

EULAR Standing Committee of PARE

Our Values and Principles

Our activities will be informed by the following values and principles:

- a) We believe that organisations of people with arthritis/musculoskeletal conditions are most effective when they are **user-led or at least user-centred**. The EULAR Standing Committee of People with Arthritis/Rheumatism in Europe should **promote and reflect this in its own activities and leadership**.
- b) We will also prioritise activities and projects which are led by and/or focus on and actively **involve people with arthritis/musculoskeletal conditions**.
- c) We will prioritise activities and projects which demonstrate that they will **benefit the wider community of people with arthritis/musculoskeletal conditions as well as the individuals directly participating; the ‘wider community’ includes people at risk of developing arthritis/musculoskeletal conditions**.
- d) We believe in promoting the **social model of disability** and will seek to promote this through our work; we are committed to equal opportunities, recognising that the diversity of the arthritis/musculoskeletal conditions community is one of its strengths.
- e) We will be **transparent, accountable, representative and inclusive** in our governance structures and activities.
- f) We will determine **objectives and outcomes** for our activities, and **monitor and evaluate** our work against these.
- g) We will be **collaborative** in our activities, seeking opportunities to work in **partnership** with others both within and outside the arthritis/musculoskeletal conditions community. We will also prioritise activities and projects which promote partnership.
- h) We will **review** our values and principles regularly.

EULAR definition on User-led Organisations (ULOs)

EULAR defined principles on “User-led organisations” to give guidance and to aid the development to build user led organisations for Rheumatic and Musculoskeletal diseases in Europe and around the world. PARE organisations should follow the recommended principles of User-led Organisations recommended by EULAR.

Firstly, there are two principal ways in which an organisation’s commitment to being user-led is manifest:

1. Structure (governance, representation on the board, accountability to people with RMD, etc)
2. Culture (a tangible commitment to involving people with RMD as active participants in all of the services which the organisation provides)

A user led organisation *must* be:

- Fully inclusive of all people with the condition/s it purports to support
- Transparent about this involvement, so that it can demonstrate its mandate to speak on behalf of all people with RMD within its proscribed geographical area
- Committed to ensuring that its governing board shall comprise at least 51% people with RMD, who are also involved with wider networks of people with RMD
- Able to show how its governance arrangements provide formal accountability to people with RMD (eg voting arrangements)
- Able to show its organisational activities as a whole provide informal accountability to people with RMD (eg consultation with people with RMD on all major projects)
- Independent, autonomous and completely unconstrained by other stakeholders (eg, funders, industry, health care professionals)
- Country wide (if it wishes to be a PARE member)

***Desirably*, the organisation should:**

optimise the potential created by being user-led and use its credibility as a voice of people with RMD by:

- Taking positive actions on behalf of its members / supporters, eg raising awareness of the impact of the condition/s on people's lives and on society
- Influencing decision makers in important areas such as health care, rehabilitation, education / work, and other social policies
- Providing peer support so that people with RMD gain personal benefit in empowering ways and are not asked just to provide external influence