
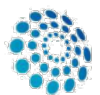
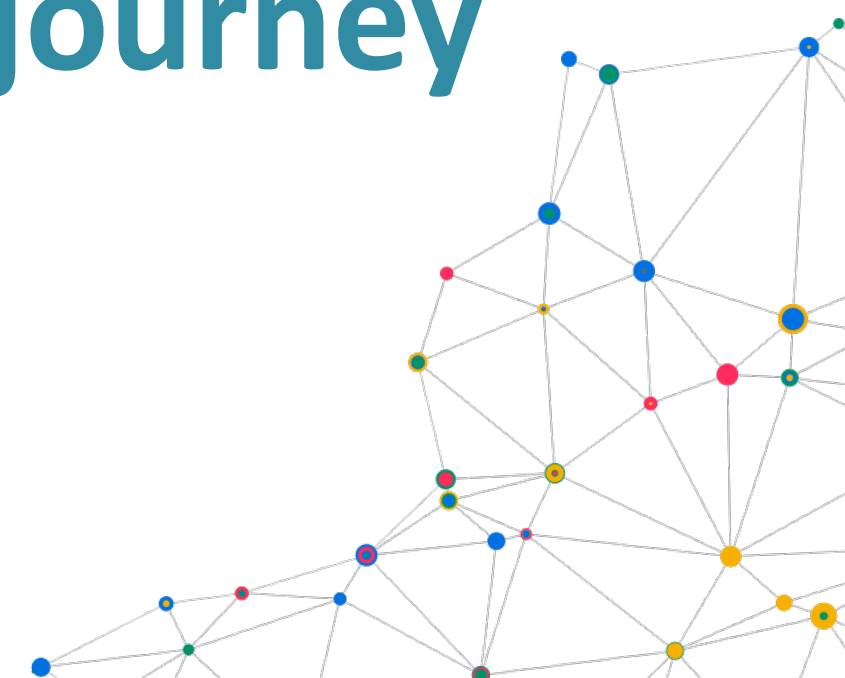


European
Reference
Network

for rare or low prevalence
complex diseases

 **Network**
Connective Tissue
and Musculoskeletal
Diseases (ERN ReCONNET)

Co-designing surveys for rare diseases: the ERN ReCONNET journey



European
Reference
Networks

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Summary

Co-designing surveys
for rare diseases:
the ERN ReCONNET
journey

○ Survey on Clinical Practice Guidelines awareness – I. Galetti

○ Survey on educational needs – S. Aguilera

○ Practical tips – D. Marinello

ERN ReCONNET - Our approach

Silvia Aguilera

Asociación síndrome antifosfolípido - SAF España

Jeanette Andersen

Lupus Europe

Coralie Bouillot

Sjögren Europe

Eva Collado-Gonzalez

Asociación Nacional de Síndromes de Ehlers-Danlos, Hiperlaxitud y Colagenopatías - ANSEDH

Alain Cornet

Lupus Europe

Charissa Frank

bindweefsel.be

Ilaria Galetti

FESCA and GILS

Vera Guimaraes

Liga Portuguesa Contra as Doenças Reumáticas (MCTD)

