



**INFORMED DECISION MAKING IN HEALTHCARE:
THE PARTECIPASALUTE TRAINING COURSE FOR PATIENTS' ASSOCIATIONS
Third edition 2008**

The 3th edition of training course organized by the PartecipaSalute project started in September 2008. Researchers, healthcare professionals, representatives of patients' associations, lay members of ethics committees and journalists are involved as tutors and speakers. The course is structured in 4 modules of two days each. The participation at the course and the educational materials are free. Travel expenses and accommodation are refunded by the project.

The course takes place at the Institute of Pharmacological Research Mario Negri in Milan. The course, as well as the project, are supported by the Compagnia di San Paolo, a non profit private-law foundation.

Going from specific examples to general topics

This is the method followed by the PartecipaSalute course. Each module begins with three parallel workshops that discuss specific topics as examples of the general issues of the module. Following lessons develop the issues in details.

**MODULE A. September 14-15-16, 2008
THE A, B,C OF CLINICAL RESEARCH**

GOALS

- To offer tools assessment of the methodology of epidemiological and clinical research
- To increase the awareness of strengths and limits of the methodology of epidemiological and clinical research
- To increase the knowledge of the association between scientific and ethical aspects of research

Opening session. Sunday, September 14, 2008

Presentation of the PartecipaSalute project. Paola Mosconi

Presentation of the training course. Roberto Satolli

Comments from a participant at the previous edition of the course

Delivery of the pre-training questionnaire

Welcome dinner

The causes of a disease

Workshops with tutor:

- Ban on smoking in public places: first evaluations of the law. Silvano Gallus
- Vaccines: the papillomavirus. Tiziana Dell'Anna
- Pollution as a cause of illness. Luigi Bisanti

Plenary discussion

Lesson:

From "incidence" to "survival": all the meanings of numbers. Roberto D'amico

Lunch

Lesson:

From absolute risk to relative risk: how to work with numbers. Exercise. Roberto D'amico

Main lecture:

Researchers in the lab: the complexity of basic research. Raffaella Giavazzi

Evaluating the efficacy of an intervention

Workshops with tutor:

- Anticancer drugs: are we really making progress? Giovanni Apolone
- To screen or not to screen. Stefano Ciatto
- Are all anti-inflammatory drugs the same? Alessandro Nobili

Plenary discussion

Lesson:

The methodology of clinical research: phases of clinical trials, standard and control groups, randomization, blindness. Alessandro Liberati

Lunch

Lesson:

Critical appraisal of a study of efficacy: how to read an article on the efficacy of a cough syrup. Exercise. Rita Banzi, Ivan Moschetti, Elena Parmelli

Debate: Are the rules of independent research different from those of research made by pharmaceutical industries? A comparison between different points of view.

Chair: Alessandro Liberati. Speakers: Francesco Trotta, Gianni Tognoni, Francesco De Santis.

MODULE B. October 16-17, 2008 UNCERTAINTY IN MEDICINE CONFLICTS OF INTEREST

Uncertainty in medicine

GOALS

- To discuss the probabilistic nature of medical knowledge
- To understand why clinical practice varies among general practitioners and clinicians, countries, and during the time
- To discuss the importance of patients' values and preferences in medical decisions

Workshops with tutor:

- Risk factors: cardiovascular risk data cards; changes in levels of blood pressure and cholesterol levels through the years. Salvatore Panico
- Hormone replacement therapy: a controversial topic? Emilio Maestri
- Uncertainty in maternal and child care: the sudden infant death. Maurizio Bonati

Plenary discussion

Lesson:

Biological and epidemiological variability in medicine. Simonetta Pagliani

Lunch

Lesson:

Systematic reviews and meta-analysis: methods to reduce uncertainty? Graziella Filippini

Lesson:

Consensus conferences and guidelines. Paola Mosconi

Debate: How to choose a good doctor or a good hospital.

Chair: Paolo Longoni. Speakers: Carlo A. Perucci, Roberto Grilli, Giulia Candiani

Conflicts of interest

GOALS

- To increase patients' and citizens' awareness of conflicts of interest in clinical research and healthcare
- To provide tools to understand the presence of conflicts of interest and their influence on clinical research and healthcare information
- To discuss methods and tools to manage the conflicts of interest

Workshops with tutor:

- The relationships between researchers and sponsors; strategies and methods to manage the conflicts of interest. Danilo Di Diodoro
- How the pharmaceutical industries inform medical practitioners and clinicians. Guido Giustetto
- Patients' associations relationships with sponsors and patients' represented: strategies and methods to manage the conflicts of interest. Pierluigi Pennati

Plenary discussion

Lesson:

Conflicts of interest in clinical research, in medical journals, in the press. Pietro Dri

Lunch

Lesson:

The industry of healthcare and the disease mongering. Roberto Satolli

Debate: The market of healthcare as a producer of wealth.

