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Patient Organisation Networking Day 2024
Breakout session report

Executive summary

- This report summarises the breakout session discussions that took place between patient organisation representatives at ELF’s Patient Organisation Networking Day 2024.

- Before the event each delegate selected a topic of interest from a predefined list and was allocated to a table to discuss the topic. The topics were: Disease Visibility and Awareness; Access to treatment; Screening; Digital Health and AI and Air Pollution and Climate change.

- Each table was first asked to discuss the challenges and issues associated with driving policy and health care change in the topic area. Then they were asked to discuss potential solutions. This could be through their own organisations’ experiences or things that potentially could work or be tried. We also asked about what ELF could do to support their actions.

- There was one online breakout group and they chose to discuss Access to treatment.

- Despite the topics being varied, a common theme found across all the topic areas was that of working together and the importance of collaboration. This was not only with other patient organisations, but also with other stakeholders such as health care professionals and researchers. Building relationships across these groups was seen as key. Collaboration and building a coalition among stakeholders were seen as crucial to influence policy and drive forward change in health care.

- Having access to different types of information and ‘evidence’ to present to policy makers and politicians was also seen as important. This could include patient stories, statistics or scientific information, depending on the audience. Being prepared with relevant information was key.

Introduction

ELF Patient Organisation Networking Day 2024 was held on Saturday 7 September both in Vienna, Austria and online. This year's theme was: *"Driving policy and healthcare change".*

After a morning of presentations, delegates moved into round table discussions. The discussion groups comprised delegates from different organisations to explore pre-selected topics in-depth. These sessions had two primary objectives:

- Facilitate experience and idea exchange for mutual learning
- Promote networking among organisations with shared interests

Prior to the day, delegates were asked to choose a topic aligned with their organisational interests from options proposed by the planning group, members of ELF's Patient Advisory Committee. Each delegate was pre-assigned to a specific table, with each table focusing on a designated topic. A facilitator and note taker were allocated to each table.

The conference centre in Vienna hosted nine tables, each accommodating 10-12 participants. The breakout sessions covered the following topics:

- Disease Visibility and Awareness (4 groups)
- Access to Treatment (2 groups)
- Climate Change and Air Pollution (1 group)
- Digital Health and AI (1 group)
- Screening (1 group)

Additionally, four online participants joined an online group focused on Access to treatment.

Each group was asked to consider two key points:

- Challenges or issues faced in driving policy change within their topic area
- Potential solutions to the identified challenges

Delegates were encouraged to share experiences from their own organisations and explore potential collaborative opportunities. Additionally, participants were invited to suggest initiatives that ELF could undertake to support these solutions.

At the conclusion of the breakout sessions, each table was required to present one solution for discussion in the plenary session.

TOPIC: Disease Visibility and Awareness

A. What are the challenges and issues that organisations have faced while trying to change policy and improve health care in this area?

This was a popular topic and four tables discussed this topic. Their comments are summarised as follows:

Patient Engagement and Self-Management

- **Encouraging adherence:** Patients often struggle to attend appointments, adhere to medication, or participate in physiotherapy. Strategies are needed to motivate them to take an active role in their health.

- **Empowering patients:** Patients need support to engage in advocacy and share their stories effectively, while avoiding tokenism by industries such as pharmaceutical companies.

- **Stigma and self-perception:** Patients often face stigma or blame for their conditions. Attendees felt it important to shift perceptions so patients are seen beyond their illness and empowered as individuals.

Awareness and Education

- **Public education:** There is a need to educate the general public about common and rare respiratory diseases to reduce misinformation and increase awareness.

- **School-based education:** Teaching young people about health, nutrition, and diseases from an early age can improve health literacy.

- **Unified awareness campaigns:** Efforts should focus on raising awareness about all respiratory conditions, not just rare ones, especially among primary care providers.

Diagnosis Challenges

- **Misdiagnosis and underdiagnosis:** Many conditions are misdiagnosed (e.g., not all wheezing is asthma), or diagnosis is delayed for years due to lack of awareness or resources.

