

VALUE OF REMISSION

An Advocacy Roundtable Summary

Vienna, Austria • June 2024



Introduction

Patient advocates and healthcare professionals working in rheumatic diseases across Europe and beyond gathered in June 2024 to explore remission's value as a key goal for patient care. The meeting, convened by the Global Alliance for Patient Access and officially related to the EULAR Congress, drew nearly 50 rheumatic disease leaders. The group responded to an [INITIAL REPORT](#) and [NEW EVIDENCE GLOSSARY](#) produced by GAfPA on the topic of remission in inflammatory rheumatic conditions. Meeting participants also discussed potential solutions for their respective patient communities.

Encouraging Adherence & Educating Patients

Meeting participants discussed the need for adherence while pursuing remission, as this plays an important part in achieving better patient outcomes and most importantly, better quality of life. Adherence to treatment, even after achieving remission, is also critical. While remission means patients aren't experiencing symptoms caused by active disease, it's not a cure. Patients risk returning to earlier states of their condition, or even disease progression, if they don't adhere to their prescribed treatment. That's why educating patients on the value of adherence and encouraging them to maintain their treatment is a critical step.

Remission is not achievable for all patients. Nevertheless, patients benefit most when they understand their condition and can work with their healthcare team to pursue remission, participants explained. They may not realise that remission is an option or that, even if attained, remission isn't a cure. Resources that walk patients through lifestyle changes or potential outcomes could also be helpful in identifying ways for patients to maintain or pursue remission.

Supporting Healthcare Providers

Education for healthcare providers is also crucial, meeting participants explained. Many providers need greater awareness of remission, its value and how to help patients get there. They also need improved access to tools and treatments to care for patients. While providers may be aware of the value of remission, they need the right resources to help patients achieve it.

While providers may be aware of the value of remission, that value can be realised only if providers have the means to help patients on this journey. Participants also emphasised the need for shared decision making in the clinic when treatment options are addressed. Involving patients can encourage them to become more empowered and proactive in the pursuit of remission. Patients and providers can

work together in considering side effects and the likely efficacy of various treatments as they search for the best health outcomes.

Planning for Remission

Meeting participants also discussed the need to better understand the financial burden on the health care system of sub-optimal treatment or, in some countries, going without treatment. Remission does not represent a cost or burden for patients, rather it will actually reduce the financial cost to the broader healthcare system if patients can avoid episodes that require additional services, especially those provided in hospitals.

Advocates need data, however, to make this case. Meeting participants identified the need for data to promote the value of remission not just on a patient outcome level, but with regard to the financial burden on the healthcare system. This type of resource is an effective advocacy tool that can be shared with patients, providers and policymakers alike, to effect the changes that could make remission more achievable.

Improving Care Systems

Participants discussed how access to care is crucial. Many patients do not raise the issue of remission with their rheumatologist or specialist nurse because they don't consider their condition serious enough, and they feel that some treatment is better than no treatment, even though remission might be an option for them.

Gaps in care also pose a serious challenge. Patients should be able to access care and treatment to pursue remission with the best resources available. The healthcare system must also be improved so that providers feel they have the freedom to test and diagnose as early as possible, as this greatly improves the likelihood of remission.

Conclusions

Remission is an investment which can deliver value for everyone – patients, families, providers, health care systems and the wider economy. Many people with inflammatory rheumatic conditions are of working age, and it is a 'win-win' when they can live independently and work, thereby paying taxes rather than needing to claim disability benefits. While achieving and maintaining remission may be challenging, the work pays off – and patients benefit.

Meeting participants recognised that access barriers and education hurdles can pose serious challenges. However, no patient should have to settle for second best when remission may be possible. The advocacy community can work together to highlight the immense benefits of remission and to further good policies that help many more patients realise remission. Advocates and policymakers have a big role to play on the collective journey to remission becoming more commonly achieved, and their work begins now.



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