



Administrative secretariat and dissemination

Linda Agresta
Email: linda.agresta@iss.it
Tel. 0039 06 49904018

Sabina Tonon
Email: sabina.tonon@gmail.com
Tel. 0039 06 49904406

Venue

Istituto Superiore di Sanità
Aula Rossi
Via Giano della Bella, 34
00162
Rome (Italy)



International Course

Health care guidelines on rare diseases: Quality assessment

February 23-24, 2015

Course Director

Domenica Taruscio
Director
National Centre for Rare Diseases
Istituto Superiore di Sanità
Viale Regina Elena, 299
Rome (Italy)

Tutors

Michele Hilton Boon - University of Glasgow
Sonja Kersten - Comprehensive Cancer
Centre the Netherlands
Paola Laricchiuta, Cristina Morciano,
Domenica Taruscio – Istituto Superiore di
Sanità
Karen Ritchie - Healthcare Improvement
Scotland
Enrique Terol - European Commission

Scientific secretariat

**Marta De Santis, Amalia Egle Gentile, Paola
Laricchiuta, Cristina Morciano** – Istituto
Superiore di Sanità
Karen Ritchie – Healthcare Improvement
Scotland

For more information visit

www.iss.it/cnmr

or

www.rarebestpractices.eu

or

www.europlanproject.eu

Organized by the
National Centre for Rare Diseases
Istituto Superiore di Sanità
Rome (Italy)



Course endorsed by ICORD
(www.icord.se)

This RARE-Bestpractices course has received funding from the European Union's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 305690. Sole responsibility lies with the authors and the European Commission is not responsible for any use that may be made of the information contained therein.

First day - 23 February

- 10:00 - Registration
- 10:30 - Introduction to the course and RARE-Bestpractices overview (Domenica Taruscio)
- 10:50 - Health care guidelines and European Reference Networks (Enrique Terol)
- 11:10 - *Coffee break*
- 11:40 - Guideline role in healthcare outcome improvement (Sonja Kersten)
- 12:10 - Development vs. appraisal: available standards and tools (Paola Laricchiuta)
- 12:30 - Trustworthiness of guidelines: case studies (Cristina Morciano)
- 12:50 - Guidelines search and RARE-Bestpractices' databases (Karen Ritchie)
- 13:15 - *Lunch*
- 14:15 - Introduction to the AGREE II instrument (Karen Ritchie)
- 15:15 - End of the day

Second day - 24 February

- 09:00 - Exercise I (facilitators: all teachers)
- 10:00 - Discussion about Exercise I (Michele Hilton Boon)
- 10:30 - *Coffee break*
- 11:00 - Exercise II (facilitators: all teachers)
- 12:00 - Discussion about Exercise II (Michele Hilton Boon)
- 12:30 - *Lunch*
- 13:30 - Appraisal work: instructions (Karen Ritchie)
- 14:00 - Certificate delivery
- 14:30 - End of the course

Course description

The present course is part of the capacity building activities of the project RARE-Bestpractices (Work package 4 and Work package 6). These activities intend to promote guideline quality standards and RARE-Bestpractices' outputs across European Member States and to support the upcoming European Reference Networks and Centres of Expertise in the development of their capacity to produce and use health care guidelines on rare diseases.

The course will provide participants with the opportunity to acquire skills necessary to appraise health care guidelines for rare diseases by using AGREE II, the international tool to assess the quality and reporting of health care guidelines, also actively involving them in the appraisal work foreseen in the project.

The course will cover the following topics:

1. Overview of the guideline and research recommendation databases
2. Basic elements of guideline development process
3. Overview of the available standards and tools for health care guideline development and appraisal
4. The AGREE II tool and its 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 or have successfully completed a professional training course
- have experience in a health-related field
- be committed to appraise up to a maximum of 5 guidelines which will be included in the guideline database of RARE-Bestpractices (please refer to the details in the paragraph "Appraisal work")
- have a good command of English.

Applicants should meet all 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.

How to apply

The application form can be downloaded from www.rarebestpractices.eu, www.europlanproject.eu, www.iss.it/cnmr.

It should be duly filled, signed and sent together with a current CV by email to rare-bestpractices@iss.it.

Applications not accompanied by a CV or not duly filled or readily comprehensible will be excluded. All applicants should return the application form together with a current CV no later than **4 February 2015**.

Please note that places on the course are limited. A maximum number of **20 participants** will be admitted. A confirmation of admittance will be sent by email only to the accepted applicants on **5 February 2015**.

Appraisal work

After the course participants will collaborate to the appraisal of the guidelines to be included in the RARE-Bestpractices guideline database. It is estimated that it takes between 30 and 90 minutes to appraise one guideline following training. The name of the appraisers will be displayed on the web page of the RARE-Bestpractices guideline database. Please note that the appraisal work will take place from March 2015 to April 2015. The topics of the guidelines to appraise and further details about the appraisal work will be discussed during the last day of the course. No funding support is envisaged for this activity.

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.