ELF Patient Organisation Networking Day
Breakout session report
November 2023

Executive summary

- This report summarises the breakout session discussions that took place between patient organisation representatives at ELF's Patient Organisation Networking Day 2023. There were two breakout sessions – one on patient and public involvement (PPI) in research, and one on mental health and lung disease. Discussions took place both in person and online.

- Organisations varied in how much they supported their members to get involved in research. Some help their members review research funding applications and be part of research projects, for example by offering training. Others provide information about available opportunities and share the results of research studies.

- Barriers to being involved included some patients not knowing that they can be part of research or what opportunities exist. The complicated language used in research can be hard to understand, especially for people who do not speak English as their first language. There can also be a lack of trust between patients and researchers.

- Participants agreed that when patients take part in research, they should be involved from the beginning to the end of the project. They should also be compensated for their time and given training and support. It is also important to make sure that the involvement suits their needs, for example having meetings at times that work for them and using simple language.

- To help reach and involve patients from 'seldom heard' communities, participants suggested recruiting through community leaders and health professionals. They also discussed making it as easy as possible for patients to participate and building trust in the research process.

- Participants shared various ways that their organisations supported members with mental health issues. This included offering direct support or connecting them with health professionals or peer supporters. They also held activities and events, such as social gatherings and educational sessions, raised awareness, and provided training to health professionals on communication. But they also face challenges such as not having enough resources and dealing with the stigma around mental health.

- Participants agreed that lung conditions can affect a person's mental health in many ways. For example, dealing with an "invisible" illness, worrying about the future, and the risks of everyday life, such as air pollution and infections.

- To help reach more patients with mental health problems, participants suggested increasing resources, working together with other organisations and health professionals, sharing patient stories, and offering accessible support that fits each patient's needs.

Introduction

ELF Patient Organisation Networking Day 2023 was held on Saturday 9th September both in Milan, Italy and online. It focussed on two themes: patient and public involvement in research, and mental health and lung disease. It included keynote and patient organisation speakers, interactive breakout groups, and question and answer sessions.

This report details the discussions that took place in the breakout groups. 82 people attended these sessions in person, and 17 participants joined online. In-person breakout groups included around 8-10 participants; online there were between 3 and 6 in each group.

Each breakout group was led by a facilitator who asked pre-set questions on the topic to the group and then guided the discussions. The facilitator made notes of the main points discussed. The group then decided on their 'lightbulb moment' - one key thing that came up in the discussion and had a big impact on the group – to feed back during the plenary.

Patient and Public Involvement in research

What is your experience of supporting your patient community to get involved in research?

The participating groups differed significantly in the amount of support they gave to their patient communities to get involved in research. Some had no experience of offering support, while others carried out a range of activities. These included:
- patients commenting on research proposals, for example on how well patient involvement is integrated into the proposed research
- patients helping to design research, including setting study parameters and outcomes
- recruiting patients to participate in research studies
- translating study materials and outcomes into lay language
- training patient representatives on how to get involved in research and assessing research proposals
- organising information sessions on research outcomes.

Lightbulb moment
Patient organisations are not recognised for their expertise and knowledge, time investment and networking efforts. They should be reimbursed like the other research partners.

What are the barriers to patients being involved in research and how might these be overcome?

Some participants felt that many patients were unaware that they could be involved in research. It was suggested that patient groups could play a role in providing information about getting involved.

On the other hand, other participants commented that while patients are often aware that they can be involved in research and are keen to take part, they are not always asked to participate or are not aware of research opportunities open to them. Suggestions as to how this might be overcome included:
- making patient involvement a requirement for research funding
- encouraging researchers to contact patient groups when planning research
- a national platform giving details of research studies open to patient involvement.

The importance of patients being involved in research from the beginning was emphasised by several participants, who commented that patients were often brought into research at a stage that was too late to enable meaningful involvement, sometimes even not until the dissemination stage after the research had been completed. Patients can help to shape the direction of a project, for example by reviewing protocols and plans and highlighting the outcomes most important to patients. It was believed that researchers need to make a conscious effort to get patients involved at an early stage and consistently throughout the project.

Participants also felt it was important to give patients equal priority to other research partners. For example, this could include:

- reimbursing patients for their contribution
- giving patients a specific role in the project
- including patients in working groups and committees
- involving patients in producing the final publication, and including them as co-authors.

Lightbulb moment
Each individual patient is crucial and the task is to make them really understand their importance.

