

ELF Patient Organisation Networking Day 2022

Self-management

Introduction

ELF Patient Organisation Networking Day 2022 was held on Wednesday 31 August 2022. The event focused on the theme of self-management. The programme included presentations from researchers, patients and patient organisations, and interactive polls and breakout discussion groups.

[Recordings from the event are now available from the ELF website.](#)

Attendance overview

125 people registered for the event. 77 individuals attended the event (62% of those registered), representing 28 countries and regions. 54 attendees represented local, national or international patient organisations; 9 attendees were individual patients; 9 were healthcare professionals and 2 were unknown.

The event webpage had 1,212 views.

Online posters and videos

Organisations from the ELF Patient Organisation Network were invited to submit a poster and short introductory video to showcase their work on the area of self-management. We received 9 posters and videos in total. The posters and videos were added to the ELF website event page and used in the weeks leading up to the event on social media to promote the event and encourage engagement with the topic of self-management. The posters webpage had 692 views, with the videos receiving 275 collective views on YouTube and 1,537 on Twitter and Instagram. The most viewed video was 'Living well with COPD in Switzerland' by the Swiss Lung Association.

The inclusion of introductory videos was a new initiative for 2022, following the suggestion of the Patient Organisation Networking Day working group. The videos received were high quality and allowed us to put together a varied promotional teaser campaign in the weeks leading up to the event.

Presentations

ELF Patient Organisation Networking Day 2022 included inspiring talks from experts in self-management, people living with lung conditions and patient organisations active in this field. A summary of each presentation is set out below and full recordings of all presentations are available on the [ELF website](#).

Interactive polls were included by several speakers to keep the audience engaged, and to understand their knowledge and experience of the topics addressed. Results of the polls for each speaker can be found in the relevant section below.

ERS President Address, Professor Marc Humbert (France) and Professor Carlos Robalo Cordeiro (Portugal)

- Highlighted major successes from 2022 including the launch of the [International Respiratory Coalition](#) and [Lung Facts website](#), providing crucial data to improve respiratory advocacy;
- Self-management, patient and carer empowerment, and integration of multi-disciplinary healthcare teams are crucial to improve respiratory care;
- Looking forward to increasing activities in priority areas including rare diseases and climate change, building on strong advocacy efforts from the patient community and working in partnership with European Lung Foundation and European Respiratory Society.

Self-management in people with chronic lung disease: from theory to implementation, Dr Tanja Effing-Tijdhof, Flinders University and University of Adelaide (Australia)

- Defining self-management for chronic respiratory diseases, including key features of effective interventions and models to support behaviour change;
- Considerations around implementation of and adherence to self-management interventions, including barriers and facilitators and tools to optimise use.

Poll 1: What is according to you the most important barrier for individuals to adhere to a self-management intervention?

(Dr Tanja Effing-Tijdhof)

Lack of professional support	30%
Individual's health literacy	22%
Accessibility of interventions	12%
Complexity of interventions	8%
Individual's mental health	8%
Lack of social support	6%
Individual's physical health	6%
Interventions focus too much on a single disease	4%
Individual's time (management)	2%
Other	2%

Patient perspective on self-management, Ilan, cystic fibrosis patient advocate and Israel Cystic Fibrosis Foundation (Israel)

- Insights into self-management practices, including home monitoring tools and daily self-management activities;
- Advantages and challenges of self-management, including the ongoing importance of support and interaction with healthcare teams.

Tips and Trips with Self-Management, Tessa Jelen, Asthma and Lung UK Westminster Support Group (UK)

- Learnings around the self-management support needs from a community patient group, including communication needs and challenges, referral pathways and support needs of home oxygen users;
- Self-management experiences of patients during the COVID-19 pandemic, support systems developed by patient organisations and recommendations for healthcare professionals.

Italian Sleep Apnea Association, from Screening Web App project to Apno-Point the digital volunteer, Luca Roberti, Apnoici Italiani (Italy)

- Development of a digital screening tool, supporting people with suspected sleep apnoea to assess their symptoms using validated questionnaires;
- Launch of digital information points in hospitals and clinics providing self-management information and guidance for those undergoing diagnostic testing or treatment for sleep related disorders.

Poll 2: In May 2021 new regulations came into force to increase security for medical devices. But this means 24,000 devices will require recertification within 2024, posing serious problems for patients. How knowledgeable are you on the matter?

