OECI

Cancer Outcomes Research Working Group Session

June 20th

IBB Andersia Hotel

Walencja Hall

CANCER OUTCOMES RESEARCH WG

Feasibility of an OECI collaborative study on cancer outcomes

SESSION 1 *Chair: Milena Sant*

15.00-15.20 **Cancer Outcomes studies and Population based cancer Registries: interest and feasibility among OECI Centres**
Milena Sant

15.20-15.50 **Outcome results from real-life treatment practice for colorectal cancer in Belgium and some European countries**
Dominique de Valeriola

15.50-16.10 **Integration of hospital based breast cancer data and population based data at the Greater Poland Cancer Centre and experiences in Poland with biobanks**
Maciej Trojanowski

16.10-17.40 **Panel of discussion on the feasibility to implement one / two pilot studies and how to finance them**
Chair: Josep Borras

Discussants: Giovanni Apolone, Otto Visser, Tanja Marinko, Maja Ebert Moltara, Kaire Innos, Maria Josè Bento and other WCO representatives

17.40-18.00 **Conclusions and next steps**

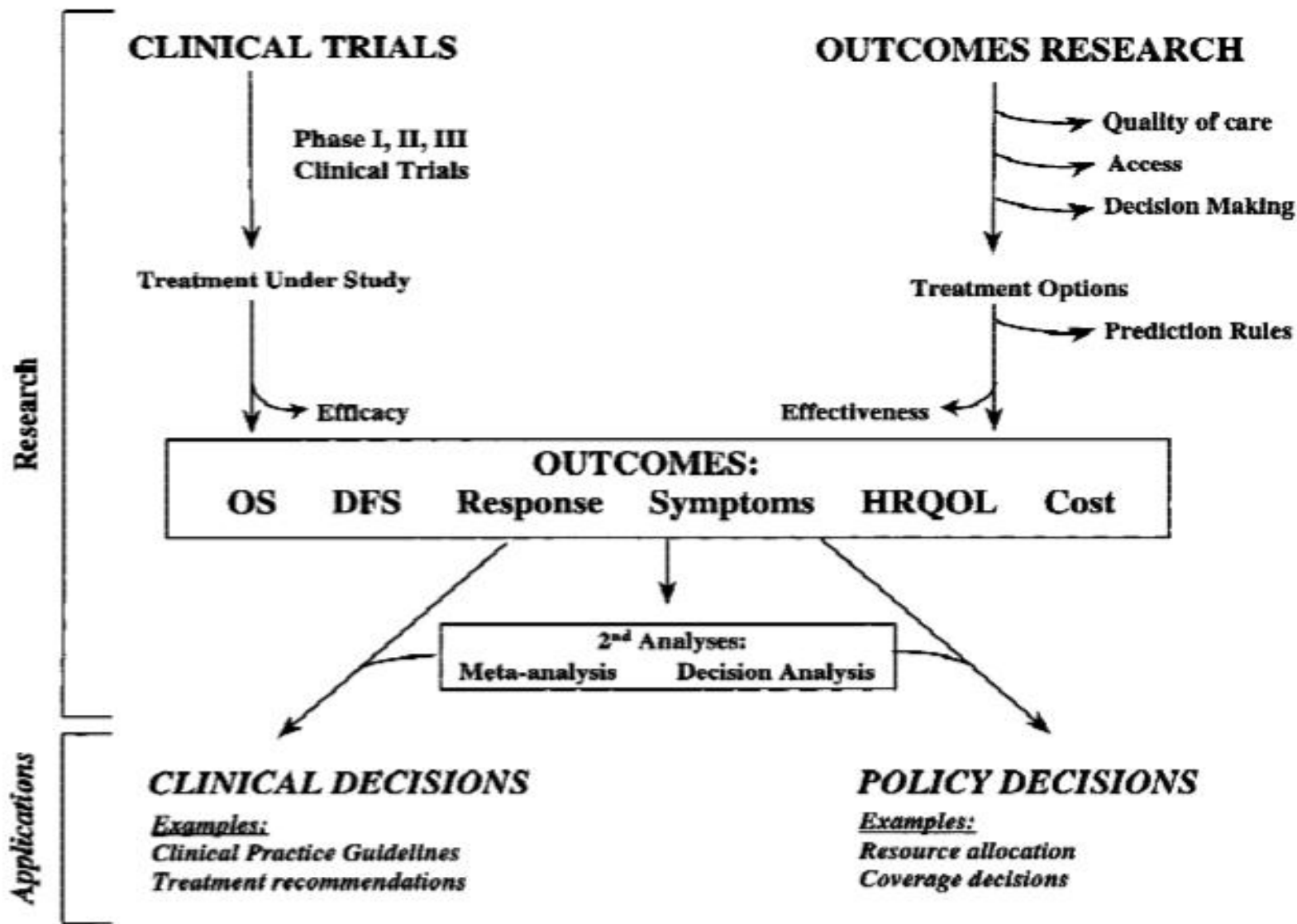**More than 20 OECI centres are represented here today**

