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REPORT WP 8.6

Integration between oncology and palliative care

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Contents

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Abbreviations

CanCon	Cancer Control Joint Action
EAPC	European Association for Palliative Care
ECPC	European Cancer Patient Coalition
EU	European Union
IASP	International Association for the Study of Pain
ICO	Institut Catalan Oncologia, Barcellona
INT	National Cancer Institute of Milan
iPAAC	Innovative Partnership for Action Against Cancer
OECI	Organization of European Cancer Institutes
PC	Palliative Care
PROMs	Patient reported outcome measures
RCT	Randomized controlled trials
WP	Work Package

Executive summary

The recommendations included in the CanCon EC Joint Action are the basis from which to improve oncology and palliative care integration using standardized care pathways, referral guidelines, and collaboration to achieve the best outcomes for patient-centred care. An integrated approach helps to develop new models of care, educational and research programmes, adequate resource allocation, and sufficient investment.

The aim of WP 8.6 of Innovative Partnership for Action Against Cancer Joint Action is to identify areas that require an update in respect to Cancon recommendations, to assess palliative care needs in oncology based on epidemiological data and to review the literature on models of integrations between palliative care and oncology, at the time of diagnosis and early therapy, particularly for life-threatening and poor prognosis cancers.The increasing recognition of the role of palliative care for advanced cancer patients is yet combined with incomplete accessibility of high quality services for all EU citizens and with lack of common policy for the integration of palliative care in the oncology care continuum.

WP8 on pain management and palliative care have been the focus of a special group meeting associated with European Association for Palliative Care (EAPC) Congress on October, 2020. The meeting remit was to share, discuss and disseminate iPAAC contributions on pain controll barriers in cancer pain patients and in cancer survivors, PROMs implementation and palliative care integration with oncology. The meeting built on the communication between EAPC, International Association for the Study of Pain (IASP), Organisation of European Cancer Institutes (OECI) and European Cancer Patient Coalition (ECPC) representatives. The presentation of integration between oncology and PC is reported in Appendix 1 (EAPC World Congress 2020). See also Appendix 2 (European Palliative Care Reseach Seminar, on Integration of oncology and palliative care , PRC Seminar, www.bit.ly/PRCresearch) .

1 Introduction

The three-year Cancer control joint action (CanCon), co-funded by the Health Programme of the European Union, (Albreht 2017, Federici 2017) identified palliative care (PC) as part of the multidisciplinary care integration process required within Comprehensive Cancer Control Networks and, in particular, within survivorship care needs together with rehabilitation and psychosocial support.

According to the WHO (WHO 2014) and professional consensus (Kaasa 2018) both primary and specialized PC resources are necessary to meet PC needs of patients with advanced incurable cancer. An accurat evaluation, screening and epidemiology of PC needs in the clinical history of advanced incurable cancer is therefore instrumental to plan cancer control programs at the national level and also for the practical implementation of services in Cancer centers, networks and institutions. Given the need of these services, scaling the resources required by their effective operation is an emerging issue implying the ability to identify referral criteria of patient to in order to maximize quality of life and of care in this patient population.

The impact of specialized PC on symptom control and quality of life is evidence based and, more recently, the early integration of PC interventions in the clinical pathways of patients with advanced disease, also proved to be beneficial for improving quality of life for patients and caregivers and use of health care resources (Haun 2017). Therefore indicators of PC integration with oncology care have been suggested as quality indicators of the cancer clinical pathway (Kaasa 2018).

The improvement of quality of care, focusing on the patients‘ subjective experience of the disease has to reflect effective patients centredness in the clinical process. Patients‘ centredness is both an health care policy principle and part of the disciplinary content of palliative care. Consensus exists on the role of adopting patient reported outcome measures (PROMs) as one element of both integration of PC and oncology (Kaasa et al 2018) and of a patient-centred approach. It can be therefore concluded that availability of PC resources, development of integration between PC and oncology, adoption of PROMs in clinical practice and research in oncology and patient centredness are part of a cultural and policy virtuous circle and that their promotion informs the remit of iPAAC for present and future cancer control programs.

In summary the purpose of the present work has been to focus on:

- Evaluating and updating the CanCon European Guide (Albreht 2017) and CanConPP (https://cancercontrol.eu/) recommendations on cancer PC in coherence with the WP10 revision of CCCN.
- Estimating PC needs in cancer care and their impact in the next future.
- Providing evidence about PC integration models in particular as far as early PCintegration in cancer care is concerned .
- Providing recommendations on how to implement patient centred decision making approaches to improve care integration focusing on the use of PROMs and building a shared vision of this task with institutional stakeholders of PC and Cancer professionals and patient representatives.
- Providing a final set of summary recommedations.

2 Methods

After revising the CanCon recommendations on palliative car, the population based epidemiology of PC needs in oncology and the instrumental role of PROMs implementation, an updated literature review was conducted to identify the models of PC integration that could be proposed for the global cancer road map. One international workshop was organized to share these concepts with international professional and patients‘ stakeholders and summary recommendations were drafted.