Several participants made practical suggestions on how to make the research involvement process easier for patients by overcoming potential barriers. These included:

- reimbursing patients for their contribution, although there is a need to be mindful of the possible impact on social security benefits and health insurance
- allocating sufficient budget for patient involvement, for example for travel to meetings
- training patients on how to be involved in research, including giving them the confidence to represent themselves and others in meetings
- providing a named person/mentor for patients to contact throughout the research project for queries and support
- holding meetings at times convenient to patients, and not necessarily during the working day
- avoiding jargon and medical terminology in meetings and communications
- not having strict criteria for the type of patients that could be involved
- emphasising the benefits to patients in getting involved, for example furthering knowledge on a rare disease and improving treatment
- keeping patients informed of the progress of a research project and communicating the results in an appropriate format.

Lightbulb moment
A personal mentor from the beginning of the research, to guide and help the participant through the process, could be really valuable. Lack of information could be one thing that makes people drop out.

There were some barriers mentioned that could be harder to overcome. While the technical language often used in research could be made more understandable to patients by producing materials in a lay format, it was acknowledged that participation could still be difficult for those whose primary language was not English.

It was also felt that there might be a lack of trust between patients and health professionals/researchers and that cultural factors may also play a part in some patients choosing not to be involved. These factors may require more in-depth work to establish trust and identify and remove the barriers to taking part. Political barriers were also mentioned:

for example, patients in non-EU countries being unable to be involved in projects funded by EU grants, and a perception that some diseases attracted less research funding and interest than others.

Some participants also highlighted the importance of involving other stakeholders in the research process, who might be able to bring different experiences and perspectives. This could include caregivers, family members, patient organisations, and allied health professionals such as nurses and physiotherapists.

Lightbulb moment
Education and information are fundamental to bridge the gap between research and patients, for patients to feel empowered and informed to shape research.

How can we involve more patients from 'seldom heard' communities?

There were fewer responses to this question and some suggestions mirrored those given to overcome barriers to being involved – for example, being flexible around the criteria required to take part in research, and providing reimbursement to patients and/or covering their expenses.

Some participants suggested looking outside the traditional patient recruitment channels to communicate about research and find patients to be involved. This could include engaging with:
- community leaders
- general practitioners/family doctors
- social media
- celebrities.

Trust was seen to be important – so using trusted people to communicate and recruit, and making sure the process is transparent and thorough to foster trust in the methods and outcomes.

It was also seen as important to continue to involve patient organisations in recruiting patients, but not to rely too much on patient groups to carry out the involvement work, especially if they are also not given funding to do so.

Other participants made suggestions on how to make research activities less daunting for those who might not traditionally want to be involved. This might involve not making research and the disease the main topic but instead choosing a fun activity in a neutral setting and adding the research activity in slowly. Also important was making it as easy as possible to take part, considering factors such as timing, methods (for example some people will not be comfortable with online participation) and reimbursement.

Lightbulb moment
It starts and ends with communication, information and education!

Mental health and lung disease

What is your experience of supporting the mental health of your patient community, alongside their lung condition?

The groups reported numerous ways in which they supported the mental health of their patient community. These included:

- support groups – online, in-person and via WhatsApp
- providing support from a psychologist and/or respiratory specialist
- providing support within hospitals
- providing support to caregivers and family members
- a holistic assessment tool to identify mental health and wellbeing issues
- facilitating peer support/patient navigator scheme with trained volunteers
- providing rehabilitation and physical activities
- offering a telephone support line – for example, one country offers a listening, advice and support service to people newly diagnosed with a rare disease
- employing staff/volunteers with lived experience
- sharing patient stories
- offering information on the effect of lung conditions on aspects of life that people might find difficult to talk about, such as intimate relationships
- online and in-person events, including social events
- patient advocacy groups
- providing communication skills training to GPs/family doctors
- educational sessions and courses for patients on mental health issues
- communication with the patient network on mental health issues, e.g. on social media
- raising awareness of mental health issues and how a lung condition might impact mental health
- providing information on new treatments/therapies, which can offer hope and reduce stress.

Lightbulb moment
To quote Dr Pagnini "mental health is wealth". Psychological support should be seen in the context of holistic care. Should also include physio, social support, mindfulness…. Patients as a constellation of conditions. Breathing is life, and not being able to breathe is highly traumatic.

Some of the barriers to providing support were also raised. These mainly focussed on lack of resources, for example long waiting lists to access mental health services and lack of funding for patient organisations to offer support. Services can also be unsustainable long-term due to lack of funding, which can mean the removal of support for vulnerable patients.

