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“Patients Included” in the European Respiratory Society International Congress

Patient involvement or inclusion in medical and healthcare conferences is currently a hot topic [1]. “Patients Included” [2] is a movement that strives to encourage organisers of health conferences to invite patients to the meetings they hold to discuss issues which affect them and ensure they play an active part in them.

The Patients Included campaign has five points which conference organisers must address in order to be recognised, including: 1) patients or caregivers actively participating in the planning of the event; 2) patients or caregivers with experience of the issues participating in its delivery and in the audience; 3) travel and accommodation expenses for patients or carers participating being paid; 4) scholarships provided by the conference organisers to allow patients or carers affected by the relevant issues to attend as delegates; and 5) the disability requirements of participants being accommodated [2].

The European Lung Foundation (ELF) brings together patients and the public with respiratory professionals to positively influence lung health. ELF works all year round with a network of national and European patient organisations representing a wide range of respiratory diseases. ELF also has a growing network of individual patients *via* the European Patient Ambassador Programme (EPAP; www.EPAPonline.org), who take part in different ELF activities.

ELF is in a unique position as it works in partnership with the European Respiratory Society (ERS) and hence has a role to play in the world’s largest respiratory health meeting: the ERS International Congress, which this year took place in Amsterdam on 26–30 September. ELF is supportive of the ideals of the Patient Included campaign; and, as described in a recent rapid response to a *British Medical Journal* article [3], one thing that ELF feels of key note is that the ERS Congress is foremost a professional meeting for the education of healthcare professionals and scientists, albeit one in which patients have a key role to play.

The aim is really to bring professionals and patients together to ensure that the best healthcare is delivered across Europe and the globe. We think that the partnership between ERS and ELF allows for a true integration of patients in an international healthcare conference and has meant that both the professionals and patients are working in unison, often with common goals, aims and ambitions.

In total, more than 90 patients, carers and patient organisation representatives took part in the ERS International Congress 2015. Here follows a summary of the multiple and diverse ways in which they were involved, illustrated with some direct feedback from these individuals and from the healthcare professionals and others who engaged with them during the Congress. It

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Patients are included, welcomed and integrated at the ERS International Congress <http://ow.ly/UpV8A>



ERS 2015

HERMES syllabus link:
modules F.1, F.6, I.4

is hoped that this article will provide key examples to other meetings and conferences and to people involved in ERS.

Diverse and wide patient representation

42 patient organisations from across Europe and the world, with over 70 representatives, took part in the ERS International Congress this year. These ranged from national single-disease organisations to European and international umbrella organisations covering a number of conditions (table 1).

ELF provided free registrations for European patient organisations, with national organisations eligible for a bursary to go towards their travel and accommodation. 16 of these organisations joined ELF in the World Village, a community space for respiratory societies and patient organisations to network, promote their activities and to exchange ideas. At the centre of the World Village was an auditorium for societies, organisations and ERS-supported projects to give short 15–25 minute presentations on their key activities. Presentations were given by nine patient organisations.

Every year, ELF consults the members of its Patient Advisory Committee (PAC) and coordinates a programme of meetings and learning opportunities for them and the other patient organisations attending the Congress [4]. The learning opportunities cover common interest topics, run by patients or organisations who have worked closely with ELF over the year. The patient organisation workshops for 2015 were:

- The James Lind Alliance (JLA) approach to shared priority setting, led by Katherine Cowan of the JLA.
- The role of patients and patient organisations in European Union (EU) projects, led by the Patient Input Platform and patient organisations involved in the U-BIOPRED (Unbiased Biomarkers in Prediction of Respiratory Disease Outcomes) Innovative Medicines Initiative EU project.
- Communications for patient organisations, led by Lauren Anderson, Press and Communications Manager for ERS/ELF.

PAC meeting

ELF involves and disseminates its activities primarily through its PAC, comprised of 15 European patient organisations representing different conditions. The aim is to develop a united voice of respiratory patient organisations across Europe. At Congress, the PAC comes together to hear about ELF's current activities, and input into

upcoming and new ERS/ELF activities. Key items covered were plans for Congress 2016 in London, including discussions on how to expand patient organisation attendance, patient involvement in EU projects from the application to the dissemination phases, and patient involvement in upcoming projects on oxygen and air travel, and occupation and lung health.

