requirements that we should be aware of? (e.g. disability, caring responsibilities, other long-term health conditions)

Joining the Patient Advisory Group

For each of the following sections, please tell us about any knowledge and experience which you feel are relevant to the work of the myAirCoach Advisory Patient Forum.

Relevant experience may have been gained from your professional, volunteering or personal background.

Please tell us why you want to join the myAirCoach Advisory Patient Forum (no more than 400 words).

Please tell us why you would be a suitable representative for the Advisory Patient Forum (no more than 400 words).

You may wish to tell us about any relevant experience or knowledge including, for example:

- Communication and team-working skills
- Experience of working with a committee or panel
- Ability to act as a patient representative
- Experience of reviewing written documents

Please tell us about anything else that you think is relevant to your application but which hasn't been covered already. (no more than 200 words)

Please send your completed application form to: Giuseppe.decarlo@efanet.org

We would like to keep you updated with the progress of myAirCoach via newsletters and updates by email. Please tick this box ☐ if you would prefer **not** to receive project updates.

Please note that if you choose to complete the above information you are consenting to a confidential record of this information being stored on paper and computer by EFA as joint coordinator of the myAirCoach Advisory Patient Forum. We take great care to safeguard this information and process it according to the amended 1992 Belgian Data Protection Act. Your information will not be passed to any other organisation who is not involved in the myAirCoach project.

Appendix 6

MyAirCoach Advisory Patient Forum

Application Form

Contact details	
Name:	
Address:	
Postcode:	
Country:	
Email:	
Telephone:	
Mobile:	

Information about you	
<p>Please tick</p> <p>*To tick the boxes in the table below:</p> <ol style="list-style-type: none"> 1. Double click on the box or right click and select 'Properties' 2. In the pop-out box under 'Default values', select 'checked' 3. Click 'OK' at the bottom of the pop-out box 	
<p>At what level of severity is your asthma?</p> <p>Please tick</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p>	
Current profession:	
<p>Are you in...</p> <p>Please tick</p> <p><input type="checkbox"/> Full-time employment</p> <p><input type="checkbox"/> Part-time employment</p> <p><input type="checkbox"/> Not currently working</p>	

At what level is your spoken and written English? Please tick	
Spoken <input type="checkbox"/> Native speaker <input type="checkbox"/> Advanced <input type="checkbox"/> Intermediate <input type="checkbox"/> Beginner	Written <input type="checkbox"/> Native speaker <input type="checkbox"/> Advanced <input type="checkbox"/> Intermediate <input type="checkbox"/> Beginner
What other languages do you speak?	
Do you have access to a computer and/or the internet? Please tick	
<input type="checkbox"/> Computers <input type="checkbox"/> Internet	
Are there any days or times when it would not be convenient for you to take part in the Advisory Patient Forum?	
Do you have any special requirements that we should be aware of? (e.g. disability, caring responsibilities, other long-term health conditions)	

Joining the Patient Advisory Group

For each of the following sections, please tell us about any knowledge and experience which you feel are relevant to the work of the myAirCoach Advisory Patient Forum.

Relevant experience may have been gained from your professional, volunteering or personal background.

Please tell us why you want to join the myAirCoach Advisory Patient Forum (no more than 400 words).

Please tell us why you would be a suitable representative for the Advisory Patient Forum (no more than 400 words).

You may wish to tell us about any relevant experience or knowledge including, for example:

- Communication and team-working skills

- Experience of working with a committee or panel
- Ability to act as a patient representative
- Experience of reviewing written documents

Please tell us about anything else that you think is relevant to your application but which hasn't been covered already. (no more than 200 words)

Please send your completed application form to: ccoleman@asthma.org.uk

We would like to keep you updated with the progress of myAirCoach via newsletters and updates by email. Please tick this box ☐ if you would prefer **not** to receive project updates.

Please note that if you choose to complete the above information you are consenting to a confidential record of this information being stored on paper and computer by Asthma UK as joint coordinators of the myAirCoach Advisory Patient Forum. We take great care to safeguard this information and process it according to the 1998 UK Data Protection Act. Your information will not be passed to any other organisation who is not involved in the myAirCoach project.

