

A large, semi-transparent anatomical illustration of a human knee joint is positioned on the left side of the slide. It shows the bones and ligaments in a light blue and pinkish hue, set against a background of green and blue gradients.

Patient Engagement in EU Projects: Insights from the SQUEEZE Project

Kristina Chingov, Scientific Project Coordinator, EULAR
Horizon Europe - Health in Action Series



1. The SQUEEZE Project at a Glance: Overview, goals and patient relevance
2. Introduction to EULAR and our team: Who we are and what we do
3. How we engage in European Consortia: collaboration pathway and roles
4. EULAR's role in the SQUEEZE Project: from proposal to implementation
5. Our approach to patient involvement: strategy, methods, evaluation





“

Maximising impact of prescription
drugs in Rheumatoid Arthritis

”

15

PARTNERS

10

EUROPEAN
COUNTRIES

€12M

BUDGET

3

CLINICAL
TRIALS

DATA FROM
>30,000

PATIENTS



SQUEEZE Partners

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EUROPEAN ALLIANCE
OF ASSOCIATIONS
FOR RHEUMATOLOGY



MEDICAL UNIVERSITY
OF VIENNA



Leiden University
Medical Center



Diakonhjemmet
Hospital



Karolinska
Institutet



KAROLINSKA
UNIVERSITETSSJUKHUSET

EU|TE|MA
RESEARCH SERVICES



inmusc
Instituto de Salud Musculoesquelética



HEALTHBUDDY



University
of Basel

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EUROPEAN ALLIANCE
OF ASSOCIATIONS
FOR RHEUMATOLOGY



Queen Mary
University of London

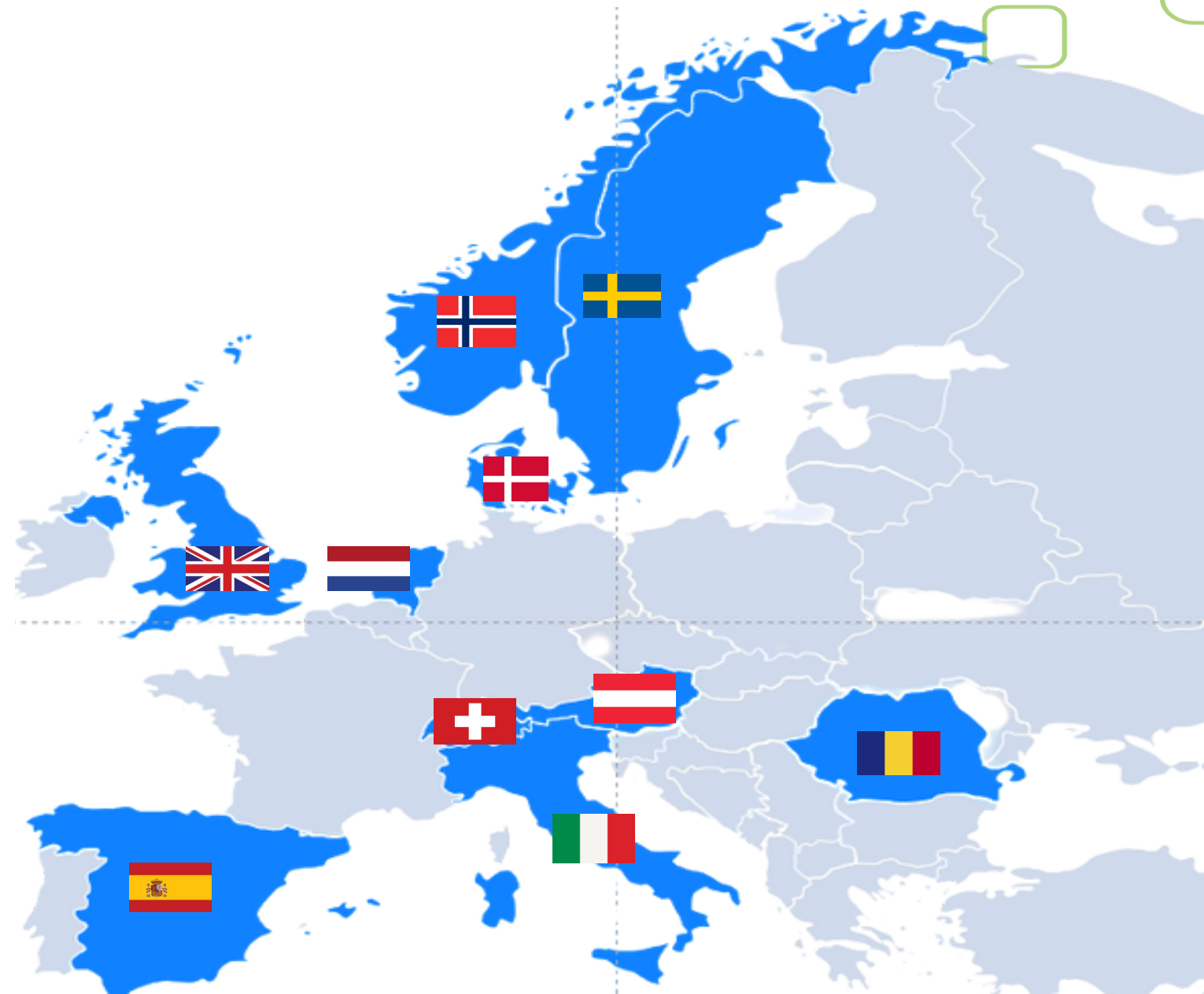


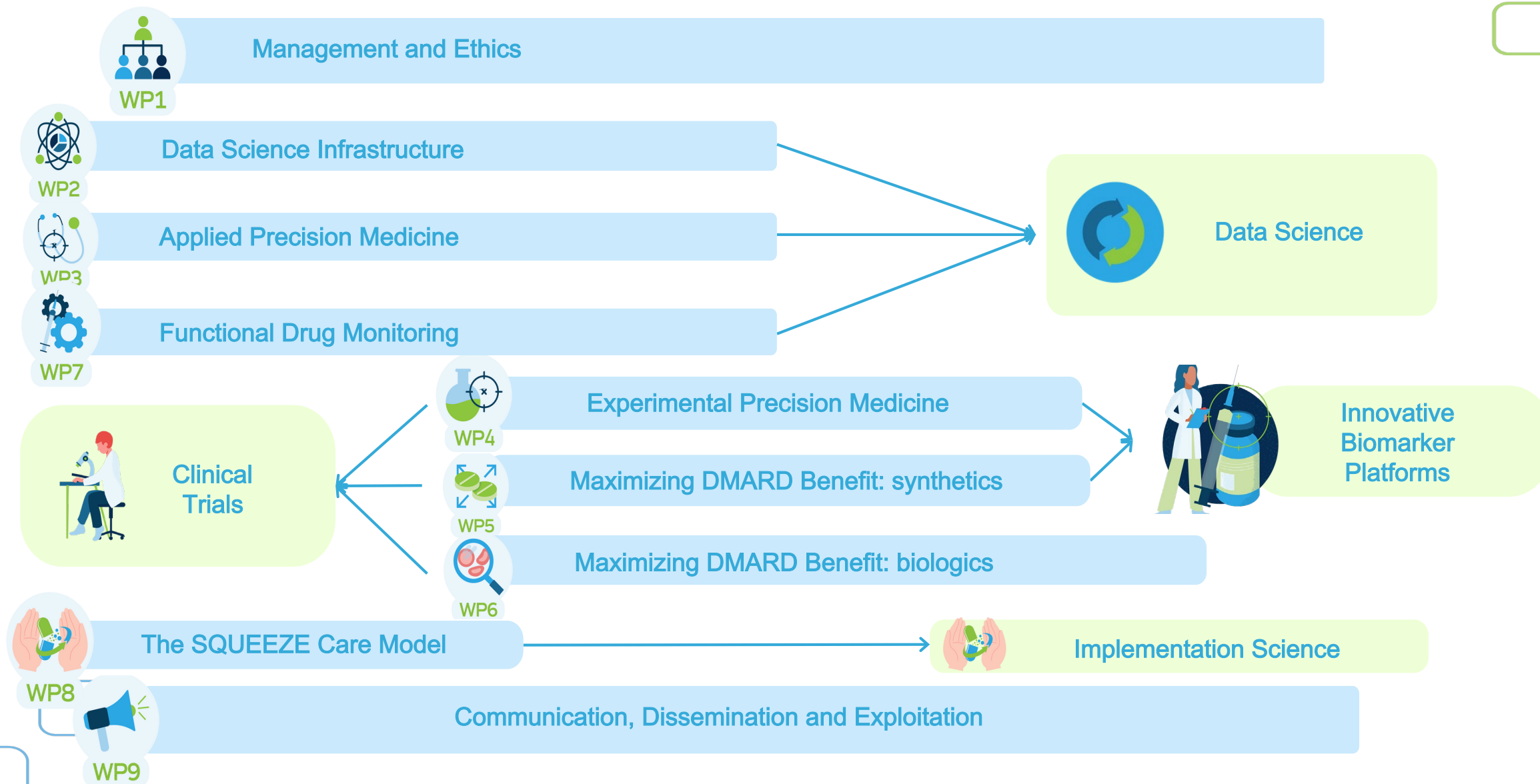
precisionlife
improving health | for everyone