- **Access to diagnostic tools:** While tools such as CT scans have improved diagnosis speeds, they may not be widely accessible, creating disparities.

Access to Care and Treatment

- **Inequitable access:** There are significant disparities in access to medications, innovative treatments, mental health care, and end-of-life care across regions.

- **Cost barriers:** High costs of treatments (e.g. rare disease drugs) and lack of reimbursement in many countries prevent equitable access.

- **Geographical fragmentation:** Access varies by location, with rural areas often facing greater challenges.

- **Post-lung-transplant care:** Managing side effects and ensuring affordable care post-transplant remains a challenge.

Healthcare System Limitations

- **Primary care gaps:** Many primary care providers lack sufficient knowledge about respiratory diseases, leading to inadequate treatment or mismanagement.

- **Medical society support:** National medical societies often lack information on rare diseases, hindering efforts to build dedicated centres or improve care.

Policy and Advocacy

- **Engaging policymakers:** It is difficult to identify the right policies or approach politicians effectively due to competing priorities and limited resources for advocacy.

- **Patient involvement in advocacy:** Patients need support to participate in policy efforts without being exploited by pharmaceutical industries. Simplified methods such as email campaigns can help.

- **Funding challenges:** Small patient organisations struggle with securing adequate funding for advocacy and support initiatives.

Social Isolation and Digital Literacy

- **Reaching isolated patients:** Many patients remain unaware of available resources due to isolation or lack of digital literacy, especially older adults.

- **Lack of patient organisations:** In some countries, the absence of patient organisations limits support networks for those affected by respiratory conditions.

Research Participation

- **Low patient involvement:** Patients are often hesitant or unprepared to participate in research efforts. Educating them on the importance of their role is essential.

Broader Perception Challenges

- **Changing attitudes:** There is a need to shift perceptions among patients, policymakers, and healthcare providers about the importance of lung diseases.

- **Media focus on other diseases:** Diseases such as cancer receive more attention in the media compared to lung diseases.

B. What are the possible solutions to the challenges and issues that were discussed?

The solutions that the groups came up with can be summarised as follows:

Awareness and Education

Public Awareness Campaigns

- Create video installations and art exhibitions for the general public and media
- Develop campaigns for general lung fitness, including spirometry as part of health checks
- Organise "Lung MOT" events with spirometry and questionnaires
- Use social media influencers, especially on platforms such as TikTok, to engage younger audiences
- Establish an International Respiratory Patient Day or World Respiratory Diseases Day

Healthcare Professional Education

- Use physician education modules and Continuing Professional Development (CPD) to increase disease visibility
- Educate healthcare providers about the importance of early diagnosis
- Provide training for young doctors and researchers, with patients involved in curriculum design

Collaboration and Networking

Building Coalitions

- Foster collaboration between different organisations, including patient groups, healthcare professionals, and researchers
- Create events where different patient groups and associations can connect
- Form umbrella associations for common issues, such as organ transplantation
- Establish informal networks focused on respiratory health

Strengthening Patient-Doctor Relationships

- Encourage doctors to refer patients to patient organisations upon diagnosis
- Distribute resources and brochures about patient organisations in healthcare settings
- Build stronger relationships between patient organisations and specialists
- Involve patients in hospital boards and decision-making processes

Lightbulb moment
Build a coalition and build relationships between young doctors/researchers and patient organisations. Have patients training doctors and helping to design the curriculum for medics/researchers.