The literature review aimed at identifying the integration models so far proposed and tested in clinical trials. For this reason all the articles included in the Cochrane review by Haun et al (2017) were revised and updated using the search strategy in table 1 covering the period between 2016 and 2020. The literature search was conducted on MEDLINE, EMBASE and Cochrane Central Register of Controlled Trials databases. The search strategy for the MEDLINE database, which used both text words and MeSH/EMTREE terms, is reported in table 1, and appropriately revised strategies were developed for each database. The search was conducted in the title, abstract, and keyword fields of the databases.

Inclusion criteria for relevant study selection were: to have been conducted in human, adult patients with cancer; to be a clinical trial; to reported data on early PC intervention.

Table 1. Search strategy

#10	#1 AND #7 AND #8 AND [2016-2020]/py AND [clinical trial]
#9	#1 AND #7 AND #8
#8	#2 or #3 or #4 or #5 or #6
#7	cancer
#6	terminal* illness
#5	terminal* disease
#4	terminal* care
#3	“end-stage disease” or “end stage disease” or end-stage illness” or “end stage”
#2	advance disease
#1	palliative care

3 Results

3.1 CanCon Recommendation update proposal

The Cancer Control Joint Action European Guide includes PC recommendations at two levels. The first level identifies PC as:

a) one of the disciplinary services contributions needed for tumor management groups under the chapter of „Comprehensive Cancer Control Networks"

b) a specific element of continuity of care from cancer screening to end-of-life care and from specialized cancer care to community level cancer care.

The second level is represented in the CanCon European Guide by the inclusion of three PC recommendations under the chapter on „Cancer survivorship and rehabilitation" addressing:

c) the requirements of professionals with both basic and specialized training in PC to guarantee a patient-centred approach,

d) that PCis integrated in survivorship care,

e) that End-of-life-care for children and adolescents should be improved across Europe

Therefore overall 5 recommedations can be found within the CanConEG across two main chapters with the difference that in describing Comprehensive Cancer Control Networks a paragraph helps in defining the PC specialized content needed to qualify CCCNs (page 89-90) while the subject in not further developed in chapter 7 on Survivorship and rehabilitation although it is included as an independend component of care in figure 7.2 at page 146.

In the CanCon Policy Papers booklet Cancer survivorship is part of several recommendation whereas there in not any specific recommendation mentioning palliative care, but one interesting proposal to include patient related outcome measure with cancer registry databases.

Interestingly the recent Cancer Mission Proposal identifies three pillars for the mission of conquering cancer: preventing what is preventable, optimizing diagnostics and treatment and supporting quality of life. The framework „Support quality of life" distinguish as separate aims a better understanding of symptoms and to relieve symptoms and improve PC and survivorship support. Recommendation 7 confirms the need for high quality research to relieve pain and improve PC as part of the program to improve quality of life for cancer patients and survivors. This documents therefore separate the needs of survivors from those of the PC cancer population while they both are considered to belong to the quality of life support pillar.

Consistenly with these considerations iPAAC suggests that PC is part of the strategy to control cancer and that it should stand alone as one component of preserving quality of life and quality of care for patients who cannot be cured making a clearcut distinction within the cancer survivors population.

3.2 Estimate of cancer patients palliative care needs in Europe

Direct epidemiology of PC needs is impossible at the moment unless specific tools for assement are used at a population level. Several authors have therefore proposed models to estimate this important health care need. These models are well described by Morin et al (2017). It is conceivable that, considering the population dying of non communicable disease and the trajectories of the diseases causing death, PC needs are to be found in between more than 60 to more than 70% of all deaths.

The provision of generalist palliative care, the implementation of various PC interventions during the disease trajectory and the access to specialized PC services are necessary to serve the demand of appropriate care of the dying population (WHO 2014). Advanced cancer trajectory of dying is characerized usually by a releatively short period of clinical decline (from months to about 1 year) that allows planning of PC interventions, yet the lack of population based physical and psychosocial symptom epidemiology allows only to estimate PC needs from indirect information. In one model it has been estimated that cancer is the cause of death of 60% of patients who have PC needs well ahead than for deaths caused by heart failure (20%) and other causes (Rosenwax 2005).

This is per se an importat reason to advocate the systematic collection in clinical and administrative databases of disease associated PROMs of patients with advanced cancer which at the moment is rarely availble even for patients referred to specialized PC services (Hansen et al 2020).

Considering these limitations it is rational to estimate that cancer is and will be a major source of PC needs, also due to the increase in cancer mortality which goes together with increased survival and increase in life expectancy in the European population. The Global Cancer Observatory data project a 29% increase in the number of deaths caused by cancer, in Europe, in 2040, in comparison with 2020, that is from about less than 2 millions in 2020 to above 2,5 millions deaths in 2040 (http//gco.iarc.fr/). According to the accepted minimum estimate of 60% of PC specific needs (Morin 2017) this results in an increase from around 1.200.000 (2020) to 1.500.000 (2040) of cancer patients requiring specialized PC interventions in Europe.

3.3 Models of early integration of palliative care and oncology care

Sixty-three papers addressing models of palliative care integration in oncology, were identified using the search strategy described above on the three databases; abstract screening lead to the full text examination of 14 papers, 5 of which were excluded because they either referred to protocol study or not reported data on cancer patients.