over 10 are from the EU
Poland, Spain, Portugal, Belgium, Italy, France, Slovenia, Finland, Norway, Czech Republic, the Netherlands, Estonia, Romania, Bulgaria, Hungary, Romania
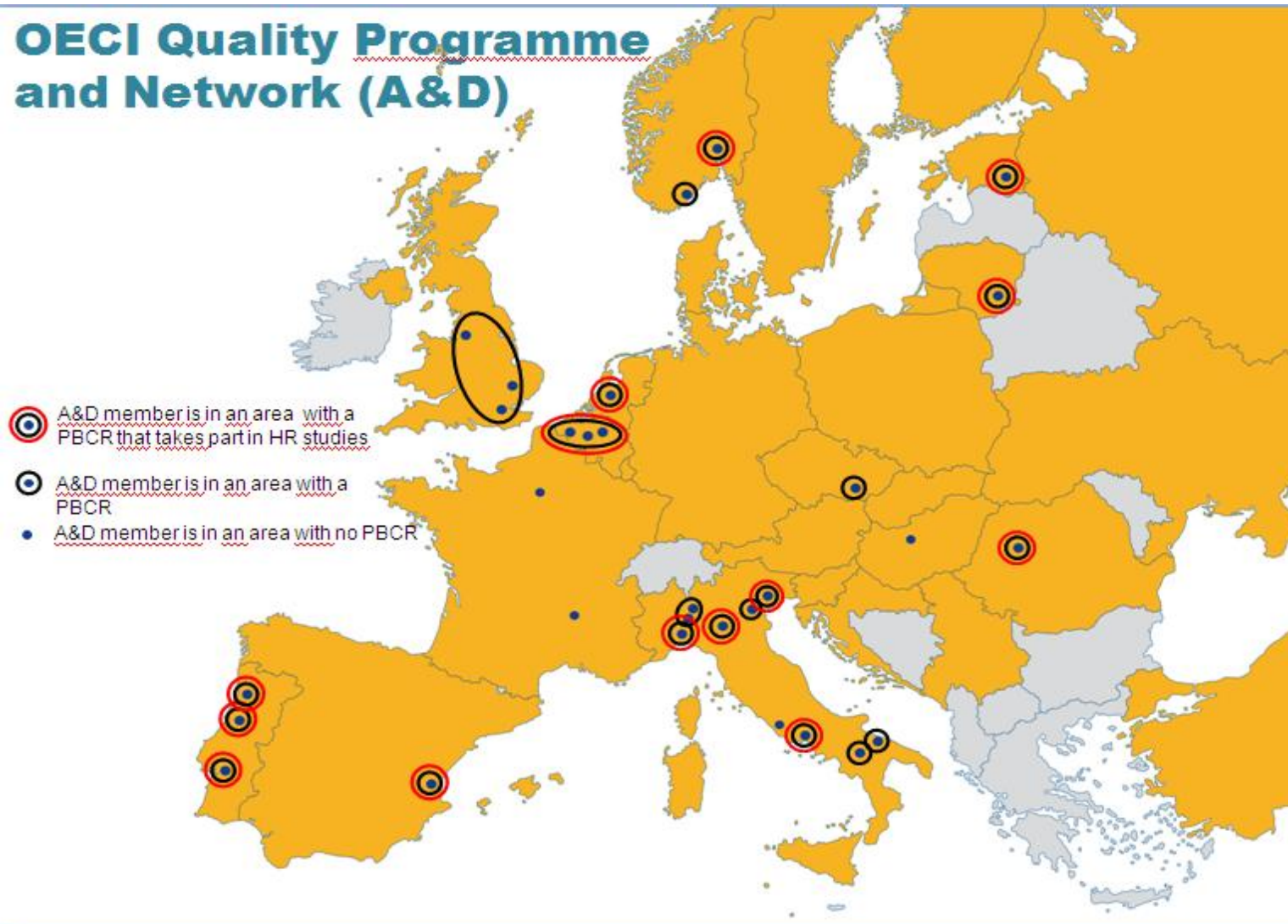
and also we welcome colleagues from Iraq, Ukraine, Russia and Colombia