Appendix 7

APF Kick-off Meeting

Meeting Minutes

09 June 2015, Teleconference

Present:

BF, AR, DH, JN, KLH, AW, LS, DS, DR, CC, GDC, JDV.

Apologies:

RL, MP, UR, MMA, EOR, LP, CJ, DG, TS, CF, PD, LB, VMG.

Advisory Patient Forum Kick-Off Meeting

Agenda

GDC welcomed everyone to the call.

Round of Introductions

All attending APF members introduced themselves and elaborated on their incentives to participate and previous involvement in EU projects (if applicable).

GDC then asked all participants if they would agree to send a short biography, with a picture. All attending APF members were in agreement. **EFA** will follow up on this.

MyAirCoach Project Update

CC gave an overview of **WP01** “User needs, system requirements and architecture” and more specifically **Task 1.2** that is under the lead of Asthma UK (AUK) “user system requirements, clinical procedures and myAirCoach use cases”. Within this task, focus group interviews, a follow-up questionnaire and a focus group guidebook are being developed, with the help of project partners. **CC** elaborates that the focus groups will be held in the Netherlands and the UK and that these will be followed up with a questionnaire.

DH remarks that holding the focus groups only in the Netherlands and the UK will not enable wide European coverage. **CC** agrees to this comment, and informs that we are aware of this issue. However, the focus groups are corresponding to the test campaigns for the system prototype, which will be organised in the UK and the Netherlands. In addition, the follow-up questionnaire on the myAirCoach prototype will enable a wider European geographical coverage, as it will be circulated among EFA and AUK membership.

JDV gave a brief overview of **WP02**; “Test Campaigns and measurements”, which will hold two phases of test campaigns throughout the project, and more specifically **Task 2.1** “Test campaign methodology and planning”, where the APF will have the opportunity to advise on recruitment plans and patient information leaflets for the test campaigns. APF members will have their first opportunity to review a project document: “Test campaign protocol” that was created within this task, in light of the upcoming test campaigns. EFA will follow up on this via email.

Since there is a lot of information to take in, it is agreed that EFA will provide an overview of all project work packages and corresponding tasks relevant for the APF members. (Please find the overview as an annex to this document).

CC then explained how **WP03** encompasses the prototypes and computer modelling for personalised information; physical sensors, heart rate monitors, to check if patients are checking their medication and all of those sensors need to be developed. They will then get to develop this further in the clinical trials.

She then followed up with **WP04**, where a computer model will be developed, that uses all sensing data, which aims to predict when people will have a full-blown asthma attack. In order to predict this, a lot of different data needs to be collected, to help develop a risk prediction model.

Lastly she informed attendees on how **WP05** plans to integrate all collected data and to present it back in an understandable way to the users. That WP hasn't started yet and holds a lot of opportunities for APF members' involvement.

DH comments that it would be very helpful for patients to be included in the development process, as it would make the system more usable.

GDC followed with a brief description of **WP06**, **WP07** and **WP08**.

He explains how **WP06** “evaluation” is related to the testing of the MyAirCoach system in a validation scenario, while ensuring compliance with the ethics standard (including the establishment of the APF). Towards the end of the project there will be a trial operation and field trials with patients to test the prototype.

WP07, which focuses on MyAirCoach dissemination and exploitation activities, will be another interesting opportunity for APF involvement, as they will be able to contribute to the development of patient-friendly myAirCoach dissemination material. The APF will also be invited to present in some multistakeholder conferences, to the extent possible. EFA will try to provide financial contribution from myAirCoach grant for this participation in events and conferences. At the same time APF members are asked for their support in the promotion of MyAirCoach through their own network.

Lastly, **GDC** explained how **WP08** focuses on the management of the project and informed APF members that an ethics advisory board will be established, which will host one APF member. EFA will follow up via email to inquire if someone would like to volunteer for this position. If more than one person applies, a candidate will be chosen based on their previous experience in European projects. **EFA** will also circulate the Ethics, Safety and mHealth Barriers Manual, following its submission.

Communication Tools

GDC explained that APF communication will mainly be done through e-mail communication and via teleconference (TC). We plan to have a TC (approx.) every six weeks - two months.