Chair: Roberto Satolli Speakers: Giuseppe Recchia, Gianfranco Domenighetti, Maurizio Mauri

MODULE C. November 17-18, 2008

THE ETHICS COMMITTEES

STRATEGIES OF HEALTHCARE INFORMATION

The ethics committees

GOALS

- To describe roles and structure of ethics committees (EC)
- To discuss aims and functions of ethics committees in Italy
- To increase the knowledge of the association between scientific and ethical aspects of research

Workshops with tutor:

- The role of lay members in ethics committees. Patrizia Copelli
- How ethics committees can improve research. Annamaria Marata
- Ethic committees within healthcare organizations. Valentina Solfrini

Plenary discussion

Lesson:

Why ethics committees have been created and how they work in Italy. Gaia Marsico

Lunch

Lesson:

The role of lay members in ethics committee: functions, strengths and limits. Alessandra Cerioli

Debate: Ethics committees: a place of participation or a leaf to hide the real quality and relevance of clinical research? Chair: Gaia Marsico. Speakers: Valter Torri, Roberto Satolli, Maria Gloria De Bernardo

Strategies of healthcare information

GOALS

- To describe strategies in healthcare information and communication (about drugs, clinical trials, clinical research)
- To offer tools for critical appraisal of healthcare information
- To suggest tools and methods for the dissemination of healthcare information

Workshops with tutor:

- Communication strategies on drugs: the example of hormone replacement therapy. Daniela Condorelli
- HPV vaccine and genetic tests: subjects of new communication campaigns. Cinzia Colombo
- Are doctors and patients informed about the treatment of pain? Oscar Corli

Plenary discussion

Lesson:

How to critically read and produce healthcare information. Luca Carra

Lunch

Lesson:

The quality of information on screening programs in Italy. Livia Giordano

Lesson:

How to surf the Net, looking for good information. Websites useful for patients' associations. Eugenio Santoro

Lesson:

Tools to critically appraise healthcare information on the web. Surfing on PartecipaSalute website. Exercise with computers. Sergio Cima.

Debate: How to give a correct healthcare information: different points of view from different media. Chair: Luca Carra. Speakers: Antonio Nizzoli, Alberto Donzelli, Paola D'Amico

MODULE D. December 1-2, 2008

CREDIBILITY AND STRENGTHS OF PATIENTS' ASSOCIATIONS SHARED DECISION MAKING

Credibility and strengths of patients' associations

GOALS

- To discuss requirements to increase patients' associations' credibility
- To identify chances of participation in healthcare debate for patients' associations'; report of experiences
- To identify roles of advocacy and lobby

Lessons with plenary discussion:

The evolution of patients' and citizens' associations: an historical overview based on international experiences. Paola Mosconi

Conflicts of interest among patients' associations: examples and suggestions from international experiences. Cinzia Colombo

Rules and regulations of volunteers associations. Luca Degani

Lunch

Lessons with plenary discussion:

Criteria of credibility of patients' associations: the opinions of the participants at PartecipaSalute course. Paola Mosconi

Involving citizens in the development of guidelines: the experience of the Italian National System Guidelines. Alfonso Mele

Debate: Spazio PARITA - A program aimed to increase the involvement of patients' associations in defining the priorities of research

- The experience of Federazione Associazioni Italiane Para-tetraplegici. Fulvio Santagostini
- First steps of the project: prioritizing clinical research with patients' associations - results of a survey
- Does clinical research answer to patients' needs? Comments and suggestions from the participants to the training course

Lecture:

Patients' associations define research priorities with clinicians: a possible scenario in Italy? Arrigo Schieppati

Doctor-patient relationship and shared decision-making: strengths and limits

GOALS

- To discuss ways and areas of negotiation between doctors and patients
- To present tools to aid patients in healthcare decision making

Chairs: participants at the training course

Shared decision-making: what does it mean? Claudia Goss

An experience with patients with multiple sclerosis. Alessandra Solari

An experience with dermatology patients. Cristina Renzi

Plenary discussion

Training course's evaluation from participants Are new drugs beneficial for patients?