Advocacy and Policy

Political Engagement

- Create a charter for politicians and healthcare professionals to sign
- Identify and engage with policymakers based on their interests (e.g., women's issues, environment)
- Prepare information (patient stories, statistics, scientific evidence) to cater to different policymaker preferences
- Work towards new laws for patient involvement in healthcare systems

Healthcare System Improvement

- Understand the specifics of each country's healthcare system
- Identify specialists and build multidisciplinary teams for advocacy
- Learn from and share best practices between countries
- Implement "secret shopper" programmes to evaluate hospital care quality

Patient Empowerment

Support and Resources

- Encourage healthcare providers to "prescribe" patient organisation contact details upon diagnosis
- Develop independent, evidence-based information sources for patients
- Involve patients in treatment validation processes
- Create personalised and holistic treatment approaches

Amplifying the Patient Voice

- Bring patients to medical conferences and policy discussions
- Use patient stories, alongside data and evidence, in advocacy efforts
- Make it easy for patients to become involved in advocacy
- Address the challenge of "invisible" illnesses through storytelling

Lightbulb moment

Sharing the patient story first and showing pictures and then providing data can be very powerful and inspiring. Disease is often hidden and because of that story telling becomes even more important.

Innovation and Research

Experiential Learning

- Develop simulations for policymakers to experience respiratory conditions (e.g., breathing through straws, using nose clips)

Industry Collaboration

- Engage with pharmaceutical companies to support drug development for identified lung diseases
- Explore private-public partnerships beyond pharma (e.g., insurers, automotive companies, banks)

Organisational Strategies

Unified Approach

- Find common ground among stakeholders to present a unified voice
- Create coalitions of patients, caregivers, doctors, and researchers
- Identify and focus on cross-disease issues to foster collaboration

Resource Sharing

- Establish mentorship programmes between larger and smaller organisations
- Apply for funding collectively
- Use funds to support smaller patient organisations

C. How can ELF help?

We asked the groups to consider how ELF could assist in driving healthcare policy and change in this area. Here is a summary of their suggestions:

Collaboration and Knowledge Sharing: Facilitate collaboration by bringing organisations together to share experiences and best practices and foster a more unified approach to challenges.

Advocacy and Policy Support: Support organisations in their interactions with policymakers to increase the impact. Offer open letters as a tool for collective advocacy.

Inclusive Network Building: Continue to expand the ELF network by introducing new groups such as PAGs to ensure diverse and comprehensive representation.

Centralise Resources and Services: Provide centralised services where organisations can seek assistance to improve their operations and effectiveness. This could include financial support for specific tasks or training and offering best practice examples

World Respiratory Diseases Day: Establish a World Respiratory Diseases Day in conjunction with ERS and open to all interested parties. This would:

- Raise awareness about the unmet needs of respiratory disease patients
- Promote access to treatment, care, and research
- Advocate for multidisciplinary care approaches
- Support patient organisations and their work
- Encourage education on respiratory diseases from an early age.

The proposed day would be guided by a steering committee to ensure its effectiveness and broad impact.

TOPIC: Access to treatment

A. What are the challenges and issues that organisations have faced while trying to change policy and improve health care in this area?

Two tables and the online group discussed this topic. Comments are summarised below:

Diagnosis

- Delayed diagnosis due to lack of awareness and visibility
- Misdiagnosis, especially in young people and children
- Lack of screening programmes or patients' reluctance to participate in screening
- Regional differences in access to diagnosis and specialists

Access to Treatment

- Delayed access to life-prolonging treatments
- Shortage of medicines and inconsistent drug availability across countries
- Long waiting times for treatment approval and reimbursement
- Limited access to non-drug treatments (e.g., physiotherapy, pulmonary rehabilitation)
- Poor access to psychological support and mental healthcare

Healthcare Systems

- Lack of national guidelines and standards of care for rare diseases
- Inconsistent disease classification across countries (rare vs. non-rare)
- Differences in care and funding distribution between countries and regions
- Budgetary constraints and pressure on healthcare providers
- Competing priorities for limited healthcare resources

Research and Evidence Gaps

- Lack of interested researchers and funding for rare disease studies
- Insufficient evidence and data usage for rare conditions
- Difficulty in finding adequate patient numbers for studies
- Limited specific research for childhood lung conditions

Communication and Coordination

- Lack of interdisciplinary communication and multi-disciplinary approach
- Insufficient inclusion of patients and patient support structures
- Limited engagement between government agencies and smaller patient associations