A specific platform, dedicated to APF’s work, will be established on the myAirCoach website, which will facilitate the sharing and review of myAirCoach documentation. This platform is currently being developed by the project coordinator. APF members will shortly receive credentials to access the intranet, together with some additional instructions.

EFA will coordinate with the different WP leaders, in order to obtain documentation for review by the APF that will be circulated among the members, together with additional instructions (where needed), a roadmap and procedure on how to edit these documents.

GDC then proposed to the attending APF members the appointment of an APF chair, which can stand up as an APF spokesperson. EFA will follow up on this via e-mail.

DH replied that it would be difficult to elect someone, without knowing all APF members involved.

GDC agrees and informs that EFA will circulate a compilation of APF members’ biographies, which will facilitate this process. EFA will follow up on this via email and calls upon interested candidates to volunteer for this position. If needed, in next TC a voting procedure will be organised to elect the chair.

Next Activities

More information on next activities within each WP can be found in the myAirCoach overview (annex).

GDC informs that the next teleconference will be held in the last week of July, and EFA will circulate a doodle poll to determine the most convenient time for the next TC.

GDC will be the main contact for APF members, in case of any questions. More specific questions on WP01 can be directed to **CC**.

DH informed that some of the APF members will be present at the ERS conference and proposes to have an informal myAirCoach meeting. **GDC** informs that at the moment, there are not yet relevant project results to present at ERS conference in Amsterdam. We do plan to disseminate a myAirCoach leaflet/brochure. **CC** informs that for those interested, we can organise an informal APF member meeting, to discuss in person.

Next Steps

- EFA will send out a **DOODLE POLL** to schedule the next APF TC meeting, in the second half of July.
- EFA will invite APF members to indicate their interest to volunteer for the position of **APF CHAIR or APF REPRESENTATIVE** in the myAirCoach Ethics Advisory Board.
- EFA will inform all APF members to send a **SHORT BIOGRAPHY**, together with a picture to EFA.
- The kick-off **MEETING MINUTES**, together with a myAirCoach **PROJECT BRIEFING**, will be sent by EFA to APF members, to give an overview of the different myAirCoach work packages.
- A **FIRST DELIVERABLE FOR APF REVIEW** will be sent to all APF members, together with some additional information by EFA.

Annex I: myAirCoach Project Overview

How will people with asthma be involved in myAirCoach?

The **Advisory Patient Forum** will give feedback for the entire project lifespan across all Work Packages (WP). The APF will input into the design of the project and advise on issues which are important to patients, including ethics, privacy, how acceptable some of the proposed measurements are and if they have any concerns about the proposed system.

Where will the Advisory Patient Forum (APF) be involved in the project?

The APF will be able to bring the patients' perspective to all questions and discussions that may arise during the project and may influence the final output of the project, so that they will be well-received. We have highlighted the work packages where the APF will play a key role in ensuring that our work remains patient-centred.

WP1: "User needs, system requirements, architecture"

The key objective of this WP is to define the overall user needs, the architecture, and the system specifications of the myAirCoach infrastructure that will be able to fulfil existing and future users' demands. It will study and specify the user and system level requirements, in order to define and deliver a number of representative use cases and user scenarios to exemplify the novelties of the myAirCoach framework.

- *T1.1 SoA analysis, technological selection and benchmarking of best practices.*
Under this task, researchers are making a "state of the art" analysis, including all latest developments, in the research area that myAirCoach addresses. The task will contribute to **Deliverable (D) 1.1** "Analysis of user practices" (M6 - June 2015).
- *T1.2 User requirements, clinical procedures and myAirCoach use cases.*
In this task, Asthma UK is collecting and analysing all requirements of the end-users, through surveys, interviews and focus group sessions (in the Netherlands and the UK). The results thereof will feed into the design of the technological system. A set of basic use cases will be created for the pilot operations in the second half of the project.
So far, a draft version of the Focus Group interview, follow-up questionnaire and manual have been developed and subjected to several rounds of review.
- *T1.3 myAirCoach UCD methodology.*
Focus group results will feed into the design of the technological system, in line with a user centred design (UCD) methodology that places people with asthma at the centre of the process. The scenarios collected within this task will be subjected to review by the APF.