HUMANITAS
RESEARCH HOSPITAL



OSLO UNIVERSITETSSYKEHUS





PRP Testimonial

Heard from our patient experts



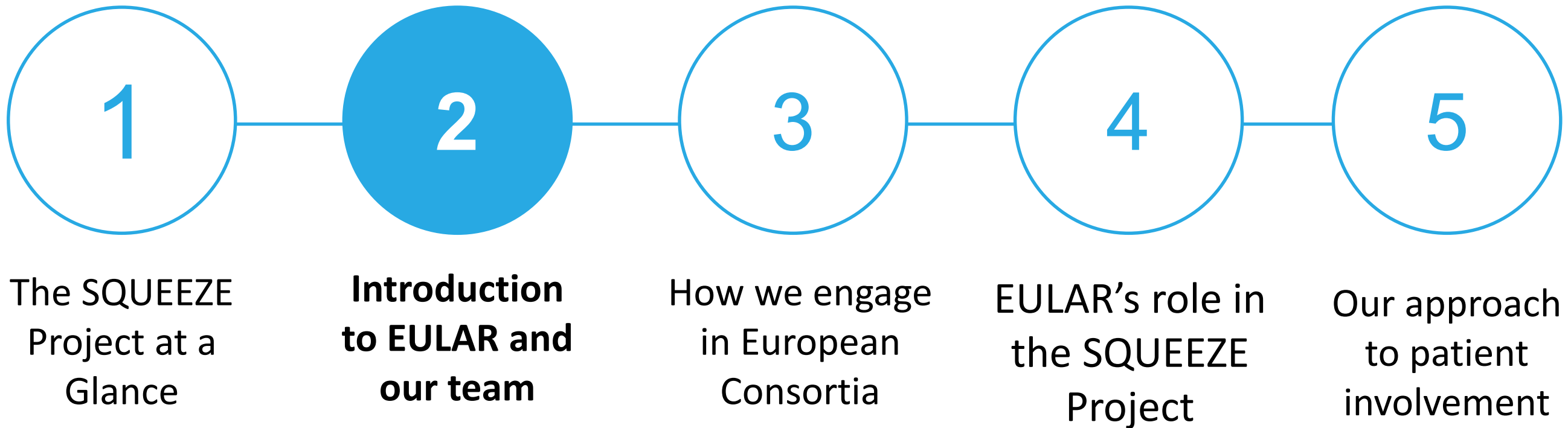
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The objective of SQUEEZE to help decide the right treatment for the right patient is revolutionary. In this way we will avoid delays in starting appropriate and effective treatments, thus having better health outcomes for our patients.

”



