



EURORDIS LEADERSHIP SCHOOL ON HEALTHCARE & RESEARCH

*Empowering patients to be
partners in European Reference Networks
(ERNs)*

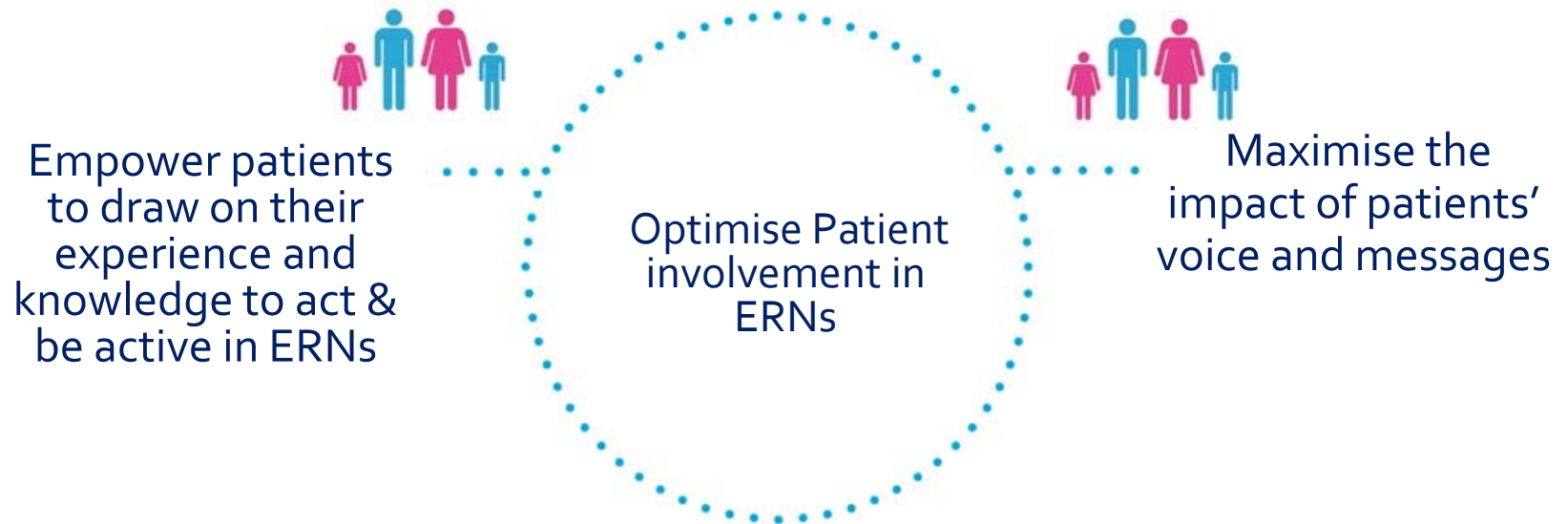
Lenja Wiehe

CNA & CEF Joint meeting, Paris,
11 December

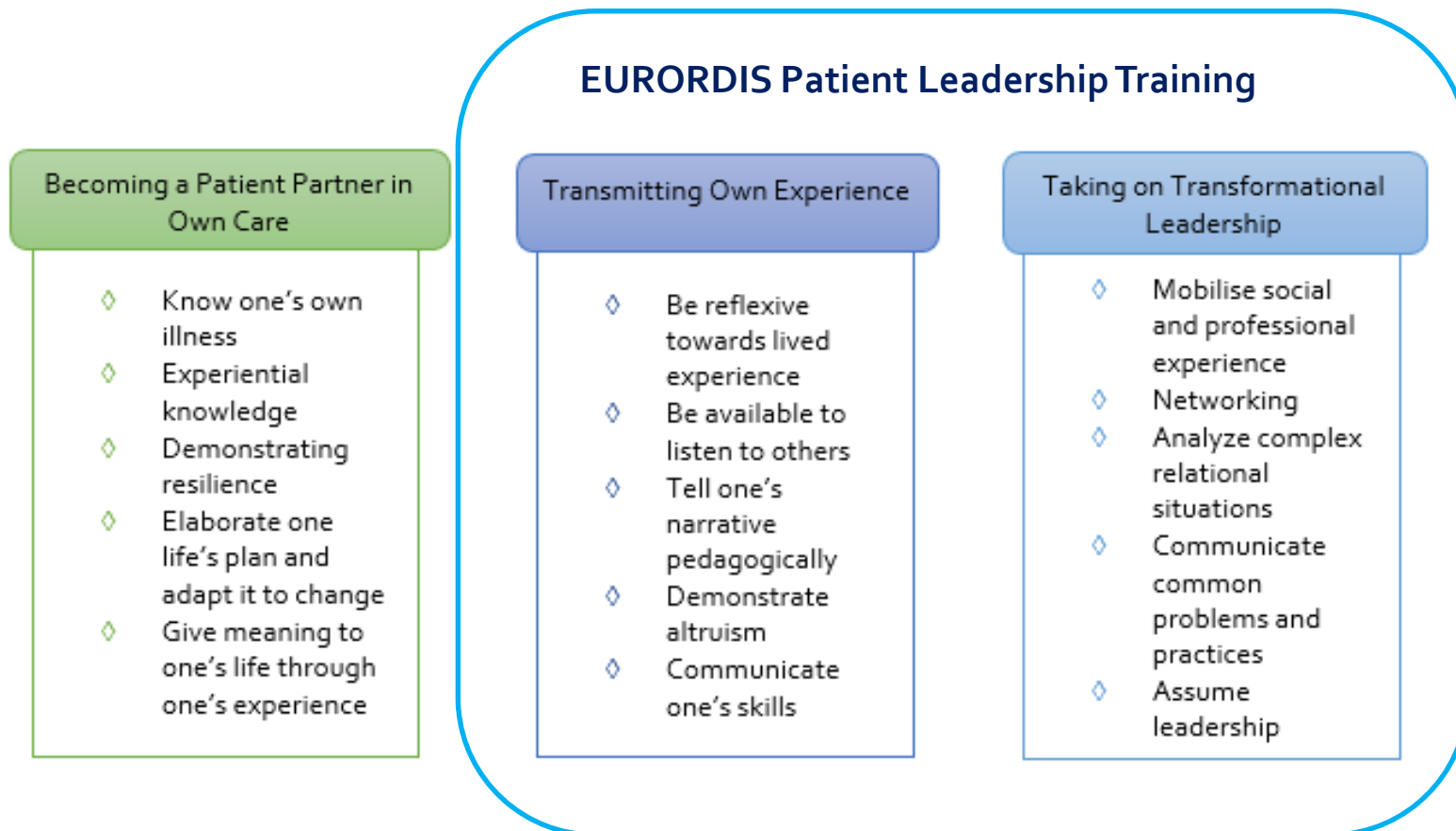
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Aims



Conceptual Model*



*Centre of Excellence on Partnership with Patients and the Public

Objectives

1. Build **interpersonal & leadership skills**, thus improving the collaboration with clinicians and among peer patient advocates.
2. Increase **knowledge about technical aspects & infrastructures** linked to healthcare delivery and research and understanding the role of ERNs within the research and healthcare landscape.
3. Improve **understanding of strategic & operational planning** in healthcare as well as the broader context in which ERNs operate.

