

Introduction and illustration of the OECl study proposal/feedback of the survey on outcome studies

Milena Sant, MD

Analytical Epidemiology and Health Impact Unit
Department of Preventive and Predictive Medicine



**FONDAZIONE IRCCS
ISTITUTO NAZIONALE
DEI TUMORI**



Discussion on feasibility of Outcomes Research studies

Construct cohorts of patients with well annotated clinical characteristics, treated in accredited OEI CCCs, to be followed up prospectively

Integrate core clinical information with data deriving from current clinical and administrative files:

- pathological reports**
- drug prescription files**
- Hospital Laboratory Files**

Population cancer registry in the CCC area allows comparing outcomes of patients treated specialized and general hospitals

Investigating the effectiveness of selected procedures/ treatments and their traslability to the current clinical practice

Suggestions from common discussion

IDENTIFY:

- a core group of persons interested to plan and develop these studies
- The CCCs where they are feasible

Scrutinise interesting and feasible cancers, and issues to investigate

Connection with indicators included in the OEI accreditation system to facilitate participation

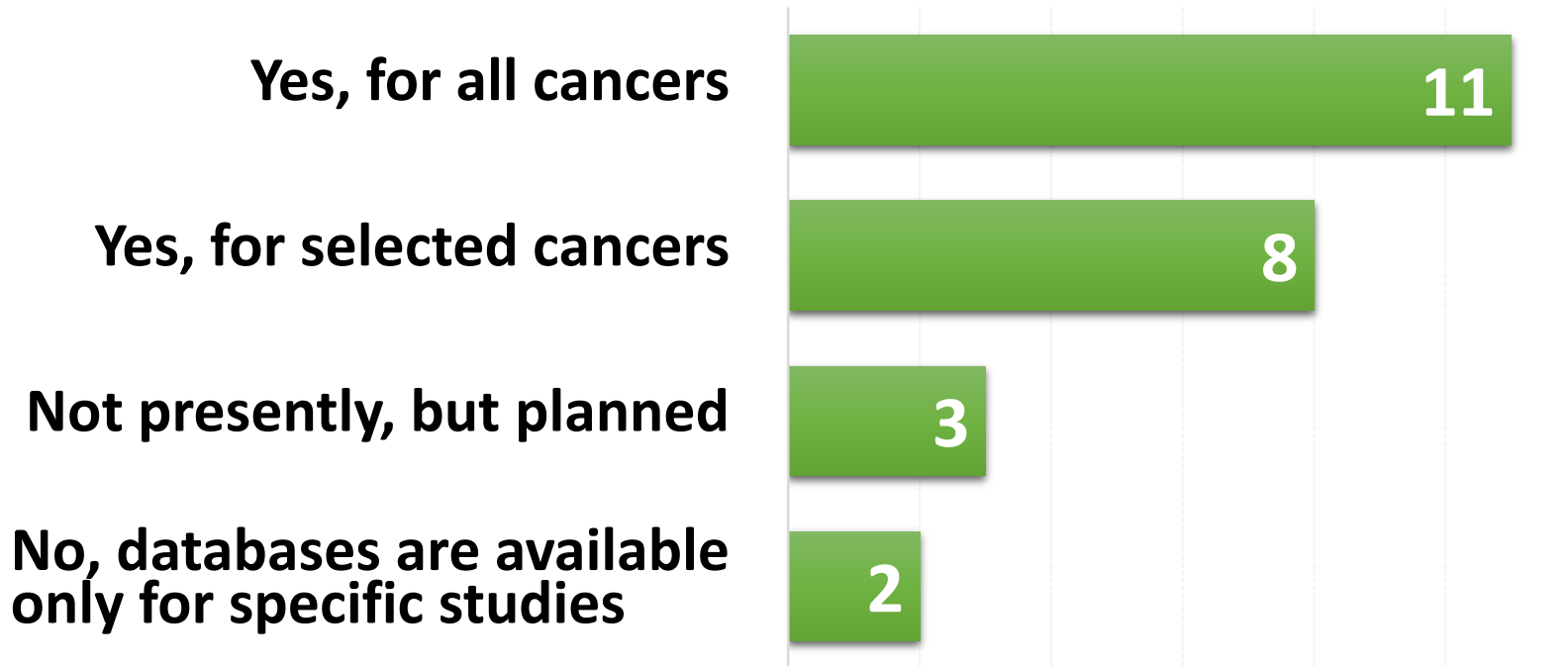
Linkage with biobanks

Create stable research consortia with stable funding; use national/local if outcome research is included among the current CCC activities