Monica Holmner

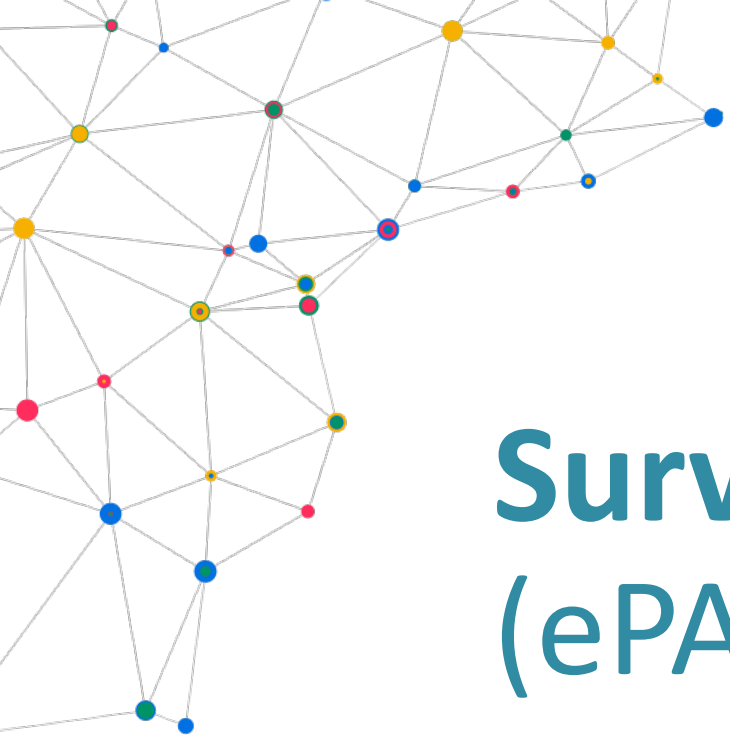
FESCA

Lisa Matthews

Relapsing Polychondritis Awareness and Support




Stronger together



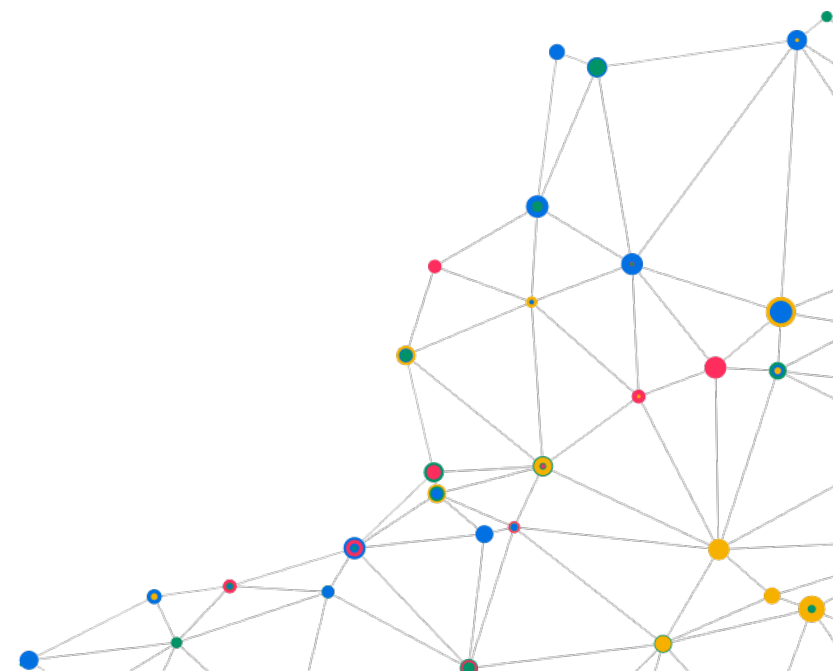
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Survey on CPGs (ePAGs and HCPs)

- Ilaria Galetti
- ERN ReCONNET ePAG, Vice president GILS, FESCA



Survey on clinical practice guidelines



Aims

- Assess the **knowledge** and **awareness** of CPGs in rare and complex connective tissue disorder patients.
- Collect the **views** of rCTDs patients, caregivers and family members on their knowledge of the purpose of CPGs, knowledge of the process of developing CPGs and to gather their perceptions and expectations.
- Better tailor **future** activities.



Survey on clinical practice guidelines

Co-designed by ePAGs and coordination team

Different kind of answers: close, open, likert scale

Understandable and clear language

Comprehensive list of Patients' Organisations

Dissemination via POs and EURORDIS

Survey questions/answers

21-item questions in English

3 sections

1 - General: demographics, level of education, disease, etc.