(Luca Roberti)

I don't know anything about it	55%
I am aware, but not thoroughly	30%
I am quite knowledgeable	15%

The evolving self-management needs of cystic fibrosis communities in Spain and Greece, Carlos Pons, Respiralia Foundation (Spain) and Anna Spinou, Hellenic Cystic Fibrosis Association (Greece)

- A joint presentation highlighting the changing support needs of cystic fibrosis patients in Spain and Greece since the introduction of Kaftrio, a new drug which has revolutionised treatment outcomes for people with CF.
- Development of new self-management support tools provided by patient organisations to target the evolving needs of their patient communities, including physiotherapy and mental health support.

Online respiratory physiotherapy programme, Armando Ruiz, Spanish Federation of Allergy and Airways Diseases Patients' Associations (FENAER) (Spain)

- Development of online physiotherapy programme for people living with chronic respiratory diseases in response to poor access to in-person sessions;
- Targeting new and hard-to-reach audiences through translations and awareness-raising activities.

Poll 3: Is access to physiotherapy in your country's health system a problem?

(Armando Ruiz)

Yes	62%
No	38%

Poll 4: Is it time to join efforts and resources to organize ourselves and implement projects with global impact?

(Armando Ruiz)

Yes	92%
No	8%

Interactive breakout groups

During the ELF virtual Patient Organisation Networking Day on 31 August 2022 attendees discussed the following questions in 8 breakout groups:

1. What experience have you had with self-management in your patient community?
2. What are the barriers to self-management, and what solutions have you found to overcome them?
3. Have there been changes to self-management approaches in your patient community since the pandemic?"

Interactive breakout groups had between 3 – 5 in most groups. Facilitators commented that this was a good number and allowed for more in-depth discussions than previous years. The breakout discussions and plenary were rated highly by attendees.

The main discussion points arising from these questions have been summarised and grouped into the themes below in this report.

Key points included:

- range of facilitators to support self-management;
- mental health as a key component of supported self-management;
- the importance of working in partnership with people living with respiratory conditions to co-produce self-management resources;
- barriers to self-management including funding, a lack of investment in health services and disparities in access;

- the importance for patients to have a good knowledge and understanding of their disease;
- the unique self-management challenges for people living with a rare disease;
- difficulties fitting self-management into daily life;
- self-management challenges when transitioning from children's to adult services;
- lack of training and understanding from healthcare professionals.

Digital health and technology are now considered key components of supported self-management and reflected on the ways patient communities and organisations have adapted to an increasingly digitised health system. Concerns around privacy, trust and compliance with the EU data protection legislation (GDPR) remain.

Patient organisations noted a wide range of changes to self-management support during and following the COVID-19 pandemic, and they want lessons learned from the pandemic to be built on to improve health services for future.

Summary of key discussion points:

All participants had experience of self-management, either as individual patients or through their involvement with advocacy organisations. Most patient organisations provide some resources, information or activities to support self-management in their patient community, and consider in-person and online peer-to-peer support and collective self-management approaches beneficial. Peer support initiatives are particularly important for people living with a rare disease in tackling isolation and providing a forum to share experiences and meet with others.

Facilitators to support self-management highlighted by participants included developing a sense of shared responsibility between patients and professionals, for example to continue physiotherapy at home, and motivating patients to actively engage in self-management activities. This was framed as 'mobilisation', 'motivation' and 'activation'. One organisation's self-management programme requires patients to commit to doing 'homework' and regularly demonstrate their ongoing learning – those not maintaining their participation are not allowed to continue the programme. The organisation reported that this approach increased adherence and supported patients to develop a sense of 'co-responsibility'.

Access to multi-disciplinary healthcare teams was considered important, including access to psychological and physiotherapy professionals.

Some participants reflected that it can be easy to feel overwhelmed by the burden of self-management. Some patients appreciate activities and resources which integrate a sense of humour or lightness into self-management programmes.

Patient organisations across all respiratory disease areas place an emphasis on **mental health as a key component of supported self-management**. Patient organisations reported that the mental health impacts of living with a chronic respiratory disease are wide-ranging, often compounding the burden of the respiratory disease and depression is a common co-

morbidity: “I feel my patient community has grief for the life lost”. Participants also discussed the unexpected psychological consequences of receiving support, for example when a patient is able to engage in activities they were previously unable to following a rehabilitation programme, they may blame themselves for not seeking support sooner. Access to mental health professionals is crucial for respiratory patients, however resources are often insufficient to meet demand. The ongoing impact of the COVID-19 pandemic has led to an increase in poor mental health among respiratory patients and organisations advocate for increased referrals to psychological support services.

