ERN ReCONNET

Training on TogethERN

ReCONNET Registry (online)

29–30.11.2023

Introduction

The "*Training on the TogethERN ReCONNET registry*" organised by the Task Partner Istituto Superiore di Sanita' (ISS) was held online on November 29-30, 2023.

The Course was dedicated to *(i)* general aims on how to establish a FAIR quality registry, *(ii)* specific needs emerged during the first phase of the project, as highlighted by the results of a specific survey, *(iii)* train the participants on the TogethERN ReCONNET registry.

The training method was based on interactive plenary session and hands-on experience.

The ERN ReCONNET Coordination Team was in charge for the dissemination to the Full Members, Affiliated Partners of ERN ReCONNET and ePAGs representatives.

A total of 33 participants attended the course. The attendees were only members of the ERN ReCONNET Network.

Day 1: 29.11.23

The first day was organised with interactive plenary sessions. The Course opened with the "Overview of the TogethERN ReCONNET project" followed by the "Results on the TogethERN ReCONNET Survey on training needs". The first part proceeded with the presentation of the "WG on Registries and eHealth tools" done by João EC Fonseca, Universidade de Lisboa, Lisbon, Portugal, and Matthias Schneider, Heinrich-Heine University, Duesseldorf, Germany. Day 1 ended with the talk of Ilaria Galetti, Federation of European Scleroderma Associations, Belgium, on "Towards a European registry infrastructure with TogethERN ReCONNET: the vision of the patient community". In the second part of the first day, Gerieke Been, University Medical Center Groningen, The Netherlands *(i)* were addressed the following points: *(i)* the

platform of the TogethERN ReCONNET registry, *(ii)* Integration of the existing registry in the TogethERN ReCONNET registry, *(iii)* findability of (meta)data of the TogethERN ReCONNET registry.

Day 2: 30.11.23

The first part of the second day, was focused on the hands-on session. Using a demo of the "Together ReCONNET registry", Joeri van der Velde, University Medical Center Groningen, The Netherlands, showed the structure and trained the participants on the different functionalities of the registry. The second part of the second day started with Giuseppe Turchetti that presented "The economic dimension of TogethERN ReCONNET". The last session of the course was focused on a plenary discussion on the accessibility and the future of the TogethERN ReCONNET registry. After that, the participants could provide their usability feedback on the platform via a Mentimeter survey.

Speakers and Chairs

Gerieke Been, University Medical Center Groningen, Groningen, The Netherlands.

Claudio Carta - National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome, Italy.

Maurizio Cutolo - Laboratory of Experimental Rheumatology and Academic Division of Clinical Rheumatology, Department of Internal Medicine and Specialties (DIMI), University of Genova, IRCCS San Martino Polyclinic, Genova, Italy.

João Fonseca - Rheumatology Department, Hospital de Santa Maria, Centro Hospitalar Universitário Lisboa Norte, Lisbon Academic Medical Centre, Lisbon, and Rheumatology Research Unit, Instituto de Medicina Molecular João Lobo Antunes, Faculdade de Medicina, Universidade de Lisboa, Lisbon, Portugal.

Ilaria Galetti - Federation of European Scleroderma Associations, Belgium.

Marta Mosca -Rheumatology Unit, Azienda Ospedaliero Universitaria Pisana Rheumatology Unit,University of Pisa, Pisa, Italy.

Matthias Schneider - Department of Rheumatology & Hiller Research Unit Rheumatology, UKD, Heinrich-Heine University, Duesseldorf, Germany.

Rosaria Talarico- Rheumatology Unit, Azienda Ospedaliero Universitaria Pisana Rheumatology Unit,University of Pisa, Pisa, Italy.

Giuseppe Turchetti – Institute of Management, Scuola Superiore Sant'Anna, Pisa, Italy.

Joeri van der Velde, University Medical Center Groningen, Groningen, The Netherlands.