2 - CPGs knowledge and awareness

3 - Subjective perspective of CPGs

Results and considerations

493 answers

Only some rCTDs have a PO

62% of respondents were aware of the existence of CPGs



This could be a bias due to the fact that the following activities have shown something slightly different

A very good result considering that the survey has been done in the first year of the ERNs activities

**RMD
Open**Rheumatic &
Musculoskeletal
Diseases

Original research

Clinical practice guidelines adherence, knowledge and awareness in rare and complex connective tissue diseases across Europe: results from the first ERN ReCONNET survey

Rosaria Talarico,¹ Diana Marinello,¹ Stefano Bombardieri,² Gerd Burmester ³,
Joao Fonseca,^{4,5} Charissa Frank,⁶ Ilaria Galetti,⁷ Eric Hachulla ⁸,
Frederic Houssiau,⁹ Ulf Mueller-Ladner,^{10,11} Matthias Schneider,¹²
Vanessa Smith,^{13,14} Giuseppe Turchetti,¹⁵ Jacob M van Laar,¹⁶ Ana Vieira,¹⁷
Maurizio Cutolo,^{18,19} Marta Mosca^{1,20}

Published in 2020, on an open access journal

3 ePAGs are co-authors of the article


Uptake of survey results

Results	How results were/are addressed
95% of the respondents thought that the creation of a patient-friendly version of CPGs would be useful	Development of Lay versions on SSc and SLE
Need for CPGs to be fully applicable in clinical practice (achievable only if CPGs are subject to local adaptations)	Adaptation of existing CPGs - ADAPTE
Difficulty in identifying reliable source of information on CPGs	Repository of existing CPGs and relevant publications on ERN ReCONNET website
Increase awareness on the existing CPGs for their disease	ERN ReCONNET webinar on CPGs and repository on website
Few CPGs available	Development of new CPGs if possible, collection of new evidence



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Survey on educational needs

- Silvia Aguilera
- ePAG ERN ReCONNET, Vice-president APS Spain (SAF España)



Co-funded by the European Union

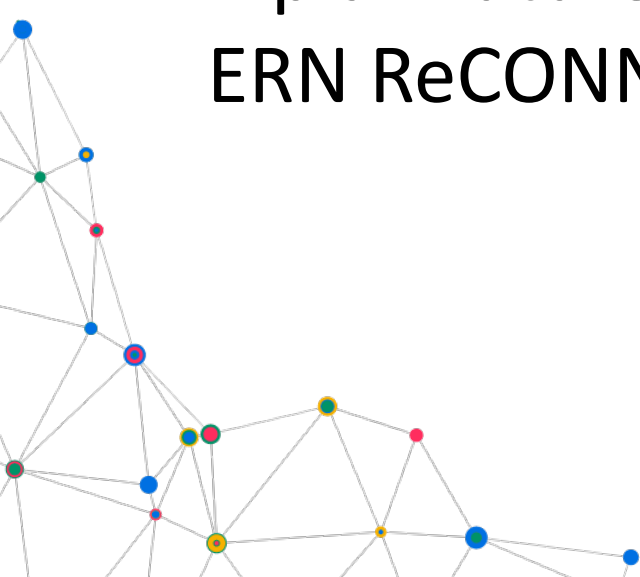


Survey on educational needs



Aims:

- collect the training needs of European patients, patients' representatives and caregivers affected by rare and complex connective tissue diseases
- plan future of educational and training activities of the ERN ReCONNET dedicated to patients and caregivers



Survey on educational needs

Steps:

ERN proposes initial draft (9 Nov '21)

ePAG uploads survey to work on it collaboratively (until 15 Nov)

Call with ERN to solve questions and comments from first iteration (16 Nov)

Second ePAG iteration (until 21 Nov)

OK from ERN

Final Survey Launch (23 Nov)



Training and educational needs of patients and caregivers living with rare and complex connective tissue diseases: ERN ReCONNET survey

Fields marked with * are mandatory.

The European Reference Network on rare and complex connective tissue and musculoskeletal diseases (ERN ReCONNET) is a Network of centres of expertise that aims at improving the care of patients across Europe (for more information, please visit our website: <https://reconnet.ern-net.eu/>).

Among other initiatives, the ERN ReCONNET has launched a survey in order to collect the training needs of European patients, patients' representatives and caregivers affected by rare and complex connective tissue diseases.

The results will also help us in planning future educational and training activities of the ERN ReCONNET dedicated to patients and caregivers.