Thus the final analysis included the 7 studies alrady considered in the Cochrane review (2017), (Bakitas 2009, Bakitas 2015, McCorkle 2015, Maltoni 2016. Tattersall 2014, Temel 2010, Zimmermann 2014) and 9 new studies retrieved in our search (Temel 2016, El-Jawahri 2017, Groenvold 2017, Vanbutsele 2018, Costantini 2018, ,Brims 2019, Scarpi 2019, Temel 2020, Vanbutsele 2020)

The articles by El-Jawahri et al (2017) and Vanbutsele et al (2020) reported additional data on the already pubished trials (Vanbutsele 2018, Temel 2016); they are therefore based on the same model of PC and on the same patient population. The article by Costantini et al (2018) is not a comparative trial but adds qualitative information about the PC model. Finally the article by Temel et al (2020) does not allow an evaluation of the content as they failed to implement the protocol.

The 12 studies contributing to this review are therefore summarized in table 2.

Table 2. Characteristics of studies included

Study first author and year of pubblication	n° of patients	Type of tumor	Primary outcome	Other outcomes
Bakitas 2009	322	advanced gastrointestinal, lung, genitourinary, breast cancer ***	change in QoL from baseline to month 13	change in symptom intensity, mood, and resource utilization
Bakitas 2015	207	advanced solid cancer and hematologic malignancy	change in QoL from baseline to month 12	symptom impact, mood, 1-year survival, and resource use
Brims 2019	174	newly diagnosed malignant pleural mesotelioma	change in EORTC C30 Global Health Status 12 weeks after randomization	HRQoL at 24 weeks, symptoms, mood, overall survival
Groenvold 2017	297	solid cancer stage IV or cancer in the central nervous system grade III/IV	change in each patient's primary need (the most severe of the 7 EORTC QLQ-C30 scales) at 3- and 8-week follow-up	change in the seven EORTC QLQ-C30 scales and survival.
Maltoni 2016	186	locally advanced or metastatic pancreatic cancer	change in QoL between randomization and 12 weeks after	change in HADS-D score and symptoms itensity
McCorkle 2015	146	late-stage gynecological and lung cancer (intervention) late-stage head and neck and gastrointestinal cancer (usual care)	change in symptoms, health distress, depression, functional status, self-reported health, 1 and 3 months after baseline	change in emotional, functional, physical, social/family well-being, one and three months after baseline
Scarpi 2019	186	locally advanced or metastatic gastric cancer	change in QoL between randomization (T0) and T1 (12 weeks after T0)	change in mood, HADS anxiety and depression subscales; family satisfaction with care and serviva
Tattersall 2014	120	metastatic solid tumor	change in QoL over time measured by the MQOL total score; symptom severity and feeling supported	end of life experiences, number of lines of chemotherapy, and place of death.

Study first author and year of pubblication	n° of patients	Type of tumor	Primary outcome	Other outcomes
Temel 2016	350	metastatic lung or non colorectal gastrointestinal cancer	change in QoL from baseline to week 12	change in QoL from baseline to week 24, change in depression , change in depression per the Patient Health Questionnaire-9, and differences in end-of-life communication
Temel 2010	151	metastatic non small cell lung cancer	change in the quality of life at 12 weeks, effect on patient reported outcome, the use of health services	Serviva
Vanbutsele 2018	186	advanced solid cancer	change in global health status/QoL scale at 12 weeks assessed by EORTC QLQ C30	change in global health status/QoL scale at 12 weeks assessed by the MQOL; changes in patient's mood, overall survival, satisfaction with care, resource utilization
Zimmermann 2014	461	lung, breast, gastrointestinal, genitourinary, gynaecological cancer	change in FACIT-Sp score at 3 months	change in FACIT-Sp score at 4 months,

******* stage III or IV according to type of tumor

QoL: quality of life; EORTC QLQ C30: European organisation for research and treatment of cancer quality of life questionnaire core 30 items; HADS-D: hospital anxiety and depression scale; MQOL: McGill Quality of Life Questionnaire; FACIT-Sp: functional assessment of chronic illness therapy—spiritual well-being;

By analysing the PC integration models tested, we obtained the results shown in table 3. The interventions which can be considered consistent with the integrated approach described by Hui et al (2015), offering access to specialized outpatient PC clinic, are tested in the trials by Groenvold et al (2017), Temel et al (2010), Zimmermann et al (2014), Maltoni et al (2016), Temel et al (2016), Vanbutsele et al (2018), Brims et al (2019) Scarpi et al (2019). The other four trials (Bakitas 2009, Kakitas 2015, Tattersall 2014, McCorkle 2015) adopted different types of coordinated care models, almost entirely relying on phone contact with advanced practice nurses with a case manager role, only one of these trials showed a positive effect on patients quality of life (Bakitas 2009), but the results were not replicated in a subsequent trial by the same authors (Bakitas 2015). Of the 8 trials on integrated models 5 gave positive results, and three did not (Groenvold 2017, Brims 2019, Scarpi 2019). In the Danish early PC trial, published by Groenvold et al in 2017, the access to PC services is very limited if compard with the other trials, of the 145 patients randomized to early PC 138 had one visit and only 74 had two or more visits (table 4). Brims et al considered patients with newly diagnosed malignant pleural mesothelioma included at any stage of disease. Therefore there are only two negative study based on a comparable model of care, in the Italian study Scarpi et al observed a considerable contamination of the standard care intervention group with PC and a trend of improvement for the intervention arm. In Brims et al at the end of the study period 34% of participants had been referred to palliative care, and they found a clear indicator of increase of overall satisfaction with care for the carers in the early PC group.