*Both T1.2 and T1.3 will contribute to **D1.2** "User requirements, use cases, UCD methodology and final protocols of evaluation studies" (M12 – December 2015)*

- *T1.4 Architecture and system specifications.*
The outcome of *T1.1* and *T1.2* will feed into the system architecture of the myAirCoach platform. This task will contribute to **D1.3** "myAirCoach Technical specifications and end-to-end architecture (first version)" (M12 – December 2015) and **D1.4** "myAirCoach Technical specifications and end-to-end architecture (final version)" (M24 – December 2016)

WP2: “Test Campaigns, measurements, clinical analysis”

The aim of myAirCoach test campaigns will be twofold. In the first half of the project they will serve as to ground the model with experimental data and input into the developed computational models. In the second half of the project, test campaigns will involve pilot execution in three pilot sites and will serve both model optimization and validation purposes.

- **T2.1 Test campaign methodology and planning.**

Within this task a proper test campaign strategy will be developed. The first test campaigns aim to start in October/November of 2015 and will run in two different phases; 1 phase of daily asthma monitoring and secondly an 11-month period of weekly monitoring of asthma control. *So far* a draft test campaign methodology has been developed and will be subjected to APF review. This will contribute to **D2.1 “Report on test campaign Methodology”** (M6 – *June 2015*)

- **T 2.2 Clinical monitoring of patients with asthma.**

Within this task a database of clinical data will be built with the collected data of the test campaigns. This will contribute to **D2.2 “Dietary and nutritional guidelines formalized”** (M18 – *June 2016*) and **D2.3 “Completion of quantification campaigns”** (M33 – *September 2017*)

- **T 2.3 Dietary, nutritional and environmental screening.**

By analysing and modelling the collected data, a personalised assessment of dietary, nutritional and physical activity patterns will be created. This will also contribute to **D2.2. “Dietary and nutritional guidelines formalized”**.

WP3: “Smart sensor-based Inhaler prototype and Wireless BAN Sensor network”

Within this WP the planning and design of the hardware components of the myAirCoach system will be performed. An optimised working prototype will be developed, that will enable the testing of the other components developed in WP4, WP5. After each prototype production phase, a decision on which components better respect user expectations and cost effectiveness will be made, leading to a system that can be tested under real conditions.

- **T3.1 Definition and planning of myAirCoach sensor components.**

Suitable technologies will be evaluated and rated, to decide what technologies will be used for the components of the myAirCoach architecture. This task will contribute to **D3.1 “Definition of sensor components and communication strategy”**. (M6 – *June 2015*)

- **T3.2. Prototype Development and Assembly of the BAN.**

This task will develop a prototype module for the myAircoach system hardware, in compliance with user and system requirements. This task will contribute to **D3.2 “Final Design of the Hardware (Sensing equipment) and the embedded Software”**. (M12 – *December 2015*)

- **T3.3. Algorithm and embedded software development.**

In this task the algorithms and software to process and transmit the collected data will be developed. This task will contribute to **D3.3 “Working prototype with algorithms and software embedded, ready for integration (first version)”**. (M15 – *March 2016*)

- **T3.4. Testing, Evaluation and production.**

This task will involve functional and performance tests of the system

hardware and verification that design/manufacture/assembly of aspects are in adherence with relevant guidelines and regulations. This task will contribute to **D3.4** “Working prototype with algorithms and software embedded, ready for integration (second version)”, “Working prototype with algorithms and software embedded, ready for integration (improved version)” (M24 – *December 2016*)

WP4: “Computational Models, Intelligent information processing and DSS module”

The major aim of this work-package is to generate myAirCoach patient models. All collected data will input into an intelligent information processing system, which aims to predict when people will have a full-blown asthma attack. In order to predict this, a lot of different data needs to be collected, to help develop a risk prediction model.

- *T4.1: Patient modelling and formal representation.*

This task will focus on the definition of a patient model representation format and will contribute to **D4.1** “Patient modelling & representation framework”. (M12 – *December 2015*)

- *T4.2 Signal Processing for extraction of asthma-related indicators.*

The sensing data captured in WP02 will be used for the design and implementation of the algorithms, to “calculate” the predictive value of relevant physiological indicators.