The detailed program is available here:

Training on "TogethERN ReCONNET Registry"

29-30 November 2023, ONLINE

Organised by

ISTITUTO SUPERIORE DI SANITÀ
National Centre

for Rare Diseases

in collaboration

with

TogethERN ReCONNET, Grant Agreement n°947700, task partners: (i) Azienda Ospedaliero Universitaria Pisana, (ii) Scuola Superiore di Studi Universitari e di Perfezionamento S. Anna

PROGRAMME

29 November 2023 (CET Time)

16:30 Welcome address & Presentation of the course
  Claudio Carta, Rosaria Talarico

Chairs: **João Fonseca**, **Matthias Schneider**, **Ilaria Galetti**

16:45 Overview of the TogethERN ReCONNET project
  Rosaria Talarico
17:00 Results of the TogethERN ReCONNET Survey on training needs
  Claudio Carta
17:15 The WG on Registries and eHealth tools
  João EC Fonseca, Matthias Schneider
17:30 Towards a European registry infrastructure with TogethERN ReCONNET: the vision of the patient community
  Ilaria Galetti

17:45 Break
18:00 The future TogethERN ReCONNET registry platform:
- Presentation of the platform
- Integration of the existing registry in the TogethERN ReCONNET registry
- Findability of (meta)data of the TogethERN ReCONNET registry
Gerieke Been, Joeri van der Velde, Fernanda de Andrade
19:00 End of Day 1

30 November 2023 (CET Time)

Chairs: Maurizio Cutolo, Marta Mosca, Ilaria Galetti

10.00 TogethERN ReCONNET registry: Hands-on
Gerieke Been, Joeri van der Velde, Fernanda de Andrade
11.00 The economic dimension of TogethERN ReCONNET
Giuseppe Turchetti
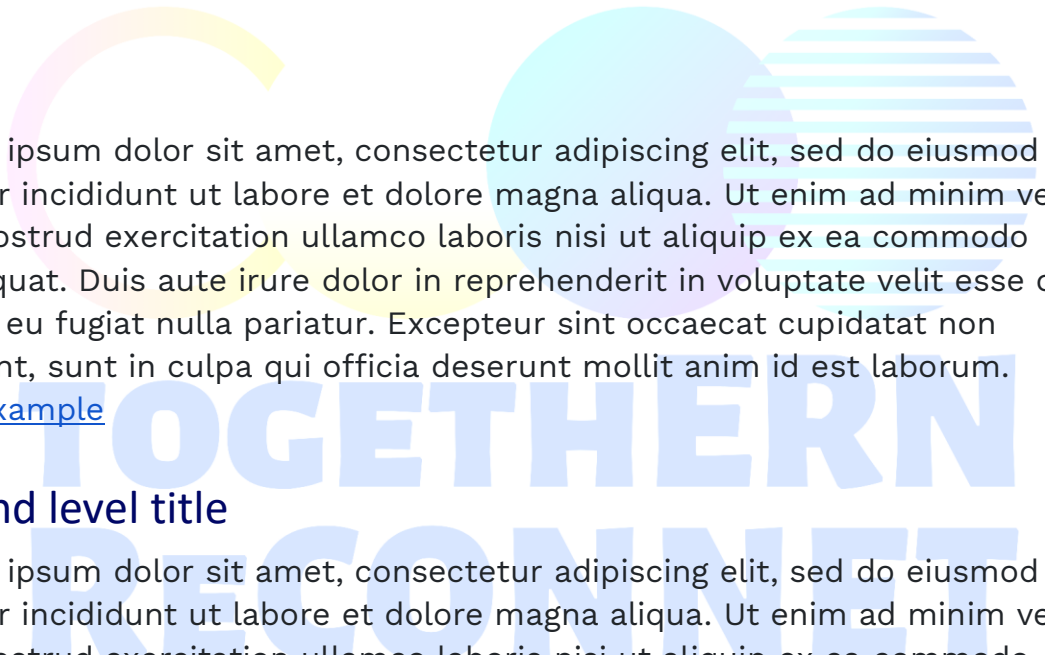11.20 Discussion
11.30 Break
11.45 Accessibility and the future of the TogethERN ReCONNET registry (plenary discussion)
Rosaria Talarico
12.10 Conclusions & Remarks
12:20 Learning assessment and satisfaction questionnaire
12.30 End of the course

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