El-Jawahri and colleagues demonstrate that the benefits of the early, integrated PC model in oncology care extend beyond patient outcomes and positively impact the experience of caregivers. In particular, the caregivers of patients assigned to early PC reported lower depression symptoms, less anxiety in the months closer to the patients' death compared with caregivers of patients assigned to usual oncology care.

In conclusion the policy and clinical quality requirement of making outpatient PC availble in comprehensive cancer centers and networks is supported by scientific evidence and clinical experience from a quantitative point of view. The criteria to refer patients timely to palliative care seem to be crucial for improving outcomes and innovative reseach efforts should aim at identifying the most effective criteria and the best intervention models to be adapted to the services of the local comprehensive cancer network.

The subjective appreciation and the specific clinical values of integrated palliative care interventions are further documented by qualitative evidences. Evidences from qualitative studies show that patients and caregivers attribute specific values to specialized outpatient PC in providing personalised and prompt symptom management, holistic support to patients and caregivers, guidance in decision making and preparation for the future (Hannon 2017). The analysis of PC outpatient interventions showed that interventions based on psychological and cognitive coping, disease understanding, decision making and care planning were associated with lower psychological distress an better use of health care resources at the end of life (Hoerger 2018). The study by Costantini et al (2018), shows that an early integration of specialised PC after the diagnosis of advanced cancer is feasible and well accepted by patients, relatives and, to a lesser extent, by oncologists.

Table 3. Elements of PC intervention and implementation models in trials on early PC for advanced cancer patients

	Bakitas 2009	Bakitas 2015	Brims 2019	Tattersall 2014	McCorkle 2015	Groenvold 2017	Temel 2010	Zimmerman 2014	Maltoni 2016	Temel 2016	Vanbutsele 2018	Scarpi 2019
Outpatient PC clinic systematic referral	-	+/-§	+	-	-	+*	+	+	+	+	+	+
Access to PC specialised doctor	-	+/-§	+	-	-	+*	+	+	+	+	+	+
Access to specialized PC nurse/ advanced practive nurse in person	+/-^	+	-	-	+#	+*	+	+	-	+	+	-
Access to specialized PC nurse/ advanced practive nurse on the phone	+	+	-	+	-	-	-	+	-	-	-	-
Guidelines for PC delivery adopted in protocol	+	+	-	-	-	-	+	+	+	+	+	-

	Bakitas 2009	Bakitas 2015	Brims 2019	Tattersall 2014	McCorkle 2015	Groenvold 2017	Temel 2010	Zimmerman 2014	Maltoni 2016	Temel 2016	Vanbutsele 2018	Scarpi 2019
Direct access to other PC services available	-	-	-	-	-	+*	-	+	-	-	-	-
Participation to multidisciplinary oncology meetings	-	-	-	-	-	-	-	-	-	-	+	-
Training for oncology staff	-	-	-	-	+	-	-	-	-	-	-	-

^ Initial interview with advanced practice nursen could be either on the phone or in person followed by 4 weekly meetings and phone care coordination was performed afterwards (nurse case manager model);

§ Initial in person visit with certified PC clinician (not sepcified if doctor or nurse) and thereafter phone contact with adavanced practice nurse

no specific competence in PC is required

* Patients were referred to specialised PC centers with outpatient clinic and specialised personnel available which component of the center provided PC intervention is not specified in protocol. Many patients did not access centre facilities

Table 4. Characteristics of studies on integrated model

Study first author and year of pubblication	Study duration weeks	Mean number of PC visits per patient during study period	Frequecy of PC visits: weeks	Patients reported outcomes	Caregiveres outcomes	Health Resource utilization
Temel 2010	12	4	3	+	NA	+
Zimmermann 2014	12 – 16	> 2.4	5	+	+	NA
Maltoni 2016	12	8.9	1.3	+	NA	NA
Temel 2016; El-Jawahri 2017	24	6.5	3.7	+	+	
Vanbutsele 2018; Vanbutsele 2020	18	3	6	+	NA	-
Scarpi 2019	12	4.3	2.7	-	NA	NA
Brims 2019	24	Not reported		+	+	
Groenvold 2017	8	Not reported ; about 50% of pts had only 1 visit	-	-	NA	NA