Country	Comprehensive Cancer Center
Austria	Comprehensive Cancer Center Graz, Graz
	AZ Groeninge, Kortrijk
Belgium	Institut Jules Bordet, Brussels
	Kankercentrum Brussel, Brussels
Croatia	Klinika za tumore Klinicki bolnicki centar Sestre milosrdnice, Zagreb
Czech Republic	Masarykův onkologický ústav, Brno
Finland	Tampereen Yliopistollinen sairaala, Tampere
	Centro di Riferimento Oncologico Istituto Nazionale Tumori, Aviano
<div data-bbox="272 505 1659 933" data-label="Text"> <p>24 out of 75 CCCs (14 countries) replied to the online questionnaire</p> </div>	
Portugal	Instituto Português de Oncologia do Porto Francisco Gentil, Porto
	Instituto Português de Oncologia de Lisboa Francisco Gentil, Lisbon
Russia	Tatarstan Cancer Center, Kazan
Slovenia	Onkološki Inštitut Ljubljana, Ljubljana
Spain	FUNDACIÓN INSTITUTO VALENCIANO DE ONCOLOGÍA, VALENCIA
The Netherlands	Erasmus MC Cancer Institute, CN Rotterdam
	Rijnstate, Arnhem
Turkey	Anadolu Sağlık Merkezi, Cumhuriyet Mahallesi 2255 Sokak No:3 41400 Gebze/Kocaeli

RESEARCH PART

The OECl recommends the constitution of institutional cancer registration. Is this in place in your CCC?



If cancer data registration is in place in your CCC, do you think it could be used to provide informations for studies on:

Diagnostic work-up	Treatment	Outcomes	Comorbidity
✓	✓	✓	✓
✓	✓	✓	
	✓	✓	✓
	✓	✓	
✓			
		✓	
18	22	23	15

Would you have the possibility to use institutional or administrative data sources (eg pharmaceutical files, pathology reports, admission/discharge files, population files) to integrate patient records on:

Diagnostic work-up	Treatment	Outcomes	Comorbidity	Patient's life status
✓			✓	
✓	✓	✓	✓	
✓	✓	✓	✓	✓
✓	✓	✓		✓
	✓			
	✓	✓		
22	23	23	19	20

Would it be possible for a researcher to access existing biorepositories for studies on outcome, providing all standard regulations are followed?

	Number of CCCs
Yes	12
Yes, if/conditional to consent by ethical committee, collaboration with local researchers, project prioritization, specific rules for the access	8
data processing must be done locally, all the information is only in the national language	1
Not available now	1
No	2

In your opinion, would it be feasible to plan the constitution of biorepositories specifically for outcomes studies?

	Number of CCCs
Yes, for all or specific cancers	15
Yes for selected cancers, but limitations (adequate funding, specific projects validity and competition with other ongoing projects...)	4
Not presently, but could be planned	4
No	1

Would you be in favour to start collaborative studies on cancer outcomes, establishing cohorts of cancer patients treated at CCCs, to be followed up?

Cancer type:	Number of interested CCCs
Breast	13
Colon & rectum	10
Hematological Malignancies (Acute leukemia, CLL, MDS, Lymphomas)	7
Skin Melanoma	6
Prostate	5
Stomach Lung Sarcoma	4

Less than 4 sites of interests: Liver, Uro-gynecology, Uterus/endometrium/cervix, Esophagus, head and neck, Pleura, Thyroid, Thymus, Testis, Osteoncology, Torax, Neuroendocrine, CNS, Pancreas, Ovary, Kindey, Bladder, Rare cancers (unspecified)

Outcomes studies suggested in the questionnaires

Outcomes commonly available to population CRs (routinely or for specific HR studies), provided by regional and national programmes for outcomes evaluation:

Relapse, overall and Disease free survival; inequalities in access to treatments

with focus on:

- **novel therapies**
- **ageing/ elderly**
- **comorbidity**

Outcomes studies suggested in the questionnaires

“Precision medicine” indicators

**Validation of potentially predictive biomarkers
evaluating clinical outcomes related to histotype, biomarkers
and molecular testing results**

**Survivorship, Quality of life, drug safety, return to work;
HTA, costs**

Conclusion

- Relatively scarce response 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



Operative meeting among interested CCCs aimed to plan a pilot study