International Patient Advisory Committee meeting

For the first time in 2015, ELF held an International Patient Advisory Committee, with a view to meeting with patient organisations from across the globe to network, share ideas and discuss areas of common interest.

19 organisations were represented on the day from across Europe and beyond, including the USA, Latin America and Japan. Lively discussions took place on lung health and the environment, international registries and global issues concerning air travel for respiratory patients with oxygen. Actions to be taken forward included a global survey of patient organisations to find out more about their activities and interests. It was also unanimously agreed that future meetings would be welcomed both at the ERS International Congress 2016, as well as taking other opportunities to meet such as the American Thoracic Society (ATS) International Conference 2016.

A strong patient perspective

Each year, patients are involved as speakers in the scientific programme of the ERS International Congress, both through ELF identifying sessions in which the patient perspective is important and, increasingly, at the request of the professionals proposing the sessions. Patients can give their perspective in two ways.

- As a patient speaker to present the lived experience of a topic or condition to help put the following clinical or research presentations into context. These presentations are usually at the start of a session, and last up to 15 minutes; these include symposia, patient forums and "how-to" sessions.
- As a patient demonstrator to be available to answer questions that the healthcare professionals might want to ask about a condition, treatment, side effect or disease management from the patients' perspective; these include technical skills workshops and courses.

This year there were 14 patient speakers and nine patient demonstrators.

The patient-professional forum this year focused on pulmonary rehabilitation. Two Amsterdam residents with chronic obstructive

Table 1 *National, European and Global patient organisations represented at the ERS International Congress*

Patient organisation	Region
ALAMBRA, Brazilian LAM Association	Brazil
Allergy & Asthma Network	USA
Alpha-1 Plus	Belgium
Amici contro la Sarcoidosi Italia ONLUS (ACSI)	Italy
Apneuvereniging	The Netherlands
ARB-TB	Romania
Asociación Española de Afectados de Cáncer de Pulmón (AEACAP)	Spain
Asociación Nacional de Enfermos de Sarcoidosis (ANES)	Spain
Asthma & Allergie	France
Asthma Society of Ireland	Ireland
Asthma UK	UK
British Lung Foundation (BLF)	UK
Canadian Pulmonary Fibrosis Foundation	Canada
ChILD UK	UK
Cystic Fibrosis Europe	Europe
DSV Deutsche Sarkoidosevereinigung	Germany
European Association of Patients Organisations of Sarcoidosis and other Granulomatous Disorders (EPOS)	Europe
European Federation of Allergy, Asthma and COPD Patients Associations (EFA)	Europe
European LAM Federation	Europe
Federasma e Allergie	Italy
Foundation for Sarcoidosis Research	USA
French Federation of Associations of Patients with Respiratory Insufficiency or Handicap (FFAAIR)	France
Global Allergy and Asthma Patient Platform (GAAPP)	Worldwide
Global Alpha 1	Worldwide
Global COPD	Worldwide
Irish Lung Fibrosis Association (ILFA)	Ireland
Irish Sleep Apnoea Trust (ISAT)	Ireland
Japanese Federation of Patient Organisations for Respiratory Diseases	Japan
June Hancock Mesothelioma Fund	UK
Longfonds	The Netherlands
Lovexair Foundation	Spain
Lung Cancer Europe (LuCE)	Europe
Lungenunion	Austria
NTM Info and Research	USA
PHA UK	UK
Pulmonary Hypertension Latin Society	Latin America and the Caribbean
Sarcoidosis Association Switlerland	Switzerland
Spanish Federation of Patient Associations of Allergy and Respiratory Diseases (FENAER)	Spain
Stowarzyszenie Walki z Rakiem Płuca	Poland
Take That TB	Germany
Vereniging Apnoea Patiënten (VAPA)	Belgium
Voorzitter SBN	The Netherlands



