



EUROPEAN CANCER CONTROL SUMMIT

Cancer Registries for better cancer control in the EU:
Unity and diversity in reporting risk and outcome

Renaissance Hotel, Brussels, Belgium
23-24 November 2011

Check out www.eurocourse.org

Wednesday 23 November 2011

12.30 – 13.30 *Registration and Networking Lunch*

SESSION 1: Reflections on population-based Cancer Registries in the EU

Chairs: Richard Sullivan (King's Health Partners Centre for Global OncoPolicy & Health) and Jan-Willem Coebergh (EUROCOURSE)

13.30 – 13.40 *Welcome by Julio Celis: Expectations on European Cancer Control Summit
The wider perspective*

13.40 - 13.50 Jan-Willem Coebergh (EUROCOURSE coordinator): Introduction

13.50 – 14.00 Jan-Willem van der Loo (DG Research and Innovation): Perspective of ongoing and future activities within FP 7

14.00 14.10 Karl Freese (DG Health and Consumers): New opportunities at EU level for cancer registries to serve patients, doctors and other providers

14.15-14.20 Anita Waldmann (MyelomaNet; ECCO Patient Advisory Committee): Interests and worries of cancer survivors

14.20-14.30 Alexander M.M. Eggermont (European Academy of Cancer Sciences): Let registry-based studies reflect the rapidly changing clinical realities and help to guide research (Example: melanoma)

14.30 – 14.40 Richard Sullivan (King's Health Partners): Need for studies of variation in the delivery of (un)affordable cancer care and impact on survival: strategic importance of European cancer registries in research

14.40 – 14.50 David Forman (International Agency for Research of Cancer, IARC): Recent progress in the fight against cancer in the EU: where is the grass greenest?

14.50 – 15.15 *Discussion:*

Registries: good indicator of current and future cancer surveillance?

15.15- 16.00 *Coffee Break*

SESSION 2: Governance for Uniform methodology & heterogeneous practice in population-based cancer registries

Chairs: Stefano Rosso (Chair, European Network of Cancer Registries, ENCR) and David Brewster (Scottish Cancer Registry)

- 16.00 – 16.05 Stefano Rosso: Introductory Remarks on the scope of current ENCR
- 16.05 – 16.15 Max Parkin (Oxford University, UK): Origin and development of registries in Europe
- 16.15 – 16.25 Jan-Willem Coebergh (EUROCOURSE-coordinator): Evolution of the population-based cancer registries: anatomy of research programming with stakeholder
- 16.25– 16.35 Sabine Siesling (ENCR/Eurochip/EUROCOURSE): Major results from the Eurochip/EUROCOURSE registry questionnaire
- 16.35 - 16.45 Susan O'Reilly (Irish Cancer Board): the floor to Programme Owners
- 16.45 – 17.10 Discussion on good governance and stakeholder involvement for cancer registries

Looking forward: New approaches and 'best practices'

- 17.10- 17.25 Lonneke van de Poll (Comprehensive Cancer Centre South/ University of Tilburg, Netherlands): via survivorship studies to cancer patient registries?
- 17.25 – 17.45 Discussants:
- Galina Velikova (EORTC Quality-of-life Study Group)
 - Louis Denis (Europa Uomo)
- 17.45 – 18.00 Gordon McVie (European Institute of Oncology):

Wrap up: The Road Ahead

Thursday 24 November 2011

SESSION 3: EUROCOURSE: a major project for ENCR-members: unity in diversity? Summary of results from work packages 2 (confidentiality), 3 (coverage, completeness, comparability) and 4 (new Data Portal)

Chair: Henrik Moller (King's College London) and Anna Gavin (Northern Ireland Cancer Registry)

- 09.05 – 09.05 Henrik Moller: Introductory Remarks: no progress without hurdles
- 09.05 – 09.15 WP 3: Roberto Zanetti (Piemonte Cancer Registry): Coverage, data quality and comparability: the long road to 'good' registries (*poster*)
- 09.15 – 09.25 Discussion**
- 09.25 – 09.40 WP 2: Hans Storm (Danish Cancer Society): Legal heterogeneity across the EU unnecessarily affected registry performance (*posters*)
- 09.40 - 09.55 Evert-Ben van Veen (MedlawConsult): Are professional codes and guidelines a solution to legal heterogeneity across EU in data protection and tissue-banking?
- 09.55 – 10.05 Discussion**
- Timo Hakulinen (Finnish Cancer Registry): How to constructively move forward
- 10.05 – 10.15 WP 4: Harry Comber (Irish National Cancer Board): Provision and future use of European data on incidence and survival: arrival of common data portal (*posters*)
- 10.15- 10.35 Discussion with** (potential) expert users on the conditions:
- Riccardo Capocaccia (ISS, Italy): Fitting the needs of survival studies (EUROCARE/RARECARE) (*poster*)
 - Adam Gondos (DKFZ, Germany): Added value for and by EUNICE-project
- 10.35- 11.00 Coffee Break**