Education and Awareness

- Lack of training for healthcare professionals

- Poor distribution of funds for education and advocacy
- Limited public awareness and visibility of rare diseases

Geographical and Cultural Barriers

- Uneven distribution of specialist hospitals and care centres
- Cultural and ethnic differences affecting healthcare engagement
- Travel difficulties for patients with lung conditions seeking specialist care

Policy and Funding

- Lack of long-term, apolitical healthcare agreements
- Inconsistent recording of rare disease patient numbers
- Complex reimbursement processes in some countries and limited coverage for effective treatments
- Many organisations staffed by volunteers and rely on goodwill

B. What are the possible solutions to the challenges and issues that were discussed?

The possible solutions that the groups came up with can be summarised as follows:

Patient Engagement and Empowerment

- Educate patients about their conditions and treatment options
- Organise patient committees within health centres
- Implement patient-centred health equity initiatives (e.g. European Patient Forum)
- Encourage participatory healthcare with decisions made by committees including patient organisations
- Improve communication skills for better advocacy

Collaboration and Networking

- Foster collaboration among patient groups, healthcare providers and other stakeholders
- Consolidate into umbrella groups for increased influence and resources
- Share solutions between groups representing related diseases or people with comorbidities
- Connect with specialists and expert networks (e.g. Orphanet for rare diseases)
- Reach out to larger international groups for support and knowledge sharing
- Use umbrella organisations such as ELF to amplify voices and pool resources

Lightbulb moment

Consolidate into umbrella groups – larger groups are more likely to have good communications and managers, who have contacts in government

Research and Evidence-Based Advocacy

- Conduct qualitative research (e.g. focus groups) to understand patient needs
- Gather real-world evidence for regulatory approvals (e.g. Patient-Reported Outcome Measures (PROMS) for European Medicines Agency)
- Standardise diagnosis and treatment protocols across Europe
- Collaborate with the pharmaceutical industry for research and development

Political and Policy Engagement

- Engage in direct contact with local health ministers
- Become involved in regional committees
- Speak to representatives from all political parties
- Participate in European government discussions
- Leverage election periods for partisan communication
- Work with opposition parties to pressure governments
- Raise voices within established networks (e.g. ELF and Lungs Europe)

Multi-level Approach

- Implement local activities in hospitals and communities
- Work simultaneously from bottom-up and top-down approaches
- Apply pressure from patient organisations at various levels
- Engage with larger groups and international organisations for broader impact

Regulatory and Industry Collaboration

- Work with regulatory bodies to improve approval processes
- Collaborate with the pharmaceutical industry for better access to treatments
- Connect with Orphanet and similar organisations for rare disease advocacy

Common Sense and Practical Strategies

- Apply common sense approaches to problem-solving
- Develop practical, actionable strategies for improving access
- Balance idealistic goals with realistic, achievable objectives

C. How can ELF help?

We asked how ELF could assist in driving healthcare policy and change in this area. Here is a summary of the groups' suggestions:

Networking and Collaboration

- Create networks for rare disease and smaller organisations
- Connect organisations in similar disease areas across Europe
- Facilitate regular meetings with ELF Patient Organisation Network members
- Establish online forums for communication and knowledge sharing

Education and Empowerment

- Provide training on advocacy skills for small organisations
- Offer education on grant acquisition and access
- Conduct training for professionalisation of small organisations

Advocacy and Political Engagement

- Introduce organisations to politicians
- Help to identify key topics through surveys

Support Services

- Organise meetings with individuals and families to assess needs and discuss available services
- Act as a partner to help organisations access European funding
- Provide information on grant opportunities and application processes

TOPIC: Climate change and Air Pollution

A. What are the challenges and issues that organisations have faced while trying to change policy and improve health care in this area? What are the possible solutions to the challenges and issues that were discussed?

One group discussed this topic. Here is a summary of their challenges and potential solutions.

