

# PATIENT INVOLVEMENT IN IDENTIFYING UNMET NEEDS ON CLINICAL PATIENT GUIDELINES

## ReCONNET

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Activity	Publication of state of the art on clinical practice guidelines per disease
Area	Clinical practice guidelines and healthcare
Duration	4 – 6 months
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### 1. SUMMARY

**i** For each disease covered by ReConnet, an ePAG patient advocate has been appointed in ReCONNET. The diseases are divided in 3 disease groups with an ePAG patient advocate per group appointed as a ReCONNET Steering Committee (SC) member.

The SC decided to publish a narrative review of existing Clinical Practice Guidelines (CPG) to perform a state of the art of the existing Clinical Practice Guidelines (CPGs) per disease group. As a result of a proposal made by the ePAGs in ReConnet SC, the clinicians agreed, as part of this exercise, to identify the unmet patients' needs in each disease. It was then decided to have clinicians and patients drafting the papers per disease; the ePAG patient advocates contribution focused on collecting and writing the patients' unmet needs of each disease. Different ePAG patient advocates were involved in this exercise and their contribution as co-authors of the papers was fully acknowledged. The papers are published in BMJ – RMD open [https://rmdopen.bmj.com/content/4/Suppl\\_1](https://rmdopen.bmj.com/content/4/Suppl_1)

Patients had a positive impact on the published papers. Their unmet needs have been acknowledged by the healthcare professionals and will eventually result in new projects.

### 2. INITIAL SITUATION

**i** During a ReCONNET Steering Committee meeting in February 2018, it was decided that the ERN would publish papers on the 'State of the Art Clinical Guidelines' per disease. Only 4 out of the 10 diseases covered by ReCONNET had previous Clinical Practice Guidelines (Systemic Lupus Erythematosus, Idiopathic Inflammatory Myopathies, Systemic Sclerosis, Sjögren Syndrome); 6 conditions were lacking CPGs and/or recommendations and were to be reviewed as well. The resulting papers would be the first in many fields, as for rare Connective Tissue

Disorders (rCTDs) there were no publications analysing the state of the art of CPGs that also covered the unmet needs and incorporated patient perspectives.

The ReCONNET Team brings together ePAG patient advocates, clinicians and also methodologists, experts in health economics, in legal aspects and in registries/guidelines and they all worked as a group, bringing their own expertise inside the project. No budget was available except for the publication. EULAR (European League Against Rheumatism) official Journal was the one chosen for the publication.

The original idea was to have clinicians performing the literature review and drafting the papers. The ePAG patient advocates involved in ReCONNET SC suggested to involve patient advocates in the review process to represent the patients' perspective and to include patients' unmet needs in the papers.

The ERN Coordinator and other SC members agreed and proposed that the ePAG patient advocates would identify in each of the CPGs the patients' unmet needs and would be co-authors of the papers. The 3 ePAG patient advocates in ReCONNET SC were tasked with reviewing the patients' contributions and would also be recognised as co-authors.

There was not an ePAG patient advocate for all of the diseases and the ePAG group had to identify one. For 4 diseases no ePAG patient advocate was found on time and therefore the unmet needs section for these diseases was fully developed by the ePAG patient advocates that are members of ReCONNET SC (with no direct experience of living with those diseases)..

Most clinicians had not previously worked with patients at this level and we had to work on building bridges to ease the communication between us.

Not all diseases had Clinical Practice Guidelines or pre-existing documentation creating a new situation for all parties involved. With no history of any documented Guidelines, it was a challenge for the parties to identify existing international evidence, as some diseases only have recent nosology's or are so rare that no previous publication existed.

### 3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

**i** ePAG patient advocates needed to actively engaged with the wider European patient community to identify unmet needs of their condition. All conditions were reviewed. The ePAG group also had to help with 4 rare conditions, for which a patient advocate was lacking., The ePAG patient advocates had to perform substantial research to understand diseases unknown to them.

All unmet needs identified by the ePAG patient advocates were discussed with the senior and junior clinical coordinators per disease and the patients wrote the patient unmet needs section of each paper,. Multiple common needs for all diseases were identified as a result of this exercise.

For most clinicians and also patient advocates it was the first time that they have collaborated together as a team. It provided the opportunity to have the patients' voice conveyed at high-level and in a meaningful way help to push for the development of better standards of care taking patients unmet needs into account.

The patients' unmet needs are now fully acknowledged by the scientific community, some projects have already started to address some of them (such as certification of the website and therapeutic education).

An ADAPTE process for the 4 diseases that have CPGs started in February 2019. The involvement of ePAGs patients advocates has been consider crucial and the methodologists that are part of ReCONNET Team will train them.

## 4. SUCCESS FACTORS

- i** 1. Having a strategic vision and acting upon it. The ePAG patient advocates involved in ReCONNET Steering Committee saw the opportunity to get involved in a new activity that would have a long-term strategic impact in the delivery of care and actively sought to find a way to get patient advocates involved.
- 2. The ERN has put in place a cross-functional team that brings together different skills and expertise (methodologists, clinicians, health economists, legal experts, patient advocates, etc). We could rely entirely on internal resources to complete the project and drive it forward.
- 3. Explaining to the clinicians involved how they would benefit from involving patients. It was the first time that such a gap analysis on Clinical Practice Guidelines included patients' views on unmet needs.
- 4. ReCONNET Steering Committee ensured, with the support and input of the ePAG patient advocates involved in this Committee, that a maximum patients' involvement was secured for each paper. In this way, the patients voice was well represented and heard.
- 5. The ePAG patient advocates did a significant effort to reach out and consult their own patient community for input and feedback. This work has contributed to build and improve the relationships between the patient advocates and clinicians bringing mutual respect and appreciation.

## 5. LESSONS LEARNED

- i** Through the active participation in ReCONNET Steering Committee and disease working groups, the ePAG patient advocates were able to represent their rare disease patient community and bring in the patients' perspective. Action is the root for change.

Explaining your ideas in a respectful and diplomatic manner may ensure that you'll be heard and strengthen your influence within the ERN.

The level of patient involvement was a first for many. The ePAGs input helped build/improve the relationships with clinicians bringing mutual respect and appreciation. It was also a learning process for all us to draft a narrative review and review CPGs.

Putting the spotlight in the patients' unmet needs brought acknowledgment by the scientific community with new projects based on the identified unmet need published on papers already starting.

Expanding the number of patient advocates involved to fully represent all diseases was a challenge. Some diseases were not represented well, and more patient advocates needed to be identified to represent these, as it was very difficult to research new diseases and fully represent these communities. More people living with rare conditions should also receive training in advocacy.

It has become evident that more people living with rare conditions need to be trained in advocacy and receive support from EURORDIS and other parties such as EULAR to raise the voice of their specific community.

Activities as this one, with a high potential impact on improving standards of care, will bring your team closer together. However, someone or some people will need to coordinate the group and work to ensure optimal teamwork

As a result of the ePAG work and input of these papers, everyone in ReCONNET agreed that clinicians will wait with developing patient pathways until the ePAG have developed their own to be used as basis.