Organisation of European Cancer Institutes

CONCEPTUAL FRAMEWORK OF CANCER OUTCOMES RESEARCH

Lee S. JNatl Cancer Inst 2000;92:195–204

OECI Quality Programme and Network (A&D)

A&D member is in an area with a PBCR that takes part in HR studies

A&D member is in an area with a PBCR

A&D member is in an area with no PBCR

Organisation of European Cancer Institutes

RATIONALE

The existence of population cancer registry in the CCC area allows:

➢Comparing outcomes of patients treated in CCC and in general hospitals

➢Investigating the effectiveness of selected procedures and their impact in the current clinical practice

➢Integrating hospital and population data on health

WHERE WE ARE *Data availability and characteristics according to sets of patients….*

	Population Cancer registries	Hospital series
Representativeness with respect to the whole incidence	Yes	No
Standardisation and Comparability of data across centres	High	Often low
Linkage of clinical data with biobanks	Difficult	Easy
Genetic and biomolecular profiling	Difficult	Easy
Relapse, disease free survival	Difficult	Yes
Long term follow-up by re-updating life status	Easy and accurate	Often difficult
Treatment details	Difficult	Easy
Contacting patients (PROMS, QoL)	No	Yes
Comorbidity	Difficult	Easy
Survivorship	Difficult	Easy

Summary results from the 2017 survey

Relatively scarce respondance to the questionnaires (30%)... *but*:

- **Institutional registries present in most CCCs responders, with biobanks available for outcomes research**

- **Interest to start working mostly on frequent/ common cancers (e.g, breast, colorectal)**

Summary results from the 2017 survey (continues)

- **Cancer Outcomes studies are feasible in at least 17/24 CCCs responding to the questionnaire**

- **Information on co-morbidity, socio-economic status, quality of life crucial for outcomes studies**

- **Patient-reported outcome measures**

- **Institutional Cancer Registration in the participating CCCs greatly facilitate outcomes research**

Conclusions of the 2017 meeting

To have one or more operative meetings among interested CCCs aimed to discuss:

- **cancer(s) more suitable for outcomes studies**

- **study design and protocol(s)**

- **best way of collecting data (Big Data from existing institutional registries or datasets), integration with population-based cancer registry data**

- **access to- and type of bio-banking (e.g, blood, paraffin-embedded)**

- **modalities and facilities for sharing and analysing data**

Cancers most suitable for studying outcomes

Breast, colorectal cancers (as resulted from our survey)
Other: melanoma, pancreas ….(?)

possible synergy 3 WPs of the new European Joint Action **IPAAC** (2018-2021) also with the collaboration of OECI

WP7 on Cancer Information and Registries
WP8 on Cancer Care Challenges
WP10 on Governance in comprehensive Cancer Care

https://www.ipaac.eu/

Conventional cancer outcomes:

- **Overall survival**

- **Relapse, Disease-free survival**

- **Survivorship**

- **Quality of life → *standard indicators, PROMS (?)***

- **Intensity of follow-up**

- **Adhesion to standard care**

- **Inequalities in access to treatments**

"Easily" collectable and comparable indicators of cancer outcomes

Discuss potentially suitable indicators available and comparable between OECI centers in Europe, e.g:
- conformity with Clinical Guidelines,
- 30-day postoperative mortality, 90-day reintervention, …etc.

Possibly using the items for the
OECI accreditation system

Selected OECI accreditation items

Patients newly diagnosed / year

Waiting times in guidelines and actual waiting times:

- Maximum allowed waiting time from 1st contact to 1st visit (days)
- Actual waiting time from 1st contact to 1st visit in the cancer centre (days)
- Maximum allowed waiting time first visit-definitive diagnose (days)
- Actual waiting time first visit-definitive diagnose in the cancer centre (days)
- Maximum allowed waiting time definitive diagnose – start treatment (days)
- Actual waiting time definitive diagnose – start treatment in the cancer centre (days)

Working with guidelines (institutional/ local / national/ international): Name and origin of guidelines. Clinical pathways available?

