

# ERN GUARD-Heart Patient-Clinician Reflection Session

## Agenda

### Objective(s) for this session:

The aim is to build up and strengthen patient-clinician collaboration. Everyone is invited to provide their perspectives and mutual feedback on different aspects of their collaboration.

More patient participation in any area of ERN GUARD-Heart's actions is meant to improve the Networks' responsiveness to patient needs. Hopefully this will ultimately lead to better outcomes for all.

**"Patient partnership implies going beyond empowerment and engagement but considering people living with a rare disease and their advocates as equal partners and actors in policy and programme design and evaluation". Rare2030 Recommendation 5**

### Target audience:

- ERN management Team: Arthur Wilde, A.S. Amin, Nynke Hofman
- ePAG advocates: Ruth Biller (Chair and ePAG Steering Committee), Ester Costafreda (Co-Chair), Simone Louisse (ePAG Steering Committee Co-Chair)
- Thematic Area Leaders: Elena Arbelo, Philippe Charron, Georgia Sarquella-Brugada, Nico Blom, Annemien van den Bosch, Alida Caforio

### Moderator:

- Rita Francisco (EURORDIS)

### Note-takers:

- Rita Francisco (EURORDIS)
- A.S. Amin (ERN Management Team)

**Date:** 15 March 2023, 11:00 am

**Session duration:** 2 hours

**Location/Format:** Trippenhuis, Anna Maria van Schurmanzaal, Kloveniersburgwal 29, 1011 JV Amsterdam

**Agenda:** see next page

| Time                                | Session moment  | Person(s) responsible   |
|-------------------------------------|---|---|
| 4 min                               | <b>Welcome and introduction</b> to the session  | Moderator   |
| 12 min                              | <b>Tour de table:</b> each participant introduces him/herself   | All participants  |
| 30 min (~3 minutes per participant) | <p><b>Challenges and Successes:</b> Each participant shares their views on challenges and successes. Potential questions may include:</p> <ol style="list-style-type: none"> <li>1. Recall a story of <b>a challenge or failure in terms of teamwork between your ERN patient representatives and clinicians</b>. What happened? When did something go wrong? When were you disappointed with the outcome of something you attempted? Why do you think this happened? What new challenges or opportunities did it create?</li> <li>2. Recall a story <b>of success you were part of this past year in terms of cooperation between your ERN patient representatives and clinicians</b>. What happened? What did you and the team accomplish? Why do you think this happened? What was the value of this collaboration – how would the result have been different if you would not have done it together?</li> </ol> | 3 ePAGs, 3 ERN management team, 3 HCPs who were there from the beginning (Philippe, Georgia, Alida)<br>-> 9 persons |
| 30 min                              | <b>Time to reflect on the Challenges and Successes:</b> Participants discuss the shared challenges and successes. Open and constructive discussion and feedback should ensue, with participants elaborating on their views, needs and expectations.   | All participants  |
| 25 min                              | <p><b>Time for action:</b> Design and commit to a work plan/outcome. Specific points you may want to add to your action plan include:</p> <p>Where do you see <b>projects and opportunities for patients and clinicians to work together e.g., overall ERN work plan, registries, consensus statements</b> (this and next year)?</p> <p><b>How are patients going to be involved</b> in these projects?<br/>If there are no projects, can we create any?</p> <p>Can we <b>involve patient or clinicians more effectively and systematically</b> in clinician-led or patient-led projects? How?</p> <p>Can <b>communication be improved</b>? How?</p>  | All participants  |
| 4 min                               | <p><b>Wrap-up and closing</b></p> <p>Moderator and note taker read the concrete actions agreed on by the participants. Reminds participants about possible follow up actions, including a feedback survey and a debriefing call.</p>  | Moderator/<br>Note taker  |