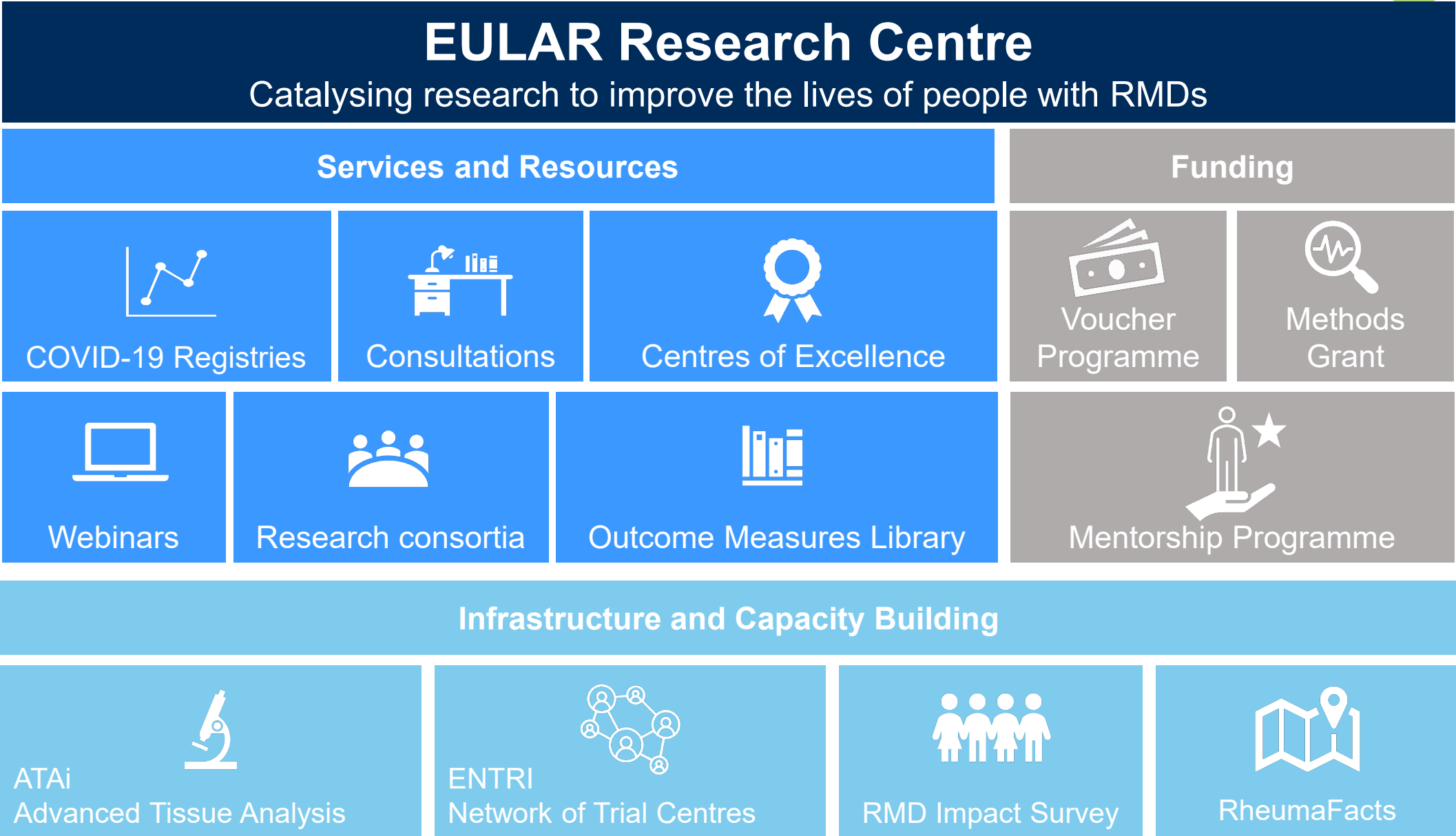
Souzi
Patient Research Partner
Marki



EULAR is a non-profit organisation that represents **people** with **musculoskeletal diseases**, **health professionals** in rheumatology, **rheumatologists**, **researchers** and **scientific societies** in the field of rheumatology of all the European nations.

- Our mission

EULAR aims to **reduce the impact** of these diseases **on the individual and society** and to **improve the quality of life** of people with rheumatic and musculoskeletal diseases in Europe.



Our EU Consortia team



Diana Rodrigues

**Senior Scientific Project
Coordinator**



Anastasiia Miendrova

Project Coordinator



Kristina Chingov

**Scientific Project
Coordinator**



Dr. Coralie Signorell

Research Manager



How do we get involved in Consortia?

EULAR collaborates with consortia across Europe **to help incorporate the patient perspective as well as advocacy and educational considerations** in all stages of international research on rheumatic and musculoskeletal diseases (RMDs). This work is led by EULAR Research in collaboration with EULAR PARE (People with Arthritis and Rheumatism in Europe).

Assessing needs for and ensuring patient involvement

Providing the patient perspective during the project proposal phase to inform and co-develop all aspects of a research project (e.g., work packages, tasks, deliverables) through the collaboration with patient research partners (PRPs) from the EULAR network.

Integrating advocacy and educational components

Offering guidance and support with formulating advocacy and educational objectives, activities and deliverables tailored to the European context and developing tailored capacity building opportunities for patients and/or professionals to help achieve the project's objectives.

Providing patient-centric advice and evaluation of impact

Advising, monitoring, and evaluating the project's impact on patients' lives and health outcomes by supporting with convening patient research partners for Patient Advisory Panels, Steering and/or Executive Committees and Ethics Boars.



Facilitating and monitoring patient involvement

Mediating discussions to align expectations across all parties while ensuring clarity on roles and expectations, organising logistics and assisting in any patient involvement-related activities at any stage of the research, continuous monitoring and evaluating the patient involvement strategies throughout the project.