Patient speaker Truus Teunissen discusses how patients and doctors can work together to improve healthcare

pulmonary disease had the opportunity to discuss their experiences of pulmonary rehabilitation in managing their condition alongside one of their healthcare professionals (in one case, a general practitioner and, in another, a pulmonary rehabilitation expert). The session worked well, with the healthcare professionals giving the clinical background of each patient at the start, before the patient spoke about their experiences, including their thoughts and feelings about pulmonary rehabilitation, with the support of their doctors who asked questions throughout. The forum was well attended, with the questions/comments on how to overcome barriers to successful pulmonary rehabilitation at the end showing that delegates were clearly engaged with it.

Feedback received from both the patients and professionals from all sessions was positive:

- One patient speaker stated "Sharing my experience made me believe that I could help the other patients to be more understandable by doctors or the community in general", while a session chair said "It was a brilliant symposium! Thank you to both the patients involved for making this an excellent symposium!"

Guides

The role of guide for patient speakers and demonstrators was new for the 2015 Congress, aiming to ensure that the patient speakers and demonstrators felt comfortable and confident throughout. Nine doctors from Amsterdam who spoke the local language and volunteered to support one or more patients (to meet and greet them, answer any questions, help them upload slides, accompany them to the session, collect burseries, etc.). Patient demonstrators are always recruited from the city/locality of the Congress, and are not required to

speak English; therefore, it is important that their guide is both fluent in the patient's language and English to help communicate between the patient and the course participants. The guides were required to attend training led by ELF prior to the Congress to brief them on the role and orientate them to the Congress centre. In return, the guides receive free registration for the full Congress. This initiative proved a great success from the perspective of the patients, the guides and the ERS/ELF.

Patient and professionals working together

The ERS International Congress is a great opportunity to bring patients and professionals together for shared learning opportunities, especially as patients and professionals can look at issues differently; therefore, a joint approach to a respiratory issue or condition can prove more comprehensive and pragmatic. To this end, patients and patient organisation representatives take part in ERS Task Forces and EU projects in which ERS/ELF are collaborators year round, but Congress is an ideal opportunity to meet face-to-face to progress activities, strengthen and integrate these networks.

EARIP asthma priority setting workshop

ELF, in collaboration with Asthma UK and Katherine Cowan, senior advisor to the JLA, held a multi-stakeholder consensus workshop to look at what asthma research topics should be prioritized in order to have the greatest impact on asthma treatment and management across Europe. The workshop brought together 31 participants (patients, patient organisations, clinicians, researchers and industry) each with relevant experience and expertise. These participants validated and contextualised the priorities, which arose from a wider survey of patient and professional perspectives, as an integral step in the development of the asthma roadmap in EARIP (European Asthma Research and Innovation Partnership), an EU-funded pan-European research initiative.

ELF is now writing up the workshop for the EARIP roadmap for asthma, and a paper on the workshop, which will be co-authored by workshop participants.

Lung cancer workshop

A lung cancer workshop was developed as part of ELF's patient priorities project and brought together 13 members of ELF's lung cancer patient advisory group with 10 healthcare professionals working in the field of lung cancer. The 13 members included patients diagnosed with lung cancer, caregivers and patient organisation representatives.

The main aim of the workshop was to discuss findings from an online questionnaire to patients and caregivers about treatment and care, as well as interview findings from lung cancer healthcare professionals in Europe about multidisciplinary team working. The patient experiences and priorities that were discussed will contribute towards the development of a joint patient-doctor statement on best practice for multidisciplinary teams working in lung cancer care across Europe.

Workshop participants were also asked to give feedback on a demonstration of the latest stage of development of the new lung cancer patient website. We took the opportunity to do some video filming with four of the patients attending the workshop about their personal experiences which will also be included on this website.

Task Forces

ELF attended meetings for eight Task Forces to either discuss patient involvement in new Task Forces or present the findings of involvement in current Task Forces. In total 21 patients and patient organisation representatives contributed to the meetings of Task Forces in non-cystic fibrosis bronchiectasis, severe exacerbation in severe asthma, mesothelioma and sarcoidosis. ELF also presented a poster on the findings of the pulmonary rehabilitation patient experience survey, conducted as part of the ERS/ATS Pulmonary Rehabilitation Policy Task Force.