Working in partnership with people living with respiratory conditions to develop self-management approaches was considered important. Some organisations had experience of using co-production methodologies to develop patient education resources. Working in partnership with patients can be an effective way to ensure support systems fit with the day-to-day reality of living with a respiratory disease. Participants had experience of ineffective self-management resources because they were not created, shared and talked through in an accessible way. Suggestions of integrating patient experiences into self-management tools included the use of illustrative examples, for example outlining what to do in specific scenario to self-manage their condition. This could help to make the information less abstract and support people with respiratory conditions to relate differently to their self-management plans.

Participants discussed a **wide range of barriers** they have encountered when supporting self-management in their patient communities. **Funding and a lack of investment in health services was considered a major barrier**, with insufficient training for professionals and poor access to services such as physiotherapy, pulmonary rehabilitation, mental health and specialist or centres of excellence, particularly in rare diseases. **Disparities in access which patient organisations have observed for their communities include rural, digital, socio-economic, age, health literacy, language and ethnic inequalities.** The current cost-of-living crisis is a concern for patients using medical devices at home such as CPAP machines and nebulisers. Patient organisations and ELF could address these concerns by showing the energy usage of different devices compared with other daily household items.

Some patient organisations have forged successful partnerships with private companies to develop their own self-management programmes, including providing physical and virtual physiotherapy sessions. Patient organisations generally avoid charging patients directly for their services, although some self-management support services require payment which can be a barrier to access for many.

Knowledge and understanding of their disease is an important basis for patients to develop good self-management routines. Participants felt this can help patients to understand the impact of their disease and how different self-management practices target specific aspects. Often it can take time to notice the benefits of self-management activities, such as breathing or physical exercises, so having an underlying knowledge of the disease course can help.

Participants from rare disease communities reflected on some of the **unique self-management challenges for people living with a rare disease**. A lack of awareness about the disease, symptoms and optimal self-management practices from healthcare professionals and patients can be compounded by friends and family not being aware of the disease because of its rare nature: “they know I have a bit of a lung thing”. As a result, the patient and their support network may not know about resources or guidance available to support self-management. Rare disease communities recognise that there are career disadvantages for healthcare professionals who choose to focus on a rare lung disease, as there are fewer opportunities for funding and career progression. This compounds the challenges of living with a rare disease.

Fitting self-management into daily life is a challenge for patients who have a range of other work, caring and family responsibilities. Patient organisations note that when patients in their community experience a downturn in their health, such as during times of exacerbation and when dealing with pre-existing mental health issues, patients can find it hard to maintain their self-management routine, particularly if they have no wider support network. Equally, **when they feel well, some patients de-prioritise self-management** activities which may put them at risk of future deterioration. Fear of being a burden to family and loved ones may prevent some patients from asking for support to manage their health. Patient organisations noted that it is important to allow for individualism and tailor self-management support to the needs of each patient.

The difficulties in transitioning from children’s to adult services were highlighted, particularly in terms of young people taking an active role in managing their health. Parents are often heavily involved up to adulthood, but then young people are expected to manage themselves without further tailored support and education.

Lack of training and understanding from healthcare professionals was considered a barrier across the spectrum of disease areas. Patient organisations serving rare disease patients have found that, outside of the centres of excellence, some healthcare professionals lack knowledge and experience of supporting self-management. For example, participants reported that family doctors sometimes told patients to rest and avoid exercise which is the opposite of the clinical practice guidelines and centre of excellence advice for that disease area. Training for healthcare professionals in communication skills was also considered an important pre-requisite to provide quality self-management support.

Digital health and technology are now considered key components of supported self-management toolkits. Patient organisations reported that the use of home monitoring tools, such as apps to track pollution levels, home spirometry testing and digital tools to monitor respiratory symptoms and quality of life are widespread. Challenges remain however, including digital exclusion due to cost, technical ability, access to the internet and lack of availability in the patient’s preferred language. Some patients report a triggering effect and poor mental health when home monitoring tools signal a deterioration in their health, for example when they note reduced lung function. Home and digital tools should not be used to replace support from healthcare professionals, and many organisations

reported concern around a lack of oversight from professionals. Questions remain around the quality of self-generated health data and the possibility of linking to individuals' electronic health records, however some patient organisations reported that new technologies had 'changed the conversation' between patients and professionals by allowing patients to share real-time data with their doctor. Ultimately, each patient's engagement with digital health is different and may vary over time according to their disease progression and wider priorities. Patient organisations and healthcare professionals must allow individual patients to recognise what works for them.

Concerns around privacy, trust and compliance with the EU data protection legislation (GDPR) remain. There is still uncertainty amongst patients and patient organisations about how data can be shared, who has access and third-party data use.