3.4 Patient centred decision making and the implementation of PROMs in cancer care

One definition of patient centred care is “... care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (Institute of Medicine 2001) in a pragmatic way it is a system of care that assure effective communication and information enabling to achieve shared clinical decisions and selfcare. The appreciation of direct systematic assessment of subjective variables describing patient’s health related physical, psychological, social and spiritual dimensions is doable by using PROMs and their use is an important contribution to a patient centred clinical approach (Jensen 2014). The implementation of PROMs in clinical practice improves patient-physician communication (Boyes 2006, Detmar 2002, Velikova 2004) and has been considered by experts one of the factors contributing to the integration of PC and oncology in patients with advanced cancer also as well as an indispensable instrument in shared decision making (Hui 2015, Kaasa 2018). The iPAAC open workshop meeting hold at the European Assiciation for Palliative Care World Research Congress (appendix 1) reviewed the need of practical implementation of PROMs in oncology care and the characteristics of the available experiences in adopting and integrating PROMs in electronic clinical records (Brunelli 2020). A common vision between the palliative care discipline which has its foundation empowering patients’ perspective as th focus of care (Saunders 2006) , oncology and patients representatives was the objective of this meeting. The worshop defined the basic and practical steps for PROMs implementation in clinical practice, including the technical requirements for integration in electronic clinical records. The meeting also confirmed consensus to guarantee access to general and specialized opalliative care in comprehensive cancer networks by different stakeholders such as EAPC, OECI , EPCP and iPAAC.

4 Discussion and final recommendations

The role of specialized PC needs to be clearly structured in Cancer Control Programs, Comprehesive Cancer Centers and Comprehensive Cancer Networks. iPAAC work packages, highlighting challeges in care for specific conditions such as pancreatic cancer (WP8) or the requirements for Comprehensive Cancer Networks (WP10), converge to recognize the access to PC as a quality and structural requirement to guaranteed continuity of care across the cancer tarjectory from diagnosis to end-of-life care and to identify the availability of specialized PC resources as part of cancer control programs as one step on the care continuity process. We can at the moment recommend, based on the available experiences, and on scientific evidences that professional expertise in PC by specialized teams working in close connection with oncology teams should be present in cancer comprehensive centers or networks. The allocation of humane and financial resources needs to be clealy planned in national cancer control programs according to the objective demand arising from the needs of the population dying of cancer and the projections of these needs in the next 20 years which show an increasing impact of cancer as a cause of death. To facilitate this policy planning and its cultural recognizion the lack of a well defined role for PC within the framework of cancer control programs is a limitation (Albreth et al 2017, Federici et al 2017, European Commission 2020). In particular it is necessary that the definition of „cancer survivorship care“ allows to specifically identitify the needs of patients with active uncurable disease who are finally dying of their disease and to adopt clinical assessment and care models that correspond to the different burden of the disease on the quality of life of this group of patients, withouth blurring this perspective with the rehabilitation and psychosocial needs of diffent cancer populations with normal life expectancy.

The timely access to PC services and resources should be part of any cancer control program. This requires that integrated care pathways are available from the diagnosis of advanced disease to end-of-life care, and cannot be accomplished without particular attention to continuity between specialized acute hospital care and hospice/ home care at the community level. This approach is part of the Comprehensive cancer care networks requirements described in iPAAC WP10. Based on the last ten years experience and evidences, one grounding step of this care network is constituted by outpatient specialized PC offering simultaneosly anticancer treatments and PC interventions. At comprehensive cancer centers this type of clinic is based on the availability of certified PC pysicians and nurses applying principles of care including multidimensional assessment, prompt symptom control, communication, support in decision making/care planning and family support. This model is often referred to an integrated care model (Hui 2015, Kaasa 2018) and it is based fundamentally on the contribution of two disciplinary independent and coordinated approaches the oncology and the palliative care approach. The clinical usefulness and validity of this model is based on both quantitative and qualitative study results

While it is accepted that specialized PC interventions can improve symptom control and quality of life in cancer patients, the timing and therefore the integration of these interventions across the cancer care pathway continuum has been the object of a number clinical trials, starting in 2010, aiming at demonstrating that the access to PC interventions of patients with advanced cancer earlier than at the end-of-life is beneficial. The Cochrane review by Haun et al performed a metanalysis (Haun et al 2017) of clinical trials distinguishing protocols which tested „integrated care models“ from other models that were defined „coordinated care models“ the main difference is that in the integrated care models patients have access to dedicated PC staff (nurses and doctors) meanwhile they are attending oncology clinics. We revised all the articles included inthe Cochrane review and performed an additional literature search with specific attention to the care models delivery and their comparability. Our work confirms the validity and feasibility of the integrated model at comprehensive cancer centers or networks. An emerging research clinical question is now how to identify selection criteria for referral of patients to specialized cancer PC in order to optimize clinical benefit, resource allocation and the cost/benefit ratio in this patient population. Joint research and policy efforts in this direction on the side on European Union would be welcome and needed, but the recent Mission Conquering Cancer proposal of the EC seems insufficient to emphasize this area of clinical and research needs (European Commission 2020)

Improving patient centredness and patients‘ participation in shared clinical decisions should improve the actual and perceived quality of care and finds specific application when clinical decisions are made in the context of advanced cancer, short prognosis, equipoise in clinical outcomes, planning of care at the end of life. The adoption of apprpriate PROMs assessment and inclusion in the medical records of patients with cancer in general with advanced cancer in particular and is a prerequisite to improve patient centredness and integration of palliative and oncology care pathways.