Tumour treatment demand and national standards

Tumour type ICD-10 code	Number of patients diagnosed yearly	Number of all patients treated in the cancer centre	Number of patients who had a resection	Re-surgery within 30-days	Radiation oncology (Number of patients	

Breast reconstructions
- Total number of direct reconstructions
- Number of breast conserving reconstruction

Follow-up data. Type of follow-up; Percentage of patients with available FU by cancer

- Do you know if patients are alive or not?
- Do you know the recurrent status?
- Do you have 1-3-5 survival rates per stage (since definitive diagnoses)?

Radiation Therapy Number of:

- linear accelerators;
- cobalt units

Number of CT scanners

Number of facilities for MRI (specify the strength and field of the techniques)

PET scan facilities (incl pet CT/MRI facilities, radio nuclide treatment facilities, SPECT, SPECT CT) ; sentinel node

Human resources: Number Cancer Surgeons. number of FTE surgeons by organ/ apparate

Availability from the Working Group to start with a pilot (on a voluntary basis)

discussion on the feasibility of starting one or two pilot studies on outcomes with the OECI centres that are here today
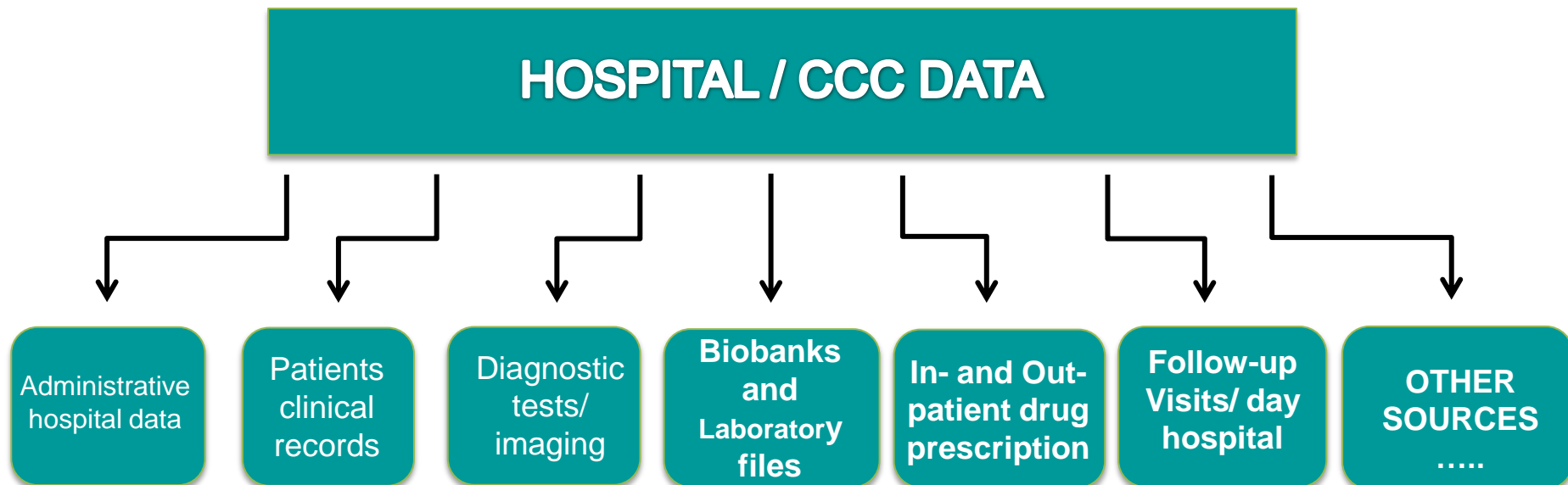
- **Individual centres ?**
- **Multicentric study ?**

We should shed light on how much effort would a study on outcomes require and the range of comparable indicators in the different centres.