We would therefore be very grateful if you would share your point of view and your perspectives replying to the following survey.

Thank you for your time and for your precious contribution.

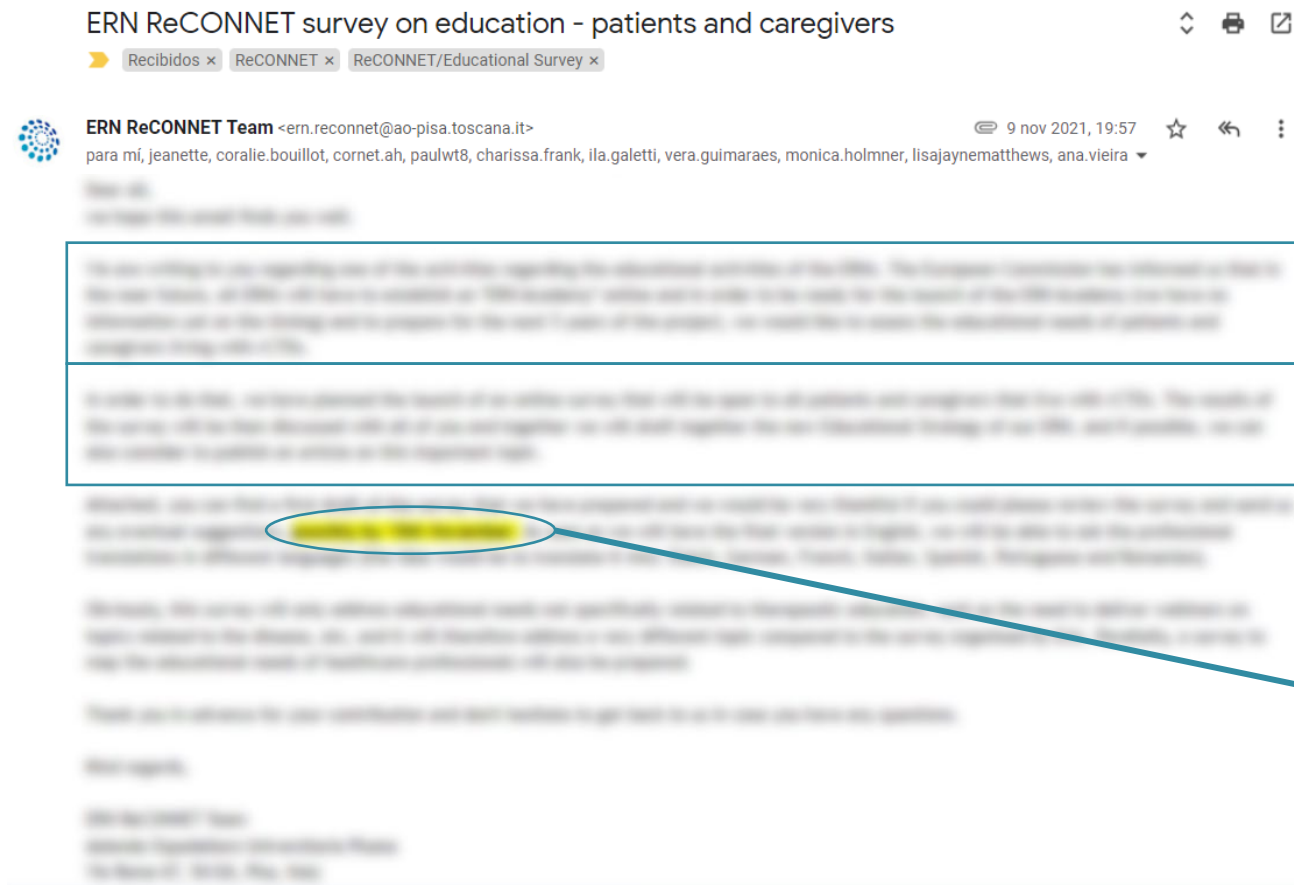
*Are you?
 A patient
 A caregiver

*Where do you live?
 Austria
 Belgium
 Bulgaria
 Croatia
 Cyprus

Survey on educational needs

Steps:

- ERIN proposes a first draft of the survey by email



Objectives for the survey

Further steps and outcomes

Clear deadline + more info on translation, dissemination, etc.