The iPAAC meeting at the 11th World Congress of Research in PC allowed to summarize the content of WP8 Task 5 and Task 6 with the active contribution of the EAPC, OECI, ECPC and IASP. The consistency of the contribution of the involved stakhColders confirmed that PC integration with oncology in cancer control programs is seen as a priority by oncology and PC professionals as well as cancer patient representatives. In a meeting organized by the PRC (European Palliative Care Research Center 2020) the iPAAC program was used to discuss the special case of integration oncology and PC perspective in the participation of patients with adavced cancer in early phase clinical trials at the Seminar of the European Palliative Care Research Center (3-4 december 2020 ,Appendix 2, www.bit.ly/PRCresearch). Finally the summary recommendations in table 5 can be seen as a result of Task 6 in WP8 of iPAAC.

Table 5. Recommendations for Palliative Care and Oncology Integration Promoting Actions

ITEM	RECOMMENDATION
Culture and Politics	Palliative care should be perceived as integral and recognizable part of cancer care continuum by professionals health care authorities and the public
Politics and Structure - Organization	Palliative care services should be available with certified palliative care specialist expertise and skills in cancer control programs
	Systematic PROMs assessment should be adopted in oncology care
Care pathways	Palliative care interventions should be integrated early in the disease trajectory and referral criteria to specialized palliative care should be urgently addressed in research and health policy making
Research	• Palliative care research should be part of cancer research priorities. • Identification of critera for referral to specialized palliative care • development of guidelines for patient centred decision making in advanced cancer management should be part of the research agenda in cancer control programs

Education	Education in palliative care and academic palliative care programs are needed to make professional workforce available to care networks and national cancer plans

5 Conclusion

Palliative care integration with oncology care has made progresses in the last 10 years, and new evidences are available to prove effective interventions. Still the availability of optimal intervention models their implementation and operational mechanisms require significant effort on service policy and organization, resource allocation, and research. The present report from iPAAC, integrates the discussion and the contribution of different stakeholders including the European Association for Palliative Care, the working group of the Organization of European Cancer Centers on Supportive and Palliative Care and the European Cancer Patients Coalition. The present report also integrates the results of other groups within iPAAC, such as the Workpackage 8 task on neglected cancers and the Workpackage 10 on Comprehensive cancer care networks.

This work resulted in the following general road map indications which include and integrates Table 5 recommendations

1) National cancer control programs and cancer comprehensive networks should reflect and endorse the priority of harmonizing across Europe the availability, accessibility and quality of specialized palliative care services within the cancer care continuum by:
    - Offering specialized palliative care services comprehensive cancer care networks
    - Encouraging early referral to palliative care services for patients with palliative care needs

- Specifically address, in Comprehensive cancer care networks, continuity of care across specialized oncology care, specialized palliative care, general palliative care and community care services, including hospice and home care services.

2) European Communitarian policies should take into account the specific health care needs emerging from cancer mortality and burden, distinguishing the palliative care needs of the population affected by incurable cancer, with limited life prognoses, from those of cancer survivors. These needs should find recognition also in global cancer control programs and research in addressing at least:

   - Quality of life and care at the end of life.
   - Service organization such as clinical and public health indicators of palliative care integration with general health care and oncology care, criteria for referral to specialized palliative care services.
   - Equity of access to effective high quality palliative care across Europe as related to minority groups and disadvantaged gender or social conditions
   - Cultural and societal factors contributing to public awareness and understanding of palliative care role in health care and cancer care in particular.

6 References

Albreth T, Kiasuwa R, Van den Bulcke. Cancon Cancer Control Joint Action, European Guide on Quality Improvement in comprehensive cancer control. National Institute of Public Health, Ljubljana Scientific Institute of Public Health, Brussels 2017

Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. JAMA. 2009 Aug 19;302(7):741-9. doi: 10.1001/jama.2009.1198. PMID: 19690306; PMCID: PMC3657724.

Bakitas MA, Tosteson TD, Li Z, Lyons KD, Hull JG, Li Z, Dionne-Odom JN, Frost J, Dragnev KH, Hegel MT, Azuero A, Ahles TA. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. J Clin Oncol. 2015 May 1;33(13):1438-45. doi: 10.1200/JCO.2014.58.6362. Epub 2015 Mar 23. PMID: 25800768; PMCID: PMC4404422.

Boyes A, Newell S, Girgis A, Mcelduff P, Sanson-Fisher R. Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? Eur J Cancer Care 2006;15(2):163–171

Brims F, Gunatilake S, Lawrie I, Marshall L, Fogg C, Qi C, Creech L, Holtom N, Killick S, Yung B, Cooper D, Stadon L, Cook P, Fuller E, Walther J, Plunkett C, Bates A, Mackinlay C, Tandon A, Maskell NA, Forbes K, Rahman NM, Gerry S, Chauhan AJ; RESPECT-Meso investigators. Early specialist palliative care on quality of life for malignant pleural mesothelioma: a randomised controlled trial. Thorax. 2019 Apr;74(4):354-361. doi: 10.1136/thoraxjnl-2018-212380. Epub 2019 Jan 19. PMID: 30661019.

Brunelli C, Borreani C, Caraceni A, Roli A, Bellazzi M, Lombi L, Zito E, Pellegrini C, Spada P, Kaasa S, Foschi AM, Apolone G; PATIENT VOICES study group. PATIENT VOICES, a project for the integration of the systematic assessment of patient reported outcomes and experiences within a comprehensive cancer center: a protocol for a mixed method feasibility study. Health Qual Life Outcomes. 2020 Jul 28;18(1):252. doi: 10.1186/s12955-020-01501-1. PMID: 32723341; PMCID: PMC7388528.