EURORDIS Patient Leadership Training - Structure

TRAINING UNITS	TRAINING LEVEL	TRAINING GOALS	TARGET TRAINEES	TIME FRAME	LEARNING METHOD
Leadership	Foundation (Soft Skills)	<ul style="list-style-type: none"> ✓ Develop soft skills needed to collaborate as a valued partner and to successfully share the unique knowledge and personal experience of living with a rare disease 	<p>Advocates' Group: ePAG patient advocates active in their own disease area, involved in a disease-specific core network and in topic-based WG within their ERN</p> <p>New Leaders' Group: ePAG patient advocates who are leaders representing the wider patient community in ERNs Boards and in topic-based working groups</p>	Sem. 1	<p>e-learning 2.5 hours per course: 1.5 hour webinar + 1 hour preparation/ follow up</p> <p>Total: 12h30m</p>
	Specialist (Leadership skills)	<ul style="list-style-type: none"> ✓ Develop the leadership skills and the legitimacy to represent the wider patient community and develop an in-depth understanding of good network governance 	New Leaders' Group	Sem. 2	<p>e-learning 2.5 hours per course: 1.5 hour webinar + 1 hour preparation/ follow up</p> <p>Total: 12h30 & face-to-face 2 days</p>
Technical knowledge	Specialist	<ul style="list-style-type: none"> ✓ Acquire in-depth knowledge of the technical aspects and infrastructures linked to research and healthcare delivery 	Advocates' Group	Sem. 2	<p>e-learning 2 sessions of 2,5 hours per course: 1.5 hour webinar + 1 hour preparation/follow up</p> <p>Total: 25h & face-to-face</p>

Training Path

TARGET TRAINEES	FIRST SEMESTER	SECOND SEMESTER
<p>ADVOCATES GROUP</p> <p>ePAG patient advocates active in their own disease area, involved in a disease-specific core network and in topic-based WG within their ERN</p>	<p>Training Unit: Leadership</p>	<p>Training Unit: Technical knowledge</p>
	<p>Training level: Foundation</p>	<p>Training level: Specialist</p>
	<p>Training objectives:</p> <p>✓ Develop soft skills needed to collaborate as a valued partner and to successfully share the unique knowledge and personal experience of living with a rare disease</p>	<p>Training objectives:</p> <p>✓ Acquire in-depth knowledge of the technical aspects and infrastructures linked to research and healthcare delivery</p>
	<p>Training courses</p> <ol style="list-style-type: none"> 360° Self-awareness Model Leaders Presenting with Impact Good Communicator Conflict Resolution Strategies 	<p>Training courses</p> <ol style="list-style-type: none"> Networks Digital Health Knowledge Generation Research Healthcare

Training Path

TARGET TRAINEES	FIRST SEMESTER	SECOND SEMESTER
<p>NEW LEADERS' GROUP:</p> <p>ePAG patient advocates who are leaders representing the wider patient community in ERNs Boards and in topic-based working groups</p>	<p>Training Unit: Leadership</p>	<p>Training Unit: Leadership</p>
	<p>Training level: Foundation</p>	<p>Training level: Specialist</p>
	<p>Training objectives:</p> <p>✓ Develop soft skills needed to collaborate as a valued partner and to successfully share the unique knowledge and personal experience of living with a rare disease</p>	<p>Training objectives:</p> <p>✓ Develop the leadership skills and the legitimacy to represent the wider patient community and develop an in-depth understanding of good network governance</p>
	<p>Training courses</p> <ol style="list-style-type: none"> 360° Self-awareness Model Leaders Presenting with Impact Good Communicator Conflict Resolution Strategies 	<p>Training courses</p> <ol style="list-style-type: none"> Creating authority and legitimacy Influencing Without Authority Negotiation Programme Management Network Governance & Assurance

Delivery Methods

1. Online Training (interactive online webinars)

- Interactive webinars as the main form of training delivery, for both training Units and both groups of participants
- **Online training provided within Unit 1: Leadership, for both levels, consists of 1 session per training course of 2.5 hours - total of 5 training course = 5 sessions**
- **Online training provided within Unit 2: Technical Knowledge, consists of 2 sessions per training course of 5 hours - total of 5 training course = 10 sessions**

2. Face to Face Workshop

- 2 day Leadership Programme training workshop

Thank you



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