

Minutes of the CANCER OUTCOMES RESEARCH WORKING GROUP
OECD ONCOLOGY DAYS Poznan 20th June 2018

Participants

from 15 EU countries plus Colombia, representing 26 Cancer Centres (see the list of [Participants](#) here)

Aims of WG session:

1. Agree on WG objectives
2. Define a list of outcomes indicators available among OECD centres
3. Cancers more suitable for outcomes studies
4. Preferred way forward –funding modality
5. OECD centres willing to adhere
6. NEXT STEPS FOR THE CANCER OUTCOMES RESEARCH WG

Introduction by WG Leader Milena Sant, Analytical Epidemiology and Health Impact “Fondazione IRCCS Istituto Nazionale Tumori” Cancer Institute of Milan. Milena Sant (MS) recalled the aims of the WG activities between 2016 and 2017 including the survey to all OECD centres (click [here](#) for more info). On these grounds, the WG Poznan session stands as an opportunity for discussing the way forward for a collaborative OECD initiative on CANCER OUTCOMES that has the aim of producing new knowledge on outcomes in the OECD centres to support clinical and policy decisions.

This will be done profiting of real world clinical data made available by the interested centres, using agreed indicators of care (e.g. OS, DFS QOL, Response to treatments, symptoms, costs) and also looking at data from population based registries which are closely connected with the oncological centres and have the possibility to integrate the clinical data of cancer centres by linkage **with current administrative** (e.g. survival, cause of death, socioeconomic status) **and health databases** (e.g. hospital admissions, visits, drugs for comorbidities). The initiative also profits from the participation of the OECD in the newly started EU Joint Action on Cancer IPAAC (www.ipaac.eu)

A pilot study on indicators that include A&D OECD criteria was proposed, and the need for a common platform for data sharing was highlighted.

The session continued with examples of Outcomes studies conducted in Belgium and Poland presented respectively by Dominique de Valeriola (DDV), General Medical Director of the Institut Jules Bordet, and Vice-President of the Belgian Cancer Registry, Brussels, and Maciej Trojanowsky (MT), Director of the Greater Poland Cancer Registry, in the Epidemiology Department of the Greater Poland Cancer Centre, Poznan (WCO)

- **Outcome results from real-life treatment practice for colorectal cancer in Belgium and in Europe**
DDV focused her presentation on ways to use outcome research to improve quality of care in hospitals and illustrated the Belgian Integrative Quality System Loop: the routinely Feedback from the Belgian Cancer Registry to the hospitals involving clinicians which improves quality of care, organisation of healthcare, and quality of registration in hospitals. The help of the artificial intelligence to extract data was also shown. Publications on Rectal Cancer Outcomes in Belgium and some EU countries were illustrated. KEY MESSAGE: using all pertinent and validated available information in order to obtain the most relevant, timely delivered and high quality information, with the aim of measuring the impact of the actions taken to improve quality, both at the cancer centre level and at the European Level through a partnership between cancer centres and cancer registries.

- **Integration of hospital based breast cancer data and population based data at WCO**

CR workers have access to the centre's hospital records, and most of the patient information is collected electronically. Patient data in the GPCC is mainly collected for billing and medical purposes (treatment types, information about comorbidities mostly stored in text files). ICD-10 classification is used but there is no information about date of incidence. MDT meetings are a great source of information, as IT tools to extract data from patient records are currently not available. MT illustrated the GPCC involvement in the the EURECCA project, and the ongoing constitution of a Breast Cancer Unit patient database in the Cancer Centre, involving a strong cooperation of clinical departments, IT departments and the Cancer Registry. The data available to the registry by this way allow participation in multicentric international studies on cancer outcomes, such as EUROCCARE and EU HIGH RESOLUTION studies.

During the Panel Discussion chaired by Josep Borrás (JB), National Cancer Plan Director, Catalan Institute of Oncology, Spain, the group addressed the definition of cancer outcomes and on the clinical information available in hospital and population based sets of oncological patients. The distinct role of hospital and population based registries was stressed, however it was agreed that for carrying out cancer outcomes research, a system of integrated clinical data should be implemented, with the final aim to construct well profiled patient cohorts using data available among our centres.

DECISION on "Objectives": The Outcome studies should include all patients treated in the centres (real world), and a collaboration with the UNICANCER initiative "EPIDEMIOLOGICAL STRATEGY and MEDICAL ECONOMICS - ESME" will be explored, as suggested by OECI President Thierry Philip.

Regarding **the way of measuring outcomes the following was agreed:**

- indicators should be already available or easy to implement among OECI centres
- they should be simple and standardised
- enabling us to produce results in a short term
- potentially useful for more than one site
- related to the OECI A&D programme in order to follow its impact and to measure quality of care in the OECI cancer centres

DECISION on "Most suitable indicators": In order to rely on data presumably available to all the OECI centres, OUTCOMES indicators should be in conformity with OECI accreditation system such as adherence to standard care (eg Radiotherapy in BCS); 30-day postoperative mortality, 90-day reintervention; time between MDT decision and first treatment; time to get results for several diagnosis techniques; Relapse, Disease-free survival.

Other possible outcomes discussed were :

the influence of comorbidity on treatment ; proportion of Multiple Myeloma patients undergoing bone marrow transplantation; Quality of life → *to discuss which indicators to use, eg standard indicators, PROMS; Overtreatment*

It was underlined that the OECI accreditation items are finalised to describe processes and quality in the centres: some of these items might be used for studying outcomes, but outcome research is not their principal aim. On the other hand, using accreditation and designation criteria offers the possibility to validate them, i.e. to investigate the influence of care organisation and delivery **and also to help the A&D WG to define quality and performance indicators.**

DECISION on "Most suitable cancer sites": The interest on Colorectal and Breast cancer was confirmed, furthermore the addition of one rare cancer was agreed, e.g. multiple myeloma, sarcoma.

DECISION on “Funding modality”: In order to obtain funds to sustain the outcomes research activity the feasibility of applying to a large EU project was addressed, either as a single project, or as a WP of a large project. An opportunity could be the EU call *SC1-DTH-01-2019: Big data and Artificial Intelligence for monitoring health status and quality of life after the cancer treatment*. Also to be considered a IMI call of possible interest that will be issued in 2019, but other possibilities should be explored.

DECISION on “Next Steps”: A WG meeting will be organised in Brussels or Milan, in Autumn 2018, to discuss a protocol for a call application and a WG working plan involving all interested OECl centres. For this purpose, the WG leader invited every OECl centre involved to confirm all necessary contact details to be used for updates and exchanges on the topic of this WG. The Autumn meeting invitation list shall include representatives from the centres listed below.

DECISION6 on “WG members”

- Institut Jules Bordet, **Belgium**;
Contacts: dominique.devaleriola@bordet.be and marianne.paesmans@bordet.be
- Masaryk Memorial Centre, **Czech Republic**;
- Tartu University Hospital, **Estonia**;
- Turku University Cancer Centre, **Finland**;
- Institute Marie Curie and Leon Berard, **France**;
- Over 10 centres under the coordination of INT - ACC, **Italy** ;
- IKNL, Rijnstaad, **The Netherlands**;
- Greater Poland Cancer Centre, **Poland** ;
- Instituto Portugues de Oncologia, IPO- PORTO, **Portugal**;
- Oncology Institute Lubljiana, **Slovenia**;
- Institut Catala Oncologia, **Spain**;

Further declarations of interest from new centres will be warmly welcome.