Cancon Cancer Control Joint Action, https://cancercontrol.eu/ (last accessed December 11, 2020).

Costantini M, Apolone G, Tanzi S, Falco F, Rondini E, Guberti M, Fanello S, Cavuto S, Savoldi L, Piro R, Mecugni D, Di Leo S. Is early integration of palliative care feasible and acceptable for advanced respiratory and gastrointestinal cancer patients? A phase 2 mixed-methods study. Palliat Med. 2018 Jan;32(1):46-58. doi: 10.1177/0269216317731571. Epub 2017 Sep 27. PMID: 28952881.

Detmar S, Muller M, Schornagel J, Wever L, Aaronson N. Health-related quality of life assessments and patient–physician communication: a randomized controlled trial. J Amer

Med Assoc 2002;288(23):3027–3034El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER, Eusebio JR, Fishman S, VanDusen H, Li Z, Muzikansky A, Temel JS. Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial. Oncologist. 2017 Dec;22(12):1528-1534. doi: 10.1634/theoncologist.2017-0227. Epub 2017 Sep 11. PMID: 28894017; PMCID: PMC5728034.

European Commission Directorate for research an Innovation PEOPLE Proposed Mission Conquering cancer : mission possible. Report of the Mission Board for Cancer.Independent expert report. https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en accessed 25/02/2021

European Palliative Care Reseach Center (2020) : PRC seminar 2 Early phase clinical trials and palliative care in oncology

https://www.youtube.com/user/Kreftforeningen/videos

Federici A. Nicoletti G van den Bulcke Cancer Control Joint Action Policy Papers , National Institute of Public Health , Ljubljana Slovenia Scientific Institute of Public Health Brussels, 2017

Global Cancer Observatory; http://gco.iarc.fr (accessed December 10, 2020)

Groenvold M, Petersen MA, Damkier A, Neergaard MA, Nielsen JB, Pedersen L, Sjøgren P, Strömgren AS, Vejlgaard TB, Gluud C, Lindschou J, Fayers P, Higginson IJ, Johnsen AT. Randomised clinical trial of early specialist PCplus standard care versus standard care alone in patients with advanced cancer: The Danish PCTrial. Palliat Med. 2017 Oct;31(9):814-824. doi: 10.1177/0269216317705100. Epub 2017 May 12. PMID: 28494643.

Hannon B, Swami N, Rodin G, Pope A, Zimmermann C. Experiences of patients and caregivers with early palliative care: A qualitative study. Palliat Med. 2017 Jan;31(1):72-81. doi: 10.1177/0269216316649126. Epub 2016 Aug 19. PMID: 27495814.

Hansen MB, Ross L, Petersen MA, Adsersen M, Rojas-Concha L, Groenvold M. Similar levels of symptoms and problems were found among patients referred to specialized palliative care by general practitioners and hospital physicians: A nationwide register-based study of 31,139 cancer patients. Palliat Med. 2020 Sep;34(8):1118-1126.

Haun MW, Estel S, Rücker G, Friederich HC, Villalobos M, Thomas M, Hartmann M. Early PCfor adults with advanced cancer. Cochrane Database Syst Rev. 2017 Jun 12;6(6):CD011129. doi: 10.1002/14651858.CD011129.pub2. PMID: 28603881; PMCID: PMC6481832.

Hoerger M, Greer JA, Jackson VA, Park ER, Pirl WF, El-Jawahri A, Gallagher ER, Hagan T, Jacobsen J, Perry LM, Temel JS. Defining the elements of early PCthat are associated with patient-reported outcomes and the delivery of end-of-life care. J Clin Oncol. 2018 Apr 10;36(11):1096-1102. doi: 10.1200/JCO.2017.75.6676. Epub 2018 Feb 23. PMID: 29474102; PMCID: PMC5891131.

Hui D, Bansal S, Strasser F, Morita T, Caraceni A, Davis M, Cherny N, Kaasa S, Currow D, Abernethy A, Nekolaichuk C, Bruera E. Indicators of integration of oncology and PCprograms: an international consensus. Ann Oncol. 2015 Sep;26(9):1953-1959. doi: 10.1093/annonc/mdv269. Epub 2015 Jun 18. PMID: 26088196; PMCID: PMC4551157.

Hui D, Bruera E. Models of integration of oncology and palliative care. Ann Palliat Med. 2015 Jul;4(3):89-98. doi: 10.3978/j.issn.2224-5820.2015.04.01. PMID: 26231806.

Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001.

Jensen RE., Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC. Review of electronic patient-reported outcomes systems used in cancer clinical care. Journal of Oncology Practice 2014, 10(4), e215-e222.

Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, Brunelli C, Caraceni A, Cervantes A, Currow DC, Deliens L, Fallon M, Gómez-Batiste X, Grotmol KS, Hannon B, Haugen DF, Higginson IJ, Hjermstad MJ, Hui D, Jordan K, Kurita GP, Larkin PJ, Miccinesi G, Nauck F, Pribakovic R, Rodin G, Sjøgren P, Stone P, Zimmermann C, Lundeby T. Integration of oncology and palliative care: a Lancet Oncology Commission. Lancet Oncol. 2018 Nov;19(11):e588-e653. doi: 10.1016/S1470-2045(18)30415-7. Epub 2018 Oct 18. PMID: 30344075.