Lecture:

New drugs: are they for the benefit of patients or pharmaceutical industries? Silvio Garattini

Delivery of the post-training questionnaire and discussion about the training course

Delivery of the degree in PartecipaSalute training course

Speakers and Tutors

Apolone Giovanni Istituto Mario Negri, Milano; **Bisanti Luigi** ASL Città di Milano, Servizio di Epidemiologia; **Bonati Maurizio** Istituto Mario Negri, Milano; **Candiani Giulia** Agenzia di Editoria Scientifica Zadig, Milano; **Carra Luca** Agenzia di Editoria Scientifica Zadig, Milano; **Cerioli Alessandra** L.I.L.A. Lega Italiana Lotta all'AIDS, Bologna; **Ciatto Stefano** CPSO Centro Prevenzione Oncologica, Firenze; **Cima Sergio** Agenzia di Editoria Scientifica Zadig, Milano; **Colombo Cinzia** Istituto Mario Negri, Milano; **Condorelli Daniela** D di Repubblica, Milano; **Copelli Patrizia** CE Arcispedale S. Maria Nuova, Reggio Emilia; **Corli Oscar** Istituto Mario Negri, Milano; **D'Amico Paola**, Corriere della Sera, Milano; **D'Amico Roberto** Università degli Studi di Modena e Reggio Emilia, Modena; **De Bernardo Maria Gloria**, Comitato Etico Azienda Ospedaliera, Verona; **De Santis Francesco**, Farindustria; **Degani Luca** Fondazione Girola, Milano; **Dell'Anna Tiziana** UO ginecologia e ostetricia, Azienda ospedaliera San Gerardo, Monza; **Di Diodoro Danilo** Knowledge Management, Azienda USL di Bologna; **Domenighetti Gianfranco** Facoltà di Scienze della comunicazione, Lugano; **Donzelli Alberto** Asl Milano, Distretto 3, Milano; **Dri Pietro** Agenzia di Editoria Scientifica Zadig, Milano; **Filippini Graziella** Istituto Neurologico Carlo Besta, Milano; **Gallus Silvano** Istituto Mario Negri, Milano; **Garattini Silvio** Istituto Mario Negri, Milano; **Giavazzi Raffaella** Istituto Mario Negri, Milano; **Giordano Livia** CPO Centro Prevenzione Oncologica, Torino; **Giustetto Guido** Medico di famiglia, Torino; **Goss Claudia** Servizio di Psicosomatica e Psicologia Clinica del Dipartimento di Medicina e Sanità Pubblica dell'Università di Verona, Verona; **Grilli Roberto** Agenzia Sanitaria Reg.le Emilia Romagna, Bologna; **Liberati Alessandro** Centro Cochrane Italiano, Milano; **Longoni Paolo** Medico di Medicina Generale, Milano; **Maestri Emilio** CeVEAS Centro per la valutazione dell'efficacia dell'assistenza sanitaria, Modena; **Marata Annamaria** CeVEAS Centro per la valutazione dell'efficacia dell'assistenza sanitaria, Modena; **Marsico Gaia** Consorzio Mario Negri Sud, S. Maria Imbaro (Ch); Grosseto; **Mauri Maurizio** Associazione Culturale ABC...Salute, Milano; **Mosconi Paola** Istituto Mario Negri, Milano; **Nizzoli Antonio** Osservatorio di Pavia Media Research, Pavia; **Nobili Alessandro** Istituto Mario Negri, Milano; **Pagliani Simonetta** Agenzia di Editoria Scientifica Zadig, Milano; **Panico Salvatore** Università degli Studi, Napoli; **Pennati Pierluigi** FEDIPSO Federazione Italiana della Psoriasi, Milano; **Perucci Carlo Alberto** Dipartimento di Epidemiologia - ASL Roma E; **Recchia Giuseppe** Glaxo SmithKline Italia, Verona; **Renzi Cristina** Istituto Dermopatico dell'Immacolata-IRCCS, Roma; **Santagostini Fulvio** FAIP Federazione Associazioni Italiane Paratetraplegici, Milano; **Santoro Eugenio** Istituto Mario Negri, Milano; **Satolli Roberto** Agenzia di Editoria Scientifica Zadig, Milano; **Schieppati Arrigo** Centro Informazione Malattie Rare, Bergamo; **Solari Alessandra** Istituto Neurologico Carlo Besta, Milano; **Solfrini Valentina** Ospedale Bellaria, Bologna; **Tognoni Gianni** Istituto Mario Negri, Milano; **Torri Valter** Istituto Mario Negri, Milano; **Trotta Francesco** AIFA Agenzia Italiana del Farmaco, Roma.