Many patient organisations and communities have embraced digitalisation in their support and education offerings which has allowed patients, for example from rural areas and rare disease communities, to bridge geographical divides. Patient organisations are conscious of digital exclusion and recognise that not all patients can and want to access self-management support online or through digital tools. Some organisations reach out by telephone to those unable to interact online, while others have set up a 'buddy' system for less confident patients to receive support from a more digitally-experienced peer. In order to expand their digital offering, most patient organisations sought technical support via volunteers or paid support. Certain activities, such as pulmonary rehabilitation, require careful consideration if offered remotely as providers cannot assess the individual patient's health or make adjustments to exercise techniques in the same way. Overall, patient organisations seem to have found a balance between offering a mix of physical and digital resources with the aim of reaching as many patients as possible. Engagement with digital services, such as online Zoom meetings, continues to change and several patient organisations reported fatigue amongst patient groups for online events and a strong desire to return to face to face interactions. Nevertheless, many patient organisations have engaged new audiences through the use of digital tools and anticipate hybrid ways of working continuing into the future.

Patient organisations noted a wide range of changes to self-management support during and following the COVID-19 pandemic. Some patients totally lost contact with healthcare professionals when services moved to telephone or online. One organisation is piloting a scheme where healthcare professionals create a referral to a patient organisation's peer support service to alleviate isolation and support self-management. Some patient organisations reported changes to the way health decisions were made by professionals, for example they have seen an increase in medication changes without discussion with the patient, which is concerning. Those communities who already had established systems of online self-management support, such as remote physiotherapy, were well-placed in the pandemic thanks to high confidence levels amongst patients in using digital tools.

Patient organisations and patient communities want the lessons learned from the COVID-19 pandemic to be built on to improve health services for future. Some felt the pandemic pushed services to be more forward-thinking in terms of patient choice and working around people's needs, and this should be retained in future service design. Challenges around remote pandemic healthcare included miscommunication between healthcare professionals and patients, for example expecting patients to have taken their own blood pressure prior to a telephone appointment, resulting in delays and frustration. Some respiratory patients were at particularly high risk from COVID-19 and it was important to them to see initiatives to help them manage risk and understand what safety precautions were in place to ensure they could continue to access medical care. COVID-19 was a very worrying time for respiratory patients and patient organisations reported that some of their community members have lost their confidence in managing their health and are seeing a rise in poor quality of life. Some patient organisations reported a downturn in the level of monitoring respiratory patients are receiving since pandemic restrictions have been lifted, which may be a cause for concern, for example some patients are now having less contact with their healthcare professionals. Patient choice is crucial and services should cater to individual preferences of online or in-person settings.

Areas for ELF and ERS to consider are as follows:

Mental health support services:

- advocacy actions to call for increased access and investment
- research to better understand the mental health needs of respiratory patients.

Training and education for respiratory and primary healthcare professionals on:

- supported self-management approaches for respiratory patients
- awareness of rare disease
- clinical practice guidelines on optimal self-management approaches for different respiratory diseases.

Advocacy efforts to raise awareness of:

- Lack of funding for respiratory health services and inequalities in access.

Information for patients on:

- Cost of using electronic medical devices during the cost-of-living crisis

Evaluation

On the day feedback

Attendees were asked at both the beginning and at the end of the event about their knowledge of ELF and of self-management. This allows us to understand how effective the

event was at increasing knowledge. Overall, participants increased their knowledge of ELF during the course of the event:

Poll 1: How much do you know about the work of European Lung Foundation?

	Start of the event	End of the event
I know a lot about ELF	38%	65%
I know a little about ELF	47%	32%
I know very little about ELF	13%	3%
I know nothing about ELF	2%	0%

Participants also reported an increase in their knowledge of self-management for lung diseases thanks to the event:

Poll 2: How informed do you feel about self-management for lung diseases?

	Start of the event	End of the event
Very well informed	25%	39%
Quite well informed	49%	61%
Quite uninformed	25%	0%
Very uninformed	2%	0%

Confidence in sharing knowledge with their patient communities also increased to a similar degree:

Poll 3: How confident are you in sharing your knowledge of self-management with your patient community?

	Start of the event	End of the event
Very confident	30%	42%
Quite confident	45%	55%
Not confident	25%	3%

We asked attendees about their preferences for future events and their overall impression of the event, with the following results:

Poll 4: Would you prefer ELF Patient Organisation Networking Day to be held:

Online, like today	38%
In person at a face-to-face event	45%
No preference	17%

Poll 5: How helpful did you find today's event?