Survey on educational needs

Steps:

• A first draft is sent to the ePAG

Training and educational needs of patients and caregivers living with rare and complex connective tissue diseases: ERN ReCONNET survey

The European Reference Network on rare and complex connective tissue and musculoskeletal diseases (ERN ReCONNET) is a Network of centres of expertise that aims at improving the care of patients across Europe (for more information, please visit our website: <https://reconnet.ern-net.eu/>).

Among other initiatives, the ERN ReCONNET has launched the current survey in order to collect the training needs of European patients and caregivers living with rare and complex connective tissue diseases.

The results will also help us in planning future educational and training activities of the ERN ReCONNET dedicated to patients and caregivers.

We would therefore be very grateful if you would share your point of view and your perspectives replying to the following survey.

Thank you for your time and for your precious contribution.

Are you?

- A patient
- A caregiver

Where do you live?

- Austria
- Belgium
- Bulgaria
- Croatia
- Cyprus
- Czechia
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Romania
- Slovak Republic
- Slovenia
- Spain
- Sweden
- In another country (please specify below)

Are you a patient representative or a member of a patient association dealing with rare and complex connective tissue diseases?

- I am a patient representative
- I am a member of a patient association

Do you think that patients living with rare and complex connective tissue diseases should receive training?

- Yes
- No

If yes, which topics should be covered in the training?

- Training on the disease
- Training on how to self-manage the disease
- Training on treatments
- Training on how to participate in the treatment decision-making processes
- Training on
- Other (please specify below)

How should the training be delivered?

- Online training
- Face to face training
- Hybrid training (online and face to face)
- Other (please specify below)

- Training on the disease
- Training on how to self-manage the disease
- Training on treatments
- Training on how to participate in the treatment decision-making processes
- Training on
- Other (please specify below)

How should the training be delivered?

- Online training
- Face to face training
- Hybrid training (online and face to face)
- Other (please specify below)

Do you think that caregivers living with rare and complex connective tissue diseases should receive training?

- Yes
- No

If yes, which topics should be covered in the training?

- How to support the patient in daily life
- Understanding the diagnosis and participating the in the care process
- Other (please specify below)

Do you think that patients representatives of rare and complex connective tissue diseases should receive training?

- Yes
- No

If yes, which topics should be covered in the training?

Open field

Survey on educational needs

Steps:

- ePAG makes an online collaborative copy and works on it



At this stage we have complete freedom to add, change or delete questions and answers from the survey

Change contributors

← November 13, 2021, 8:19 PM [Restore this version](#)

100% Total: 1 edit

Who should deliver the training?
The ERN
The patient associations/federations
The doctors
The Health service
GP
Other (please specify below)

How should the training be delivered?
Online training
Face to face training
Hybrid training (online and face to face)
At the hospital
Other (please specify below)

Do you think that caregivers living with rare and complex connective tissue diseases should receive training?
Yes
No

If yes, why?

Version history

All versions

- November 14, 2021, 10:35 AM
Silvia Aguilera
- November 14, 2021, 9:19 AM
Silvia Aguilera
- November 14, 2021, 8:45 AM
Ilaria Galetti
- November 13, 2021, 9:57 PM
Silvia Aguilera
- November 13, 2021, 8:19 PM
Ilaria Galetti
- November 13, 2021, 8:19 PM** [Show changes](#)
Ilaria Galetti
- November 13, 2021, 8:19 PM
Ilaria Galetti
- November 13, 2021, 8:15 PM
Ilaria Galetti
- November 12, 2021, 9:12 PM
Ilaria Galetti

Changes

Survey on educational needs

Steps:

- During this process, questions and comments arise and a call between the ERN and the survey leads is done
- The ERN replies so that a final iteration of the survey can be conducted

Survey on educational needs

Steps:

- An email informing the rest of the ePAG is sent for a final call for changes



Change on
the survey
structure
(PO/ no PO)