This task will contribute to **D4.2** Signal processing algorithms for extraction of asthma related indicators. (M24 – *December 2016*)

- *T4.3: Multiscale computational modelling of airways and respiratory system.*

This task will develop a multi-scale computational model of the lungs.

This task will contribute to **D4.3** Signal processing algorithms for extraction of asthma related indicators. (M24 – *December 2016*)

- *T4.4: myAirCoach clinical state prediction engine and Risk assessment.*

A clinical state prediction engine will be developed, integrating environmental and physiological data of an individual patient and simulating the behaviour of the computational model of the lung. This task will also contribute to **D4.3**.

- *T4.5 Personalised context-aware, medical information visualization and DSS.*

This task will develop the myAirCoach information visualization and DSS module that is an essential element of the Personal Guidance System. This task will contribute to **D4.4** “myAirCoach Information Visualization and Decision Support System”. (M28 – *April 2017*)

WP5: “Integration and Personalised Guidance System”

The overall aim of this WP, is to implement the Personal Guidance Application, the Virtual community and to orchestrate the system development tasks, to produce an integrated myAirCoach system, taking into account security and privacy issues.

- *T5.1 myAirCoach “Personal Guidance and support” Application.*

The design and development of the cloud-based software module responsible for the customisation, co-design of medical treatment and interaction with the users via a mobile device. This task contributes to **D5.1** “myAirCoach PGS Application”. (M28 – *April 2017*)

- *T5.2 Asthma related mHealth 2.0 Virtual Community.*
The structure of a myAirCoach Virtual Community (MVC) platform, for caregivers, patients, and their families will be developed, in support of interactions among peers having similar health issues, the promotion of positive health-related activities, education and training whenever required. This task contributes to **D5.2** Asthma related Virtual Community. (M32 – August 2017)
- *T5.3 Security and Privacy subsystem.*
Given the sensitive nature of health data, specific and suitable security safeguards will be developed within this WP for myAirCoach solutions. This task contributes to **D5.3** “myAirCoach mHealth Integrated version”. (M18 – June 2016)
- *T5.4 System integration.*
This activity will integrate the developed sub systems and components and prepare the final integrated system. This task will also contribute to **D5.3** and to **D5.4** “myAirCoach mHealth Integrated version (second version)” (M25 – January 2017) and **D5.5** “myAirCoach mHealth Integrated version (final version)” (M32 – August 2017)

WP6: “Creation of the myAirCoach Consultative Patient Forum”

This work package has the objective of testing the myAirCoach integrated system in validation scenarios, by ensuring compliance with ethics standards.

- *T6.1 Creation of the myAirCoach Consultative Patient Forum-CPF.*
The patients’ perspective will be mobilized through the APF, consisting of asthma patients that consistently assist with provision of input across the project’s various work packages. The APF Kick off TC took place on the 09th of June 2015. This task will contribute to **D6.1** “Advisory Patient Forum” (M6 – June 2015).
- *T6.2. Operational planning and Assessment protocol.*
This activity will consist of designing and planning the way the pilot studies will be organized, supported and managed throughout the duration of the project. This task contributes to **D6.2** “Assessment protocol”. (M26 – February 2017)
- *T6.3. Trial operation in semi-controlled environments.*
This task aims to evaluate the first version of the developed system (WP5) in simulated real-life environments and will contribute to the optimization of the manufactured hardware and software components. This task contributes to **D6.3** “Small-scale evaluation report”. (M36 – December 2017)
- *T6. 4 Field trials with patients.*
The final evaluation of myAirCoach will happen through a two-stage clinical trial in the UK and the Netherlands, with ten patients from each centre where the test campaign were organised. This task contributes to deliverable **D6.4** “Field trials report & Soc.-eco. Guidelines”. (M36 – December 2017)

- *T6.5 myAirCoach Evaluation of users' acceptance and socio-economic impact.*
The applicability, acceptance and effectiveness of the overall system will be assessed, as well as the effectiveness of myAirCoach concepts applied in asthma patents and healthcare professionals, through written validated questionnaires, to ensure that these will be understandable for the end users and their carers. This task will also contribute to **D6.3** and **D6.4**.