Extremely helpful	38%
Very helpful	59%
Somewhat helpful	3%
Not so helpful	0%
Not at all helpful	0%

Post-event feedback

Following the event, all registered attendees were sent a feedback survey. 16 people completed the survey: 10 attended the whole event; 7 attended some sessions; 1 did not or was not able to attend.

71.43% rated the event as excellent overall; 21.43% as good and 7.14% as quite good. No one rated it as poor or very poor. People attended the event for a range of reasons: to learn more about self-management (71.43%); to network with other patient organisations (57.14%); to share their / their organisations experience (50%). Other reasons listed by attendees were: to learn from different perspectives of living with respiratory conditions; and to cater better respiratory care to my patients and train the Healthcare Providers.

Areas for improvement were:

- Less medical jargon, a greater level of insight from across Europe designed to reflect back the sense of progress, perhaps only the ELF have this perspective. Nothing on ILDs, this is a big area of progress. More about air quality and climate change... this affects us all
- longer sessions and maybe some more practical examples
- The sound in the presentation was sometimes poorly as it broke sound.
- I would suggest that consideration be given to extending the event from 'one day' to a 2 day event so more related topics can be covered and presentation times can be extended? The ability to use a 'community cafe' to post and respond to discussions, develop connections and networking?
- According with the circumstances, I think in-person events are better.
- Some of the presentations were a little rushed to keep to the allotted time slots, slightly extending the time slots for organisations to share their experiences would have helped this.
- It was excellent. A sharing of Patient Education materials soft copies/link would have been more beneficial to all.
- When the event will be held in a hybrid way it will be fantastic.

Attendees liked best:

- Online participation is very good
- very interactive
- It was wonderful to hear that others were doing that give us ideas and opportunities to work together at the same issues.
- The topic - 'self management' - to listen and learn from different perspectives and experiences.
- The topic you chose is excellent.
- Opportunity to share experiences and network with other organisations.
- Interactive Sessions, Clarification of the Devices use during the Pandemic like the value of a Simple PEAKFLOW METER.

- I always like the need of people to share both their problems and their achievements.

When asked about topics for future events, respondents valued:

Patient and public involvement in research	78.57%
Diet and nutrition for lung health	71.43%
Rare diseases	64.29%
Climate change and respiratory health	57.14%
Smoking cessation and tobacco control	35.71%
I do not plan to attend future ELF events	0%
Other: (see below for full details)	35.71%
<ul style="list-style-type: none"> • Long-COVID & microbiome • Respiratory health and the environment • Breathing techniques • Digital Health • Physical exercise and respiratory health • Mental health and chronic respiratory disease 	

Detailed suggestions for future topics:

- Long covid and respiratory health microbiome and respiratory health the environment / weather and breathing breathing and relaxation kids breathing techniques
- Digital Health - How health data is managed/controlled/used, safety/efficacy of digital health technologies in research, patient treatment/management. Information/knowledge/understanding of 'wearables', inequalities in access to health technologies. Can/do digital health technologies improve patient management/outcomes? Trust and transparency in the use of digital health. Telehealth, use of health technologies in 'remote' clinical trials. Patient involvement in the design/use of digital health technologies. Adverse events monitoring/recording etc.
- Physical exercise and respiratory health

- Mental health in CRD.
- Help with mental health especially for those newly diagnosed.

When asked about the preferred format for future events, responses were similar to those on the day:

To help us plan for future ELF Patient Organisation Networking Days, would you prefer:

An in-person event as part of the ERS Congress	50%
An online event	35.71%
No preference	14.29%

Other comments and suggestions:

- Well done!
- really liked it but i would only do it virtually
- Online have been good opportunity and I have been attend the meetings that would not be able to do otherwise.
- A weird comment: I couldn't see the mouth of some speakers, it caused less good understanding, especially when the articulation was not all too well. Could you ask speakers to show their whole face and articulate properly? Thank you in advance.
- On- line participation works but has time limitations and lacks the ability to 'mingle', personally I think in-person face to face meeting improves developing networking discussions and collaboration etc.
- Excellent opportunity and forum to share experiences and network with other organisations. Thank you to all those involved.
- It was Very Well Organised and an Excellent program from all point of view.

Future planning

ELF will take the feedback received from participants into consideration when planning future events for the patient organisation network including exploring ways to:

- Increase opportunities for in-person networking and discussion
- Address priority topics through future ELF events
- Share information about events run by other organisations, including ERS, which address topics of interest to patient organisations
- Consider the access needs and preferences of the diverse patient organisation community when planning future events.