



Technical secretariat

Linda Agresta
Daniela Bernardo
Giuseppe Bernardo
Patrizia Crialesi
Stefano Diemoz
Andrea Vittozzi
National Centre for rare Diseases
Istituto Superiore di Sanità

Contact:
e-mail: contact.cnmr@iss.it
phone: (+39) 06 4990 4418

Venue

Istituto Superiore di Sanità
Aula Marotta
Viale Regina Elena, 299
00161
Rome (Italy)

Map of the venue:
<http://tinyurl.com/y7k2xj4n>

For more information visit:
www.iss.it/cnmr



Clinical Practice Guidelines for Rare Diseases: development and quality assessment

October 9-10, 2018

Organised by
National Centre for Rare Diseases

Istituto Superiore di Sanità
Rome (Italy)



Course Directors

Domenica Taruscio
National Centre for Rare Diseases
Istituto Superiore di Sanità

Primiano Iannone
Clinical excellence, healthcare quality and safety
Istituto Superiore di Sanità

Tutors and Didactic coordinator

Daniela Coclite, Antonello Napolitano (Tutors)
Clinical excellence, healthcare quality and safety
Istituto Superiore di Sanità

Amalia Egle Gentile (Didactic coordinator)
National Centre for Rare Diseases
Istituto Superiore di Sanità

Scientific Secretariat

Domenica Taruscio
Primiano Iannone
Daniela Coclite
Antonello Napolitano
Istituto Superiore di Sanità

First day Tuesday October 9

- 09:30** - Registration
- 10:00** - Introduction to the course (*D. Taruscio*)
- 10:20** - Healthcare guidelines and European Reference Networks (*M. Scarpa*)
- 10:45** - Introduction to healthcare guidelines development (*P. Iannone*)
- 11:15** - Coffee break
- 11:30** - GRADE for healthcare guidelines development in rare diseases (*G. Filippini*)
- 12:30** - **PART I**-Assessing the quality of healthcare guidelines: AGREE reporting checklist and AGREE II (*D. Coclite, A. Napoletano*)
- 13:00** - Lunch
- 14:00** - Exercise in small groups: application of AGREE instruments (*D. Coclite, A. Napoletano*)
- 16:30** - Presentation of group works
- 17:00** - End of the day

Second day Wednesday October 10

- 09:00** - **PART II**-The GRADE process: from defining the question and collecting evidence to rating evidence quality (*G. Filippini, S. Minozzi*)
- 11:00** - Coffee break
- 11:15** - Exercise in small groups (*G. Filippini, S. Minozzi*)
- 12:40** - Presentation of group works
- 13:00** - Lunch
- 14:00** - **PART III**- Evidence to decision framework (*S. Minozzi*)
- 15:00** - Practical session: tutorial on the use of GRADEpro GDT software (*D. Coclite, A. Napoletano*)
- 16:30** - Discussion
- 17:00** - End of the course

Speakers and Tutors

Daniela Coclite - Clinical excellence, healthcare quality and safety, Istituto Superiore di Sanità, Rome, Italy

Antonello Napoletano - Clinical excellence, healthcare quality and safety, Istituto Superiore di Sanità, Rome, Italy

Graziella Filippini - Foundation IRCCS Neurological Institute Carlo Besta, Milan, Italy

Silvia Minozzi - Lazio Regional Health Service, Rome, Italy

Primiano Iannone - Clinical excellence, healthcare quality and safety, Istituto Superiore di Sanità, Rome, Italy

Domenica Taruscio - National Centre for Rare Diseases Istituto Superiore di Sanità, Rome, Italy

Maurizio Scarpa - Coordinator, European Reference Network For Hereditary Metabolic Diseases (MetabERN)

GENERAL INFORMATION

How to apply

The online application form is available at: <https://it.surveymonkey.com/r/cpgRD2018>
It should be duly filled by **September 25, 2018**.

Please note that places on the course are limited. A maximum number of 30 participants will be admitted. A confirmation of admittance will be sent by email only to the accepted applicants on September 27, 2018. Accepted participants should come with their own laptop.

How much will it cost?

The course is available free of charge. The organizers will provide refreshments (tea, coffee and biscuits) and lunch but will not pay for travel and accommodation expenses of attendees.

Methods of Assessment

There will be no formal examination but a Certificate of Attendance will be awarded only to those completing the full course.

A pre-post test and a satisfaction questionnaire will be administered to the participants to assess changes in knowledge and to seek feedback on the perceived overall value and quality of delivery of the training.

Course description

The present course intend to promote guideline quality standards in rare diseases and to support the European Reference Networks in the development of their capacity to produce and assess clinical practice .

The course will provide participants with the skills necessary to develop and appraise clinical practices guidelines for rare diseases by using international methods and tools such as GRADE and AGREE.

1. The course will cover the following topics:
2. The guideline development process
3. The GRADE methodology for the development of clinical practice guidelines for rare disease.

The AGREE instruments to assess clinical guidelines quality and their application to rare disease guidelines

The course format consists of: lectures and small groups work/exercises.

Eligibility requirements

Participants will be identified through open application. To apply for the course applicants should:

- be a graduate
- have experience in a health-related field
- have a good command of English
- be involved / interested in developing clinical practice guidelines for rare diseases.

Applicants should meet the above requirements. Applications will be reviewed to determine whether applicants meet the eligibility requirements for admission. A geographical distribution of the participants will also be taken into account in the selection process.

Priority will be done to ERN health professionals involved in developing and assessing clinical practice guidelines