



### Course Directors

**Domenica Taruscio**

National Centre for Rare Diseases, Istituto Superiore di Sanità

**Primiano Iannone**

National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità

### Tutors and Didactic Coordinator

**Daniela Coclite, Antonello Napoletano**

National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità

**Graziella Filippini**

Foundation IRCCS Neurological Institute Carlo Besta

**Amalia Egle Gentile** (*didactic coordinator*)

National Centre for Rare Diseases, Istituto Superiore di Sanità

**Silvia Minozzi**

Lazio Regional Health Service

### Scientific Secretariat

**Daniela Coclite, Antonello Napoletano**

National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità

**Linda Agresta**

National Centre for Rare Diseases, Istituto Superiore di Sanità

### Technical Secretariat

**Daniela Bernardo, Giuseppe Bernardo, Patrizia Crialessi, Stefano Diemoz, Andrea Vittozzi**

National Centre for Rare Diseases, Istituto Superiore di Sanità

**Contact (Andrea Vittozzi)**

**e-mail:** [contact.cnmr@iss.it](mailto: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](http://www.iss.it/cnmr)



## Clinical Practice Guidelines for Rare Diseases: development and quality assessment

**October 9-10, 2018**

*Organised by*

ISTITUTO SUPERIORE DI SANITÀ

National Centre for Rare Diseases

and

National Centre for Clinical Excellence, Healthcare  
Quality and Safety



## First day

### Tuesday October 9

- 09:00** Registration
- 09:30** Introduction to the course (*D. Taruscio*)
- 09:50** Clinical Practice Guidelines and European Reference Networks (*M. Scarpa*)
- 10:15** Introduction to Clinical Practice Guidelines development (*P. Iannone*)
- 10:45** Coffee-break
- 11:00** GRADE for Clinical Practice Guidelines development in rare diseases (*G. Filippini*)
- 12:00** **PART I-** Assessing the quality of Clinical Practice Guidelines: AGREE reporting checklist and AGREE II (*D. Coclite, A. Napoletano*)
- 12:30** Lunch
- 13:15** Exercise in small groups: application of AGREE instruments (*D. Coclite, A. Napoletano*)
- 16:00** Presentation of group works and feedback from peers and tutors
- 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 and feedback from peers and tutors
- 13:00** Lunch
- 14:00** **PART III-** Evidence to decision framework (*S. Minozzi*)
- 15:00** Future initiatives (*D. Taruscio*)
- 16:00** Discussion
- 17:00** End of the course

## Speakers

- Daniela Coclite** - National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità, Rome, Italy
- Graziella Filippini** - Foundation IRCCS Neurological Institute Carlo Besta, Milan, Italy
- Primiano Iannone** - National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità, Rome, Italy
- Silvia Minozzi** - Lazio Regional Health Service, Rome, Italy
- Antonello Napoletano** - National Centre for Clinical Excellence, Healthcare Quality and Safety, Istituto Superiore di Sanità, Rome, Italy
- Maurizio Scarpa** - Coordinator, European Reference Network for Hereditary Metabolic Diseases (MetabERN), Padua, Italy / Wiesbaden, Germany
- Domenica Taruscio** - National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome, Italy

## 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

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. CME credits will not be assigned.

## Course description

The course intends 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.

By the end of the course participants will be able to:

- Describe the process of developing Clinical Practice Guidelines (CPG) for rare diseases;
- Use AGREE Instruments.

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