Participants felt that there is a big unmet need for mental health support for respiratory patients, and no easy answers as to how to meet that need. The stigma attached to both

lung conditions and mental health issues was also cited as a difficulty that might prevent patients from seeking help, alongside patients not always acknowledging or recognising that they had a mental health issue. This was seen as a particular issue for older people and men. Also seen as important is the management of expectation in patients. This could include providing clear and unbiased information on lung conditions, which can help to foster realistic expectations and allay fear.

> **Lightbulb moment**
> Information, education and continuing treatment needs to be holistic, accessible and transferable.

How does the lung disease you represent affect patients' mental health?

Participants felt that there was a high prevalence of mental health issues in people with lung conditions, with one group estimating that between 30 and 50% of patients were depressed, and others saying that as many as 90% of patients experienced anxiety and/or depression, although this was not always acknowledged by the patients themselves.

Ways in which participants believed that lung disease affected the mental health of patients included:
- diseases being hidden or invisible which can lead to others not taking a patients' condition seriously
- fear of the future – for example of the disease worsening
- feeling judged and dealing with stigma – for example, assumptions that smoking has caused the lung disease. There can also be guilt in people whose lifestyle habits may have contributed to their condition
- lack of support
- side effects of drugs
- mental health issues causing difficulty in treatment adherence, which could worsen the condition and increase the mental health burden
- difficulty using medical devices/new technology
- lack of access to treatments and equipment.

> **Lightbulb moment**
> We (different respiratory diseases) share the same mental health challenges. We can work together and learn from each other and the same thing will work. It's important that health professionals help the newly diagnosed to get in contact with patient associations.

The COVID-19 pandemic was also believed to have had a negative impact on patients' mental health, especially those who needed to shield or isolate due to their lung condition. The decision as to whether to wear a mask could also increase anxiety. Participants pointed out that everyday life often presented risks and dangers to people with lung conditions, for

example from air pollution and airborne infections, and this could induce anxiety and social isolation. It can also be difficult to convey these risks to family and friends.

It was also suggested that all lung conditions should have set standards, guidelines and pathways for care and treatment – currently there is much variability between different diseases and countries – and that these standards should incorporate mental health assessment and treatment.

How can we reach more patients experiencing mental health problems?

Participants suggested several ways that more patients with mental health issues can be reached and supported. Many of these suggestions were about increasing resources, for example to provide quicker access to psychological support. An example was given of where a patient reached out to a patient organisation for support, but then faced weeks of waiting for therapy – it would be better for this support to have been offered as soon as a patient felt ready to 'open up'.

Lightbulb moment
Start a Resource Centre for Mental Health to educate patients, doctors and caregivers/patients coaching patients.

Other suggestions for reaching and supporting more patients included:
- offering psychological assessment when patients are first diagnosed/assessed
- ongoing mental health reviews/'check ins' at consultations with existing patients
- more collaboration between lung organisations
- lung organisations working together with mental health organisations and healthcare professionals, including GPs/family doctors
- being able to offer a longer course than the standard 6 sessions of therapy treatments, to build up trust for patients who might be reluctant to seek help
- offering support that is different to the usual – for example, fun activities
- an ELF mental health working group or Europe-wide mental health collaboration
- offering tailored support for different age groups and genders – such as a men-only group
- making support accessible – for example for people with disabilities and offering support in different languages
- using patients who are already members of an organisation to reach out to other patients who are not currently involved
- offering peer support from those with lived experience
- organisations surveying their patients on mental health, to gather a comprehensive picture to help with offering and tailoring support
- hospitals providing small group courses on managing a particular lung condition.

Lightbulb moment
Acceptance. Accepting the "new normal" – how your life changes – is key to strengthening your mental health.

Another suggestion was to use personal stories, for example with existing patients being open and honest about their mental health issues to encourage others to do the same. An example was given of a patient organisation representative who shared her personal story during patient organisation networking day, which made a great impact on many participants. These messages could be particularly powerful when delivered by a patient who might not traditionally be expected to speak about mental health issues – for example, older people, men and people from ethnic minority communities. Patients could learn to acknowledge and accept their mental health issues if they see someone they can relate to doing the same. Sharing these stories with healthcare professionals could also lead to greater understanding.

There was dissent over whether young people were more or less likely to seek help; some participants felt that younger people are more reliant on emotional wellness and find it easier to ask for help, while others felt that this group was harder to reach by traditional means. Others felt that psychological support was particularly needed during the transition from child to adult services, and that some patients could be 'lost' in this process.

Lightbulb moment
It's essential to continue to breakdown mental health stigma. It's really important to support families and caregivers and to continue to raise awareness of the importance of psychological support in early stages of the disease and focusing on expectation management.

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.