

ELEVATING THE VOICES OF PATIENTS WITH RHEUMATIC & MUSCULOSKELETAL DISEASES

*in European Health Technology
Assessments*

A Summary of the June 2021
Virtual Meeting of
RMD Patient Advocacy Groups



On 4 June 2021, in a Related Meeting of the EULAR Congress, the European Alliance for Patient Access convened rheumatic and musculoskeletal disease, or RMD, patient advocacy groups. Their discussion explored the need for the patient perspective in decision-making about health care value and access, as well as the challenges that patient groups encounter in the health technology assessment process.

Presenters & Topics



Neil Betteridge

Strategic Advisor, European Alliance for Patient Access, welcomed participants to the meeting.

Betteridge underscored the importance of patient engagement in health technology assessment. He urged participants to speak openly about their experiences with national and European assessment agencies and to think collaboratively about overcoming barriers to RMD patient involvement.



Brian Kennedy

Executive Director, Global Alliance for Patient Access, presented a summary of a study undertaken by the Global Alliance for Patient Access to determine what patient engagement in health technology assessment looks like in Europe and the United States.

The study highlighted certain strengths, Kennedy explained, such as organised engagement opportunities in the UK and patient representation on working groups and committees in Germany. But the need for improvement is clear, Kennedy emphasised, especially when it comes to making patient engagement more meaningful.

Health technology assessment organisations need to empower more patients in the decision-making process, Kennedy noted, and use widespread, plain-language materials to encourage greater participation and engagement.



Anne Willemson

Zorginstituut Nederland and formerly of the European Network for Health Technology Assessment, or EUnetHTA, provided the keynote presentation, “How Patient Impact in HTA Can Be Strengthened.”

Willemson described some of the challenges EUnetHTA faced when aiming to strengthen Europe’s health technology assessment appraisal process through direct patient involvement. Challenges included:

- Tight timelines
- Burden of disease on patients
- Trouble identifying patients
- Language and visibility barriers
- Conflicts of interests

Patient perspectives in health technology assessment are vital, as patients provide experiential knowledge of living with and treating a disease. They also offer insight into the signs and symptoms that have the greatest impact on quality of life. EUnetHTA looks to bolster patient involvement through patient input templates, individual interviews and group conversations.



Serena Mingolla

Communications Consultant, Associazione Nazionale Persone con Malattie Reumatologiche e Rare, presented on her organization’s efforts in Italy to enhance patient access in fibromyalgia through patient training.

Associazione Nazionale Persone con Malattie Reumatologiche e Rare attended a health technology assessment training course organised by the Puglia HTA Center CREHTA that fosters collaboration between patients and patient groups and guides effective participation and influential input in assessments.

Ailsa Bosworth

National Patient Champion, National Rheumatoid Arthritis Society, outlined possible reasons for the lack of organisational involvement in health technology assessment in the UK. These include:

- Inadequate financial compensation
- Extensive and hard-to-comprehend documents
- Lack of resources
- Need for training courses

In the UK, the National Institute for Health and Care Excellence is improving meaningful patient involvement in these assessments through training, greater support, and more questions to patients and patient groups. Bosworth recommended that other organisations across Europe also adopt this approach.





Key Themes

The meeting's discussion made one point clear: RMD patient organisations across Europe encounter a number of barriers to getting their voices heard during health technology assessments. Certain themes in particular loomed large during the online discussion.



Recruitment

Participants agreed that it can be hard to recruit patients for health technology assessment participation. This can be attributed to the burden of disease that patients living with RMD face. Patient organisations may also have scarce resources – further exacerbated by the COVID-19 pandemic.

Patient advocacy groups can raise awareness about the importance of patient involvement and encourage participation in a number of ways, including:

- Explaining in non-technical terms the purpose and nature of health technology assessment and the process for input
- Conveying the role of patients in the health technology assessment process

- Disseminating widespread plain-language materials in translated languages



Process Complexity

Health technology assessments are complicated, with tight deadlines and multiple stages that may not be familiar to patients and patient organisations. Oftentimes, patients are unclear about what is expected of them.

Training for patient groups can be a valuable resource and can empower them to become active partners in the process. Training can also ensure that patients provide meaningful, usable input on issues relating to disease impact and quality of life.



Lack of Support

Agencies in charge of the health technology assessment process tend to adopt a 'build it and they will come' approach, with little help to guide patient groups.

Improved communication about what is wanted, why and when, as well as sufficient lead time, would encourage patient representative recruitment and engagement. Health technology assessment organisations also need dedicated staff to support and guide patient organisations in their participation.



Lack of Resources

Participating in a health technology assessment can require expertise, time and manpower. Meaningful compensation,

however, is non-existent or inadequate, leading to the lack of patient organisation involvement.

Financial compensation would help account for the significant time required for patient involvement and improve participation.



Impact & Accountability

To ensure that patient organisations are meaningful collaborators in the process, health technology agencies should include patients on committees or grant voting rights.

Furthermore, patient groups could benefit from a statement of how the health technology agency plans to use patient input and a report accounting for how they followed through. This ensures that, when patient organisations do engage, their efforts are not overlooked.

Conclusion

EAFPA concluded the meeting by urging the groups in attendance to continue national advocacy efforts and work together to more meaningfully engage RMD patient voices in national and regional decisions about health care value and access.

There are millions of people living with RMDs in Europe who need timely access to innovative and life-changing treatment. By coming together and sharing insights and strategies, patient groups can make strides toward improving health technology assessments and ensuring that patient input becomes more meaningful in Europe.

Participants

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About the European Alliance for Patient Access

The European Alliance for Patient Access is a division of the Global Alliance for Patient Access, an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.

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