Developing communication & dissemination activities

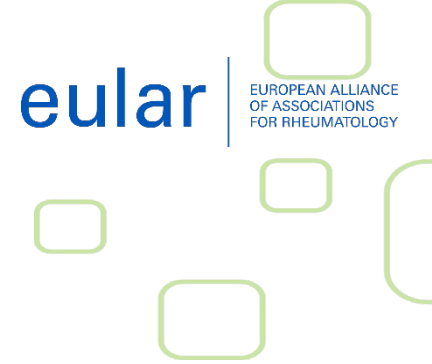
Enabling effective communication among PRPs, researchers and other relevant stakeholders, assisting with developing and disseminating project findings and materials to diverse patient communities and the public through the EULAR communication channels.

Reviewing relevant project documents and deliverables

Contributing to internal and external progress reports and project deliverables, and ensuring that all tasks, protocols, and project documents that require patient input are completed within established timelines.



Eligibility criteria



Eligibility:

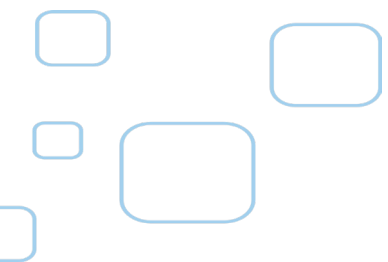
- Consortia and its topic must be **rheumatology** led or co-led.
- Consortia must be based in **EULAR-affiliated countries**.
- Consortia must apply for funding **external** to EULAR (e.g., Horizon Europe, Innovative Medicines Initiative, Innovative Health Initiative).
- Consortia **must contact EULAR as soon as proposal development is initiated** and with at least eight weeks in advance of proposal submission deadline.
- EULAR must be recognised as a **full partner** in the consortia (depending on the activities during the project, EULAR will determine the required budget to carry out these activities).
- Consortia must **ensure the active engagement and equitable participation of patient research partners** (PRPs) from the EULAR network in discussions from the start of the project's design phase.

Terms and Conditions

Support will **depend on EULAR's capacity to accommodate requests**, as well as on the **projects' alignment to EULAR's mission and community**. Kindly note that due to the high volume of inquiries, there might be a delay in responding to collaboration requests. It is recommended to contact the EULAR Research team well in advance to maximize the likelihood of collaboration.

Research Ethics

EULAR expects a **high standard in the conduct of research** it supports. For researchers this includes **scientific integrity** and adherence to the principles of **good research practice**. Patients subjected to investigation shall be included with due **adherence to the declaration of Helsinki**.





Collaboration request form



Interested consortia are invited to submit a [collaboration request online](#).

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Research Consortia Partnerships

Thank you for your interest in working with EULAR. Please fill in the form below for a partnership request on collaborating with EULAR/PARE in an international research consortia focusing on rheumatic and musculoskeletal diseases (RMDs). The form will take approximately 10 minutes to complete.

* Required

Overview of planned project

Please tell us about your project and its objectives, as well as the kind of collaboration expected from EULAR PARE.