SESSION 4: 'Best practices' in population-based clinical evaluation (WP 6)

When demography, oncology and professional and political environments change

Chairs: Peter Naredi (ESSO) and Jan-Willem Coebergh (EUROCOURSE)

11.00 – 11.05 Introduction Jan-Willem Coebergh

11.05 – 11.15 Valery Lemmens (Comprehensive Cancer Centre South): Major clinical research topics of future relevance – can registries serve multidisciplinary clinical dynamics through outcome assessment?

11.15 – 11.25 Anders Green (South Odense University Hospital): Can clinical cancer databases offer sustainable and independent quality-of-care assessment

11.25- 11.35 Francesco Pignatti (European Medicines Agency): New arrangements for (population-based?) pharmaco-vigilance through Phase 4 studies

11.35-11.45 Cornelis van de Velde (ECCO): European comparative approach through monitoring colorectal cancer: EURECCA project (*poster*)

11.45- 11.55 Riccardo Audisio (International Society for Geriatric Oncology, SIOG): Advancing knowledge of management of elderly with cancer cannot do without population-based approach

11.55- 12.00 Ferdinand Hofstädter (Kooperationsverbund durch Klinische Krebsregister): Current plans for clinical registries in Germany

12.00-12.15 *Discussion on methodology, sustainability and complementarities*

SESSION 5: Permanent monitoring of effectiveness of population-based screening for cancer (WP 5)

Chairs: Ahti Anttila (Finnish Cancer Society) and Elsbeth Lynge (Copenhagen University)

12.15 – 12.20 Ahti Anttila: Introductory Remarks (*poster*)

12.20 – 12.30 Lawrence von Karsa (International Agency for Research of Cancer): Why are 'best practices' in mass screening not enough?

12.30 – 13.00 *Brief statements: Information to 'healthy' candidates for mass screening of cancer needs to be based on a prompt cancer registry with accurate data*

Case Studies:

- Cervical cancer: Arkadiusz Chil (Holycross Cancer Centre, Kielce. PI)
- Breast cancer: Antonio Ponti (CPO, Italy)
- Prostate cancer: Anssi Auvinen (Tampere School of Public Health)
- Colorectal cancer: Wendy Atkin (Imperial College London)

13.00 –14.00

Lunch

SESSION 6: Cancer registration under different circumstances: from Scandinavia to the Balkans (WP8)

Chair: Hans Storm (Danish Cancer Society), Jan Willem Coebergh (EUROCOURSE)

14.00-14.05

Hans Storm: Introduction

14.05-14.15

Laufey Tryggvadóttir (Icelandic Cancer Registry): Maximum use of registries in the study of occupational cancer risks: the NOCCA study

14.15 – 14.25

Ariana Znaor (Institute for Public Health, Croatia): Recent data of cancer risk in southeast Europe (Wp8) (poster)

14.25-14.35

Discussion: Challenges for new EU Member States

SESSION 7: Translational medicine, research, repositories and biobanking (WP 7)

Chairs: Julio Celis (European Association of Cancer Research, EACR) and Joakim Dillner (Karolinska Institute)

14.35 –14.45

Joakim Dillner: Biobanking in translational cancer research and oncological practice (poster)

14.50- 15.00

Eero Pukkala (Finnish Cancer Registry): Linking biobanks with cancer registries

15.00-15.10

Discussion: on modern biorepositories and cancer registries

15.10- 15.30

Needs and input from current European collaborative programmes

- European Partnership for Action against Cancer
 - Tit Albreht (Slovenian Institute of Public Health): progress to date
 - Milena Sant (National Cancer Institute, Milan): plans for coordination of European cancer data registries
- PanCare SurfUp
 - Lars Hjorth (University of Lund): care needs for childhood cancer survivors

15.30 -15.40

Stefano Rosso (ENCR): Challenges for European Network of Cancer Registries

15.45- 16.15

Panel discussion with EUROCOURSE WorkPackage Leaders

Moderator: Max Parkin (Oxford University, UK)

Take Home Messages

Networking Tea & Coffee