

# Challenges in the production of rare disease patient information



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## Summary:

Information can help reduce isolation for people with rare diseases, helping to reassure them that they are not alone. ELF collaborated with ECPC/RARECARENet on a factsheet covering rare lung cancers and encountered a number of challenges while carrying out this important task.

## Introduction:

European Lung Foundation (ELF) produces simple factsheets for people with lung conditions in a range of languages. Each factsheet is co-created with experts from the European Respiratory Society (ERS) and people with experience of the particular lung condition from the ELF patient organisation network.

RARECARENet (Information Network on Rare Cancers) is a European Commission-funded project to build an information network on rare cancers.

As a coordinator of RARECARENet, the European Cancer Patient Coalition (ECPC) asked ELF to produce a factsheet on rare lung cancers for this project.

## Results:

The ELF/RARECARENet rare lung cancers factsheet is a valuable resource for patients and their families in an area where there is little or no information.

Once produced, the factsheet was published in the journal *Breathe* and disseminated to 88,000 ERS members, shared with over 7,000 ELF contacts and their networks, reached over 23,000 followers on social media, and via ECPC/RARECARENET networks and is in the RARECARENET library.

The process of this factsheet production proved much more difficult and challenging than usual ELF factsheets. The average time spent on an ELF factsheet is 35 hours, but on this occasion it was 53 hours.

The main challenges in the development of this factsheet include:

- It was difficult to identify and engage with both professionals and patients with experience in this area.
- It was hard to find sufficient information to add to the factsheet as research and knowledge is scarce.
- These rare cancers tended to have particularly negative outcomes, which was a challenge to communicate in a positive manner.
- Much of the information on rare lung cancers was similar to more typical lung cancer, so it was difficult to select which aspects to highlight as being specific to the different subtypes.

It was particularly hard to find patients for the following reasons:

- Fewer people to approach
- Poor survival rates/quality of life of people with a rare lung cancer diagnosis
- Lack of registries
- Language/translation issues

“Being able to access reliable information is incredibly important for people who are diagnosed with any rare condition as they can often feel alone and isolated. In the case of rare forms of lung cancer, individuals not only have a daunting cancer diagnosis, but they may also face uncertainty as they are informed inadequately about the type of cancer they have.

Since fewer people will experience these conditions, and thus benefit from the information, resources are not always allocated to developing it. In addition, the difficulty in finding scientific data, experts and patients to consult in the production of this information – as experienced in this project – can pose another barrier.

I am hopeful that we can find solutions to these issues and help to serve these patients, and empower them to make informed choices about their health.”

**Dan Smyth, ELF Chair**



## Methods:

On behalf of RARECARENet, ECPC conducted a search for patient information on rare cancers in Europe and was unable to find any, so asked ELF to produce a factsheet

ELF agreed to produce a factsheet covering:

- Adenosquamous carcinoma of the lung
- Large cell neuroendocrine carcinoma
- Salivary gland-type lung carcinoma
- Sarcomatoid carcinoma of the lung
- Granular cell lung tumours
- Carcinoids

ELF contacted relevant stakeholders through its professional (European Respiratory Society) and patient (the ELF patient organisation network/European Patient Ambassador Programme) networks to source patients with experience of rare lung cancers and healthcare professionals with expertise in the specific field to co-produce the factsheet

Upon sourcing patient and professional experts, ELF conducted telephone interviews and used the responses from these interviews to develop a first draft

The draft was reviewed by the patient and professional experts, whose feedback informed each new version until the final draft stage was reached

The factsheet was given a final review for medical accuracy and patient-friendliness by the ELF Professional Advisory Committee and the ELF Lung Cancer Patient Priorities Patient Advisory Group

ELF translated the factsheet into 7 further languages: French, German, Greek, Italian, Polish, Russian and Spanish

The factsheets were disseminated via ELF, ERS and ECPC channels

## Conclusions:

We found that, when preparing information for rare conditions; for example a longer time period is required to identify patients, or better ways of identifying patients are essential (e.g. via registries), to ensure that they have the opportunity to contribute their point of view. Strong patient and professional networks are also needed to help find patients. Translation capability is important, in order to work with patients who do not speak English, as this greatly increases the likelihood of finding someone with experience of the condition.

The project showed the value of collaborative working both with patients and professionals, but also of bringing together organisations with an interest in rare diseases (ECPC and RARECARENet). This process helps to strengthen the community around a condition and allows for networking and future collaboration opportunities, which can ensure that we provide the best possible support for patients.

## References

Dana Ladd. General and Health Information Challenges of Patients With Rare Diseases: The Importance of Health Information Provision and Web Sites for Locating Rare Disease Resources. *Journal of Hospital Librarianship* 2015; 15 (2): 189-197  
European Lung Foundation. Rare lung cancers. <http://breathe.ersjournals.com/content/11/4/323>, [published 1 December, 2015; accessed 4 February, 2016]

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