1. Name of contact person: *

Enter your answer

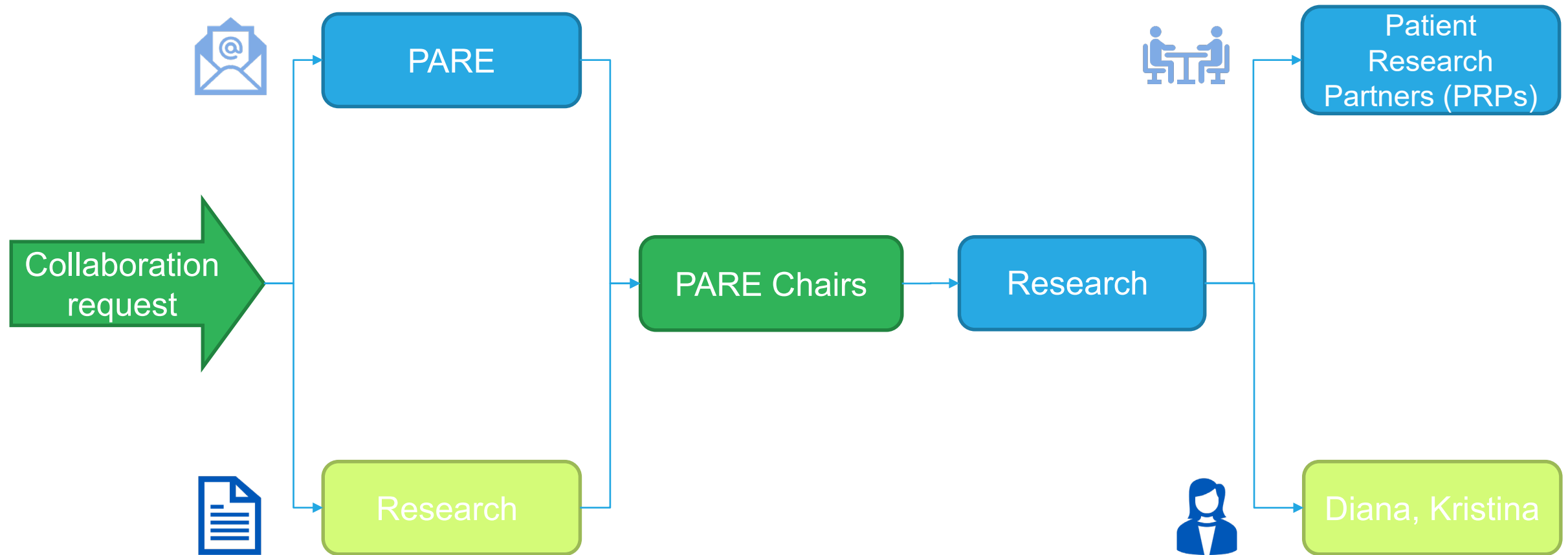
2. E-mail address of contact person: *

Enter your answer

3. Project title: *

Enter your answer

How do we tackle collaboration requests?





EULAR's role in SQUEEZE

EULAR facilitates patient engagement through coordination and communication activities

Recruiting
PRPs from
EULAR
network

Creating
Patient
Advisory
Panel and
assigning
PRPs to WPs

Developing
the Package
of Resources

Organising
introduction
meeting in lay
language

Organising
Meet and
Greet
between
PRPs and
WPs

Facilitating
regular PRP
meetings

Preparing
workshops
and/or
trainings

Evaluating
patient
engagement
via
questionnaires

EULAR's roles in SQUEEZE

EULAR collaborates
Communication,
Dissemination,
Exploitation (WP9), and
other relevant activities





Two-fold approach to Patient Involvement

1



Strengthening Patient Engagement



PRP Recruitment



Patient Panel & Match-Making



Package of Resources



Introduction Meetings



PRP-WP Meet & Greet



Regular PRP Meetings



Workshops & Trainings



In-Person Meetings

2



Coordinating Project & Management Tasks



Proposal & Application Support



Comms & Dissemination



Collaborative Research Support



Deliverables Review



Technical & Financial Reporting



Travel Logistics



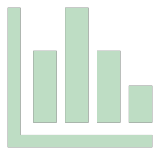
Admin Support



Patient Involvement Evaluation

Cooperation with Consortium Partners

- We always tailor our collaboration based on partner type and stakeholder group
 - Early discussions on patient involvement in each WP – **forms which are filled by each WP leader** themselves
- Preparation is key:
 - Agendas, slides, and materials are requested **at least 1 week in advance**. This helps patients prepare, understand context, and contribute meaningfully
- Proactive outreach:
 - EULAR identifies opportunities where patient input would add value, this is why we contact relevant partners and support the design of engagement activities



For technical/data partners:

- Dedicated meetings with patients
- Partners formulate questions in lay language
- Follow-up alignment meetings to ensure shared understanding



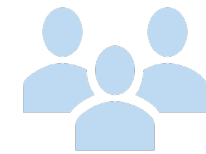
For clinical trials:

- Patients review all patient-facing materials (1–2 weeks in advance)
- Written feedback sent to trial team (content, visuals, logistics)
- Joint discussion meetings to clarify feedback and discuss incorporation
- Meeting minutes shared post-meeting for transparency



For communication work packages:

- At least one patient actively involved
- Usually smooth collaboration, often a good entry point for new patient partners



For ethics and project management:

- Patient partner sits on the ethics group or board
- Input on ethical aspects, project direction, and decision-making



TAKE HOME MESSAGES

- Involve patients **from the start** (the proposal stage)
- Ensure **diverse and meaningful** participation
- Use **flexible approaches tailored** to project needs
- Always **follow up on patient input**
- **Evaluate** patient involvement regularly
- Keep patients **engaged and informed** throughout



Thank you for your time and attention!

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www.squeeze-project.eu



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Confederazione Svizzera
Confederaziun svizra

Swiss Confederation

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Education and Research EAER
State Secretariat for Education,
Research and Innovation SERI



UK Research
and Innovation

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