Help for
translations

Survey on educational needs

Comparison

	Draft by ERN	Final version
Target population	European patients, patients' representatives and caregivers	Differentiate people in PO or not
No. questions	13	21

Short comparison of the 2 surveys

- 493 Replies

- ePAG in SC involved as authors in the publication

- Survey developed in English

- No question to profile respondents

- 1426 Replies

- All ePAGs involved in the publication

- Survey developed in 15 EU languages

- Respondents profiled (pts, caregivers, both)


- Calls to co-design and discuss results

- Co-planning of initiatives



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Practical tips based on our experience

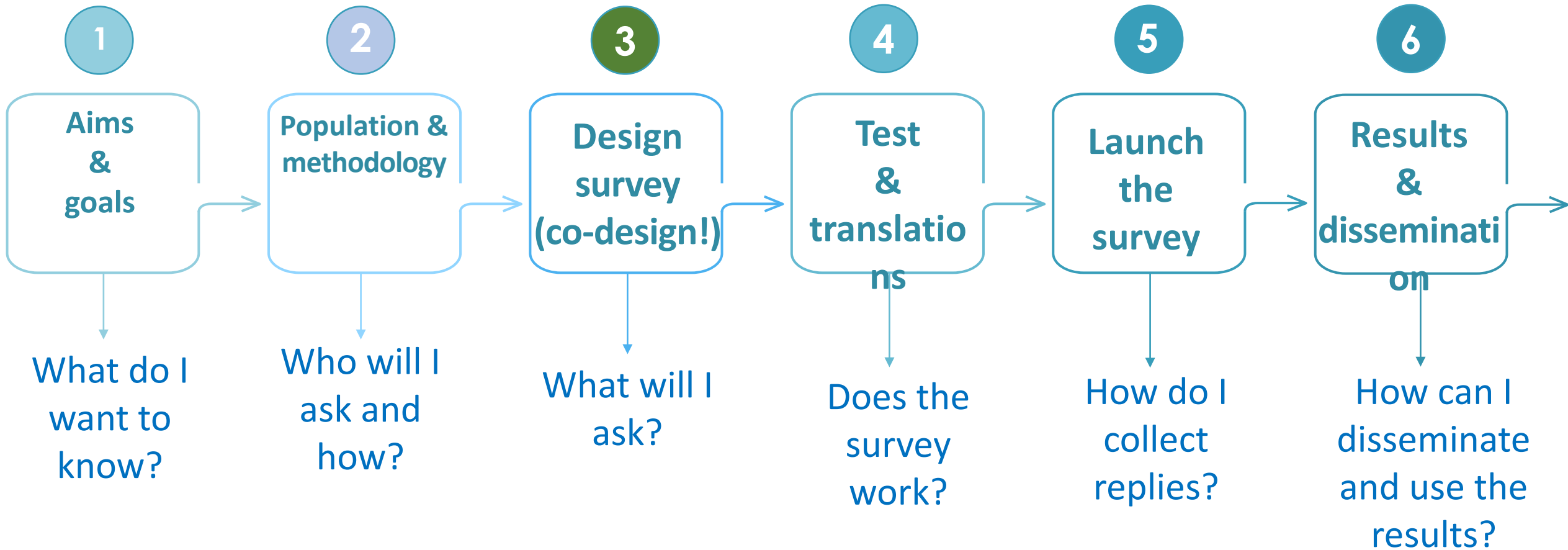
Diana Marinello
Network Manager, ERN ReCONNET Coordination Team, AOUP



Co-funded by the European Union



I want to create a survey, where do I start?



Do's and Don'ts in co-designing surveys

Do's



Be ready and Team Up to Plan together



Ask the right questions to the right people – explain and thank them



Exploit/Build your Networks!



Test the survey and ensure that is patient-friendly – propose!



Make the most out of your results

Don'ts



Don't feel afraid to bring your contribution



Avoid too long questionnaires if it's not needed



Don't underestimate the power of data, but don't overload your community with surveys



Don't keep results for your self, share and disseminate



Don't ask questions you already know the answers to