

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 www.eurocourse.org for more information

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 – 13.45 *Opening Remarks: Overview of European context*

Richard Sullivan: Strategic importance of European cancer registries in research

Jan-Willem Coebergh: How registries support the entire cancer continuum

13.45 – 13.55 Maria-Jose Vidal-Ragout, DG Research and Innovation: Cancer registries in the EU Horizon 2020 agenda

13.55 - 14.05 TBC (DG Health and Consumers): challenges and opportunities for cancer registries to serve citizens and patients.

14.05 - 14.15 TBC (MEP): Importance of population-based data for monitoring variations in cancer incidence and survival in the EU

14.15 - 14.25 Anita Waldmann (MyelomaNet; ECCO Patient Advisory Committee): on the interests of cancer survivors

14.25 -14.40 Alexander M.M. Eggermont (European Academy of Cancer Sciences): Registry-based studies of melanoma across Europe- data use for research policy

14.40 – 15.00 *Discussion and Questions and Answers*

15.00 - 15.15 David Forman (International Agency for Research of Cancer (IARC)): Recent progress in the fight against cancer in the EU: where is the grass greenest?

15.15 – 15.25 Laufey Tryggvadóttir (Icelandic Cancer Registry): Maximum use of registries in the study of occupational cancer risks: the NOCCA study

15.25 - 15.40 *Discussion and Question and Answers TBC*

15.40- 16.00 *Coffee Break*

SESSION 2: Matching uniform requirements to heterogeneous practice and governance in 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: scope of ENCR
- 16.05 – 16.15 Max Parkin (Oxford University, UK): History and development of registries in Europe
- 16.15 – 16.30 Jan-Willem Coebergh (EUROCOURSE): Uniform methodology, divergent context and research programming of population-based cancer registries in Europe
- 16.30 – 16.40 Sabine Siesling (ENCR/Eurochip/EUROCOURSE): Geographical patterns in coverage and output
- 16.40 – 16.50 Ariana Znaor (Institute for Public Health, Croatia): Recent data of cancer risk and outcome in southeast Europe
- 16.50 - 17.10 *Discussion on the need to address heterogeneity: challenges and pitfalls***

Looking forward: New approaches and ‘best practices’

- 17.10- 17.25 Lonneke van de Poll (Comprehensive Cancer Centre South/ University of Tilburg, Netherlands): through survivorship studies to cancer patient registries?
- 17.25 – 17.45 Discussants:
- Galina Velikova (EORTC Quality-of-life Study Group)
 - Louis Denis (Europa Uomo)
- David Brewster: Concluding remarks

Thursday 24 November 2011

SESSION 3: EUROCOURSE: a major project for ENCR-participants: unity in diversity? Summary of results from work packages 2 (confidentiality), 3 (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): Data quality and comparability: the long road to "good" registries
- 09.15 - 09.25 Discussion**
- 09.25 – 09.40 WP 2: Hans Storm (Danish Cancer Society): How legal heterogeneity across the EU unnecessarily affected registry performance
- 09.40 - 09.55 Evert-Ben van Veen (MedlawConsult): Are professional codes & guidelines a solution to legal heterogeneity across EU in data protection and tissue-banking
- 09.55 – 10.05 Discussion**
- Timo Hakulinen (Finnish Cancer Registry): constructively forward
- 10.05 – 10.15 WP 4: Harry Comber (Irish National Cancer Board): Provision and use of European data on incidence and survival : arrival of the common data Portal
- 10.15- 10.35 Discussion with a.o.:**
- Riccardo Capocaccia (ISS, Italy): fitting the needs for survival studies (Eurocare)
 - 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)

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

11.00 – 11.05 Jan Willem Coebergh: introduction: challenges are enormous: panta rhei

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

11.15 – 11.25 Anders Green (South Odense University Hospital): Synergies between clinical and population-based cancer registries for quality-of-care assessment

11.25 – 12.00 *Discussion: pros and cons of population-based and clinical databases*

- Cornelis van de Velde (ESSO-ECCO): monitoring colorectal cancer through the Eurecca-project
- Riccardo Audisio (International Society for Geriatric Oncology (SIOG)): Advancing knowledge of management of elderly with cancer
- Francesco Pignatti (European Medicines Agency): new arrangements for (population-based?) phase 4 studies
- Ferdinand Hofstädter (University of Regensburg): plans for clinical registries in Germany

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)

12.00 – 12.05 Ahti Antilla: Introductory Remarks

12.05 – 12.15 Lawrence von Karsa (IARC): Why are 'best practices' in mass screening not enough?

12.15 – 12.20 *Discussion*

12.20 – 13.00 *Can programmes for mass screening of cancer be carried out properly without a cancer registry? 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: Translational medicine, research, repositories and biobanking (WP 7)

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

14.00 –14.15 Joakim Dillner: Biobanking in translational cancer research

14.15- 14.25 Eero Pukkala (Finnish Cancer Registry): Linking biobanks with cancer registries

14.25-14.40 Discussion: synergy between modern biorepositories and cancer registries

SESSION 7: Cancer registration in the future: how can Programme Owners afford promoting research ?

Chair: Hans Storm (Danish Cancer Society)

14.40-14.50 **Introduction:** Jan van der Loo (DG Research and Innovation): ERA-net revisited

14.50- 15.15 Needs and Input from current European collaborative programmes

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

In search of Governance: Identification & Responsibilities of Programme Owners

15.15-15.20 Jan Willem Coebergh (EUROCOURSE): From stakeholders to programme owners

15.20- 15.30 Susan O'Reilly (Irish Cancer Board): a manifesto by and for Programme Owners

15.30 -15.40 Stefano Rosso (ENCR): Horizon 2020 for European Network of Cancer Registries

15.40-16.00 Recommendations for development, governance and funding of population-based cancer registries and their European network in the EU: unity in diversity

16.00 – 16.15 discussion: a bright future for Cancer registries in the EU is with us

Networking Tea & Coffee