

Work Package 3

Patient Centered Research

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ERICA

European Rare Disease Research
Coordination and Support Action

WP3

Patient centered research

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Kick-off Meeting 27th -28th May

WP3: Patient centered research

Name	Institution	Role
Mar Mañú Pereira - Leader	Vall d'Hebron Research Institute	ERN-Eurobloodnet Scientific Director
Ana Rath - Leader	Institut National de la Sante Et de la Recherche Medicale	ORPHANET Director
Sonia Bothorel	Mapi Research Trust	Mapi Research Trust Managing Director
Mariangela Pellegrini	AP-HP H. St Louis	ERN-Eurobloodnet Patients' program manager
Eduardo López Granados	Madrid Health Service	ERN-TransplantChild Research WG Coordinator
Michael Wilbur	European Organization for Rare Diseases Association	EURORDIS Chief Operating Officer
Alexis Arzimanoglou	Hospices Civils de Lyon	ERN-EpiCare Coordinator
Irene Mathijssen	Erasmus Univeristarir Medish Centrum Rotterdam	ERN-Cranio Coordinator
Hélène Dollfus	Hopitaux Universitaires de Strasbourg	ERN-EYE Coordinator
Ansgar Lohse	Universitaetsklinikum Hamburg-Eppendorf	ERN RARE-LIVER Coordinator
Arthur Wilde	Academisch Medisch Centrum BIJ de Universiteit van Amsterdam	ERN GUARD-HEART Coordinator

WP3: Patient centered research

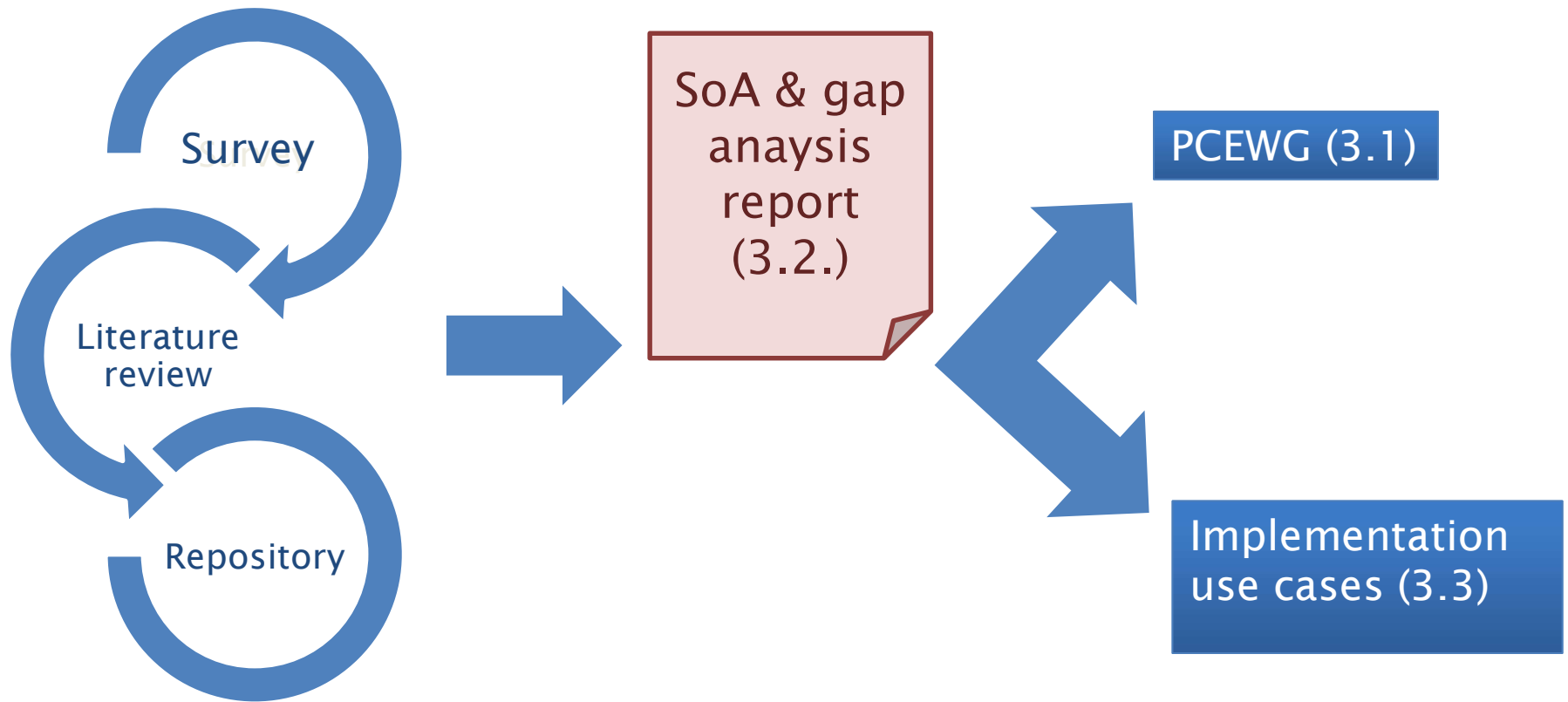
- to create a central repository of (validated) common and domain specific RD PCOMs/PROMs for ERNs
- to define priority areas for future PCOMs/PROMs development
- to support ERNs in the implementation of validated instruments for PCOMs/PROMs

PCOM: Patient Centered Outcome Measure

PROM: Patient Reported Outcome Measures

WP3: Patient centered research

- Task 3.1: Strategic steering of identification, development and implementation of patient-centred outcome measures in ERNs-lead clinical research (VHIR, INSERM/Orphanet);
- Task 3.2: State of the art of available PCOMs/PROMs and overlap/gap analysis (INSERM/Orphanet; Mapi Research Trust, VHIR, EURORDIS, ERNs coordination teams);
- Task 3.3. Supporting ERNs on implementation of validated instruments for PCOMs/PROMs ((VHIR, INSERM/Orphanet, SERMAS, interested ERNs).



WP3: Deliverables

- D3.1. Central repository of (validated) PCOMs for RDs (M18)
- D3.2. Report on the state-of-the-art of available PCOMs/PROMs and overlap/gap analysis (M18)
- D3.3. Report on priority areas for future PCOMs/PROMs development (M24)
- D3.4. Report on at least 3 use-cases scenarios for PCOMs/PROMs implementation (M48)