

## ERN Support and Training programme- WP17- EJP RD

### Report Workshop “Rare Together”

#### Date/Venue/Format

May, 8-9<sup>th</sup> 2023

#### Numbers (participants, speakers, ERNs represented, patient representatives)

23 participants from seven different EU countries (The Netherlands (13), Italy (2), Bulgaria (1), United Kingdom (2), Germany (2), Norway (2), and Sweden (1)). The participants consisted of clinicians, researchers, clinician researchers, therapists and a patient representative.

#### Analysis of the workshop satisfaction survey.

Data from the satisfaction survey was obtained from 12 participants. The participants rated the usefulness of the workshop useful (n=7) or extremely useful (n=5). The program was rated as fairly good (n=1), good (n=6) and excellent (n=5). For future workshops, participants encouraged to include more patient representation or to extend the duration of the workshop (e.g. to 3-3.5 days).

#### 2-3 participants' testimonials

##### Participant 1 (Bulgaria):

“The best aspect was the opportunity to exchange knowledge and experience with experts from leading centers on rare diseases in Western Europe”.

##### Participant 2 (Norway):

“This workshop will influence my current practice by giving more effort in psychological follow up”

#### If applicable a main result of the workshop (e.g. working group created to do xxxx)

A working group was created to exchange psychosocial expertise and advocate for the importance of mental health representation in rare disease. One of the deliverables of the workshop will be a consensus statement in



which the most important psychosocial needs and future research directions in rare diseases will be addressed.

**Conclusions, lessons learned, best practice to keep in mind.**

Altogether, participants addressed that the workshop created an important network for patient well-being in rare diseases and to address the current research gaps.