Challenges:

- Creating and implementing new and effective policies
- Economic and financial constraints limiting available resources
- Research needed into long-term health effects of pollution
- The need to prioritise immediate health concerns while addressing long-term environmental impacts
- The potential link between air pollution and diseases such as lung cancer
- Need to effectively communicate the link between climate change and air pollution
- Change requires global coordination

B. Possible solutions:

Collaborative Action

- Recognise that tackling these issues requires collective effort; it's not possible alone
- Form alliances among patients, patient organisations, and healthcare professionals to amplify advocacy

- Start with individual actions but aim for global impact, emphasising that we are stronger together

Education and Awareness

- Educate and persuade the public about the urgency of climate change and air pollution issues
- Influence children and young people through social media and influencers to create early awareness and action
- Provide better evidence demonstrating the impact of pollution on people's health

Immediate Action

- Emphasise the importance of taking immediate action rather than delaying responses
- Leverage support for the World Health Organization (WHO) to push for delivery on climate and pollution goals

Research and Measurement

- Conduct research to show the link between air pollution and health exacerbations
- Consistently measure the impact of interventions and policies to guide future actions

Holistic Approaches

- Link advocacy to One Health approaches and pandemic preparedness
- Develop resilience in advocacy efforts and continue working together despite challenges
- Approach climate change and air pollution issues with greater gravity and commitment

Lightbulb moment
Resilience is needed - we are stronger together! More advocacy, more serious evidence, measure the impact.

TOPIC: Digital health and Artificial Intelligence (A.I.)

A. What are the challenges and issues that organisations have faced while trying to change policy and improve health care in this area?

One group discussed this topic. Here is a summary of their challenges and potential solutions.

Challenges:

Accessibility and Inclusivity

- Limited comfort and knowledge with digital health technology among certain populations
- Cost barriers associated with digital health technologies
- Potential exclusion of specific groups, such as older people
- Risk of health inequality due to biased AI training datasets

Technological Barriers

- Broad and uncertain definition of digital health
- Incompatibility between different systems

Regulatory and Security Concerns

- Need for strong regulations in the digital health sector
- Integrity and security issues with health data
- Lack of transparency in data sharing and usage

Patient Trust and Involvement

- Uncertainty about data destination and sharing practices
- Massive opt-outs from data sharing due to mistrust
- Concerns about potential misuse of data by health insurance companies
- Insufficient patient involvement in digital health product development

Ethical Considerations

- Balancing data protection with effective data usage
- Ensuring digital health solutions address real patient needs

B. Possible solutions:

- Build platforms to coordinate and integrate different data systems
- Develop guidelines and standards for constructing medical information systems in the EU, involving patients as key stakeholders
- Educate patients about digital health technologies and the European Health Data Space
- Develop robust regulations for digital health and AI
- Involve patient organisations to enhance trust and transparency
- Ensure patients have control of their data
- Create working groups or committees to focus on digital health challenges

TOPIC: SCREENING

A. What are the challenges and issues that organisations have faced while trying to change policy and improve health care in this area?

Challenges:

- Inadequate screening, including early screening initiatives
- Some screening initiatives too focussed
- Lack of awareness among patients, healthcare professionals, and policymakers
- Low patient attendance
- Limited follow-up for patients who miss lung screenings
- Challenges for specific diseases, including:
  - Sleep apnoea: Lack of simple screening tools, reliance on complex processes
  - Pulmonary fibrosis: Absence of reliable biomarkers for early diagnosis
- Inadequate education for general medicine practitioners, patients and caregivers
- General practitioners acting as gatekeepers, potentially limiting access to screening
- Need for improved pre- and post-screening care

B. Possible solutions:

- Use existing patient registries for screening insights
- Generate data on the cost-effectiveness of screening
- Broaden screening checks
- Fund/grants for young researchers to build capacity
- Use new technologies
- Educate patients, caregivers and clinicians

Thank you

Thank you to the Patient Organisation Networking Day Working Group who helped organise the day, and to all who took part and shared their views and experiences.