WP7: "Dissemination and Exploitation"

WP07 aims to (1) raise public awareness of project developments among key user groups, (2) to facilitate sharing of knowledge within the Consortium, (3) to develop a business plan for the project outcomes and (4) to manage Intellectual Property Rights.

- *T7.1 Dissemination activities, material and publication policy.*

To ensure project web presence, a dedicated project website (www.myaircoach.eu) and social media representation (Twitter, Facebook, Youtube, LinkedIn) was established at the start of the project. In addition, a 2015 Dissemination Plan was developed that details the dissemination strategy for 2015. The APF will be able to contribute to dissemination documentation from the project, in order to ensure they are patient-friendly. This task contributes to D7.1 "Dissemination Plan and myAirCoach dissemination material" (M12 – December 2015), D7.2 Project Web Presence (Website, Wiki, Blog, Social Media) (M3 – March 2015) and D7.6 "Data Management Plan" (M24 – December 2016)

What lies ahead?

D7.1. Dissemination Plan and myAirCoach Dissemination Material (M12)

- Asthma Patient Testimony (Blog Entry) (*June 2015*); Blog entry on myAirCoach Concept and Benefits to daily life
EFA will develop guidelines to facilitate blog entry
- myAirCoach Project Brochure / leaflet (*July 2015*)
- myAirCoach Blog & LinkedIn Post "new paths towards mHealth solutions for respiratory patients" (*September 2015*)
- myAirCoach Newsletter (*November 2015*)

- *T7.2 Exploitation and myAirCoach Business models.*

Within this task, different activities will be developed to transfer and promote the further use of the project results of myAirCoach. This task contributes to **D7.3.** "Exploitation Report and myAirCoach Business models". (M36 – *December 2017*)

- *T7.3 IPR management.*

Activities within this task, will aim at ensuring that all project results are formulated and compiled into a protectable form, and all measures necessary to protect the knowledge generated are taken into account before exploitation. This task contributes to deliverable **D7.4** "IPR Protection Plan" (M24 – *December 2016*)

- *T7.4: Standardization and concertation actions.*

The actions within this task; creation of an inventory of existing standards impacting the solutions developed in the myAirCoach and the proposition of new standards or amendments of the existing ones, building upon identified

absent and/or inadequate available standards will be central to myAirCoach standardisation work.

This task contributes to deliverable **D7.5** “Standardisation and concertation activities report”. (M24 – *December 2016*)

WP8: “Management & Ethics”

The management work-package is responsible for guaranteeing the efficient functioning of the project, to resolve possible conflicts that may arise and the timely completion of deliverables and milestones.

- *T8.1 Project Management.*

This task deals with the daily management and control of the project, as well as the liaison with the Commission and external organizations and contributes to all WP8 deliverables.

- *T8.2 Risk management and contingency planning.*

Risk management activities will be performed, by continuous monitoring of the project’s progress. This task contributes to all WP8 deliverables.

- *T8.3 Ethical, safety, mHealth Barrier issues.*

This task will be responsible for providing the Commission with appropriate ethical and safety approvals of the proposed applications at the pilot sites and the establishment of a project Ethics Advisory Board, which will host an APF member. The Ethics Board will monitor the clinical trial pilots and the overall work plan.

Within this task, an “Ethics, Safety and mHealth Barriers Manual” (D8.5.) has been submitted (May 2015).

Core ethical issues that the ethical advisory board will deal with; privacy protection and confidentiality, Informed Consent, Incidental Findings, Transparency of the collected data management by the final system and during its pilots, IT-security and identity management, Risk assessment, delegation of control and incentives.

WP8 deliverables

- D8.1: Project reference manual and quality plan (M3 – *March 2015*)
- D8.2: Periodic Management Reports [6]; issued every 6 months (M18 – *June 2016*, M32 – *August 2017*)
- D8.3: Yearly Project Periodic Reports; issued every year, (M12 – *December 2015*, M24 – *December 2016*)
- D8.4: Project Final Report (M36 – *December 2017*)
- D8.5: Ethics, Safety and mHealth Barriers (regulation, legislation, etc.) Manual; updated version (M5 – *May 2015*; M35 – *November 2017*)