Pilot might be used as a basis for a collaborative project among OECI centres
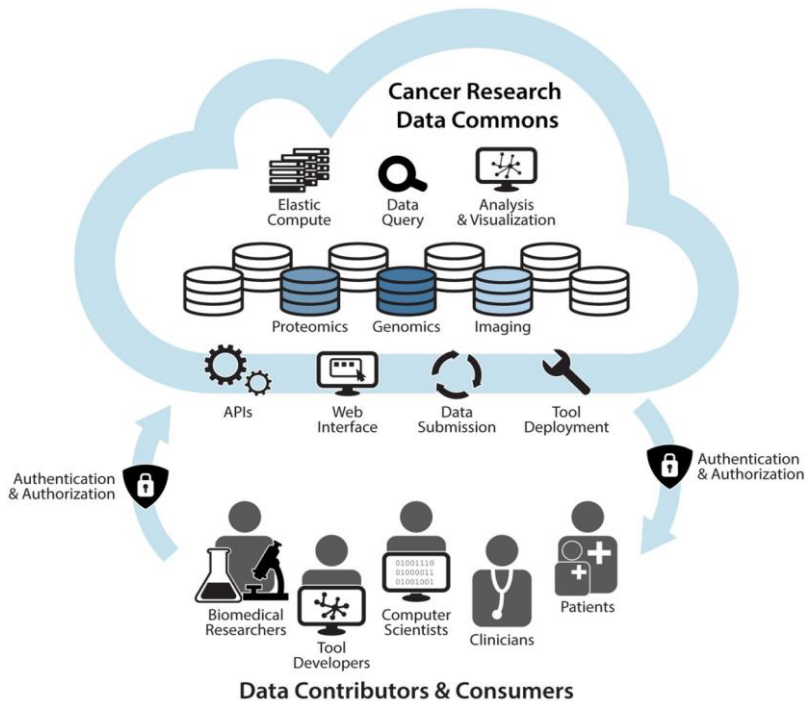
... pilot based on (currently) available data

HOSPITAL / CCC DATA

Administrative hospital data	Patients clinical records	Diagnostic tests/ imaging	**Biobanks and Laboratory files**	**In- and Out-patient drug prescription**	**Follow-up Visits/ day hospital**	**OTHER SOURCES .....**

Linkage with Current administrative and health databases of Population cancer registry (where possible)

A Comprehensive Infrastructure for Big Data in Cancer Research: Accelerating Cancer Research and Precision Medicine

Izumi V. Hinkson [1,2], Tanja M. Davidsen [1], Juli D. Klemm [1], Anthony R. Kerlavage [1*] and Warren A. Kibbe [1,3]

Cancer Research Data Commons

Elastic Compute · Data Query · Analysis & Visualization

Proteomics · Genomics · Imaging

APIs · Web Interface · Data Submission · Tool Deployment

Authentication & Authorization · Authentication & Authorization

Biomedical Researchers · Tool Developers · Computer Scientists · Clinicians · Patients

Data Contributors & Consumers

The availability of clinical data repositories functionally connected with bio-banks can help clinical cancer research and surveillance of outcomes along the course of the disease:

- **Survivorship, PROMs, Quality of life**
- **Relapse, Disease free survival**
- **Intensity of follow-up**
- **Inequalities in access to treatments**

Need of Common platforms for data sharing:

- **Informatic (structured / unstructured data bases, datawharehouse)**
- **Biological repositories**

Need to link clinical, pathological, genetic profiles with outcomes

Create stable research consortia

(stable funding to avoid expiring experiences when funds finish)

Address ethical and legislative issues

(confidentiality, data property, communication of results…)

EU call planned 2019

SC1-DTH-01-2019: Big data and Artificial Intelligence for monitoring health status and quality of life after the cancer treatment

...how to acquire, manage, share, model, process and exploit big data .... to effectively monitor health status of individual patients, provide overall actionable insights at the point of care and improve quality of life after the cancer treatment.
.... determining and monitoring the **combined effects of cancer treatment, environment, lifestyle and genetics** on the quality of life, enabling early identification of effects that can cause development of new medical conditions and/or impair the **quality of life.**
Proposals preferably address relevant **health economic** issues, use patient reported outcome and experience measures (**PROMs and PREMs**) and take into account the relevant **social aspects of health status** and quality of life after cancer treatment

Next Call **IMI** **(2 steps proposal). Type of actions: Research and Innovation Actions**

NEXT STEPS!

Autumn 2018: meeting to prepare an application for funding research on cancer outcomes and/or drafting of pilot study?

Could this be supported by OECI secretariat?

✓**One large project ?**

✓**WP of a wider collaborative project ?**

✓**Other options ?**

Expected outcomes for today's discussion

- **Which centres would be available to officially enter this WG on a voluntary basis**

- **Agree on a "NEXT STEP TIMELINE"**