ELF has found that Task Force meetings at Congress, and the entire Task Force process, are most successful when the Task Force chairs and members are highly engaged with patient involvement and the integration of patient

Table 2 Feedback received from the sarcoidosis and bronchiectasis Task Force members

- This Congress was a great experience for me. I learned and shared a lot of things, and also had the opportunity to meet a lot of great people. Seeing an auditorium full of people interested in bronchiectasis and willing to listen to all what you have to say and share about your work and this disease was just outstanding. As well as it was seeing the involvement and work of all parts in the EMBARC meetings. I'm just so excited about keep on working in this project!
- Marta Almagro, non-cystic fibrosis bronchiectasis patient
- Your contribution was just amazing. I think that we should keep working hard on this collaboration not only for patients with bronchiectasis but also for patients with any respiratory disease within the ERS.
- Stefano Aliberti, non-cystic fibrosis bronchiectasis Task Force member.

perspectives into their work. This was especially reflected in the high levels of satisfaction from patients and professionals involved in the sarcoidosis and bronchiectasis Task Force meetings at Congress (table 2).

Ensuring local public and patients have access to the key messages of the Congress

Not only does ELF strive to ensure that patients can play a part in the ERS International Congress, but also works to explain to patients and the public outside the conference walls the key messages from the meeting. This is achieved *via* the Healthy Lungs for Life campaign (www.healthylungsforlife.org). As part of the campaign, ELF organised a free



Volunteers at the public lung function event leading the way in taking the active option (left) and Hendrien Witte of Longfonds speaking at the meet the expert evening at the University of Amsterdam's Academisch Medisch Centrum.

public lung function testing event and a "meet the expert evening" for patients, in partnership with the local respiratory patient organisation, Longfonds (www.longfonds.nl).

Public event

The public lung function testing event took place across two sites in central Amsterdam, on Dam Square and Beursplein, on Saturday 26 and Sunday 27 September. Members of the public were able to come to the event and have their lung function tested, take part in physical activities and classes, and learn more about how to ensure they are being active in clean air. The event was hugely popular, with almost 1200 lung function tests being performed across the 2 days. Many more people also took part in physical activity demonstrations, an interactive bike challenge and photobooth. They also had the opportunity to find out more information about lung health and how air quality is measured.

Expert evening

We also held an extremely well-attended meet the expert evening on Monday 28 September, at which local patients learned about the latest lung health research being presented at Congress, and about the importance of exercise and clean air to the lungs. The event was attended by more than 130 patients from the Amsterdam area. Both during and after the presentations, patients had the opportunity to ask questions of leaders in the field.

Healthy Lungs for Life cycling and walking routes

One of the legacies that the campaign left in the city was two Healthy Lungs for Life routes. Prior to the Congress, volunteers from Longfonds and

local universities monitored air quality along a cycling and a walking route in the city of Amsterdam. These routes were followed by volunteers daily over a course of 4 weeks to ensure that a full picture of the air quality was mapped on different days, in different weathers.

Air quality was based on measurements of black carbon taken with equipment supplied by VITO. When these data were combined with the annual exposure levels based on air pollution models from TNO, the team was able to modify and alter the routes to ensure that all bad air quality hotspots could be avoided and two Healthy Lungs for Life routes were developed. The routes were incorporated into the city tourist map by iAmsterdam (www.europeanlung.org/assets/files/healthylungsforlife/amsterdam-map-take-the-active-option.pdf).

Looking forward

So, are "patients included" in the ERS International Congress? Yes; included, welcomed and integrated! Fostering the relationships between healthcare professionals and patients is key to the future of lung healthcare, finding solutions to chronic conditions from both the professional and patient perspective will only be possible through integration, dialogue and interaction.

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Conflict of interest

P. Powell and S. Masfield are employees of the European Respiratory Society.

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