Maltoni M, Scarpi E, Dall'Agata M, Zagonel V, Bertè R, Ferrari D, Broglia CM, Bortolussi R, Trentin L, Valgiusti M, Pini S, Farolfi A, Casadei Gardini A, Nanni O, Amadori D; Early PCItalian Study Group (EPCISG). Systematic versus on-demand early palliative care: results from a multicentre, randomised clinical trial. Eur J Cancer. 2016 Sep;65:61-8. doi: 10.1016/j.ejca.2016.06.007. Epub 2016 Jul 26. PMID: 27472648.

McCorkle R, Jeon S, Ercolano E, Lazenby M, Reid A, Davies M, Viveiros D, Gettinger S. An Advanced Practice Nurse Coordinated Multidisciplinary Intervention for Patients with Late-Stage Cancer: A Cluster Randomized Trial. J Palliat Med. 2015 Nov;18(11):962-9. doi: 10.1089/jpm.2015.0113. Epub 2015 Aug 25. PMID: 26305992; PMCID: PMC4638201.

Morin L, Aubry R, Frova L, et al. Estimating the need for PCat the population level: A cross-national study in 12 countries. Palliative Medicine. 2017;31(6):526-536. doi:10.1177/0269216316671280

Nakajima N, Abe Y. Concurrent Specialized PCUpon Initiation of First-Line Chemotherapy for Cancer Progression: Is It Early Enough? Am J Hosp Palliat Care. 2016 May;33(4):340-5. doi: 10.1177/1049909114560370. Epub 2014 Nov 28. PMID: 25433067.

Rabow M, Small R, Jow A, Majure M, Chien A, Melisko M, Belkora J, Esserman LJ, Rugo H. The value of embedding: integrated PCfor patients with metastatic breast cancer. Breast Cancer Res Treat. 2018 Feb;167(3):703-708. doi: 10.1007/s10549-017-4556-2. Epub 2017 Oct 30. PMID: 29086230.

Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential PCpopulation. Palliat Med. 2005 Oct;19(7):556-62. doi: 10.1191/0269216305pm1067oa. PMID: 16295289.

Saunders C. Templeton prize speech. In Cicely Saunders, Selected writings 1958 – 2004. New York: Oxford University Press; 2006 pp 157 – 162.

Scarpi E, Dall'Agata M, Zagonel V, Gamucci T, Bertè R, Sansoni E, Amaducci E, Broglia CM, Alquati S, Garetto F, Schiavon S, Quadrini S, Orlandi E, Casadei Gardini A, Ruscelli S, Ferrari D, Pino MS, Bortolussi R, Negri F, Stragliotto S, Narducci F, Valgiusti M, Farolfi A, Nanni O, Rossi R, Maltoni M; Early PCItalian Study Group (EPCISG). Systematic vs. on-demand early PCin gastric cancer patients: a randomized clinical trial assessing patient and healthcare service outcomes. Support Care Cancer. 2019 Jul;27(7):2425-2434. doi: 10.1007/s00520-018-4517-2. Epub 2018 Oct 24. PMID: 30357555.

Tattersall MHN, Martin A, Devine R, Ryan J, Jansen J, Hastings L, et al. Early contact with PCservices: a randomized trial in patients with newly detected incurable metastatic cancer. PC& Medicine 2014;4(1):170. [DOI: 10.4172/2165-7386.1000170]

Temel JS, Greer JA, El-Jawahri A, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER, Eusebio JR, Li Z, Muzikansky A, Ryan DP. Effects of Early Integrated PCin Patients With Lung and GI Cancer: A Randomized Clinical Trial. J Clin Oncol. 2017 Mar 10;35(8):834-841. doi: 10.1200/JCO.2016.70.5046. Epub 2016 Dec 28. PMID: 28029308; PMCID: PMC5455686.

Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early PCfor patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42. doi: 10.1056/NEJMoa1000678. PMID: 20818875.

Temel JS, Sloan J, Zemla T, Greer JA, Jackson VA, El-Jawahri A, Kamdar M, Kamal A, Blinderman CD, Strand J, Zylla D, Daugherty C, Furqan M, Obel J, Razaq M, Roeland EJ, Loprinzi C. Multisite, Randomized Trial of Early Integrated Palliative and Oncology Care in Patients with Advanced Lung and Gastrointestinal Cancer: Alliance A221303. J Palliat Med. 2020 Jul;23(7):922-929. doi: 10.1089/jpm.2019.0377. Epub 2020 Feb 7. PMID: 32031887; PMCID: PMC7307668.

Vanbutsele G, Pardon K, Van Belle S, Surmont V, De Laat M, Colman R, Eecloo K, Cocquyt V, Geboes K, Deliens L. Effect of early and systematic integration of PCin patients with advanced cancer: a randomised controlled trial. Lancet Oncol. 2018 Mar;19(3):394-404. doi: 10.1016/S1470-2045(18)30060-3. Epub 2018 Feb 3. PMID: 29402701.

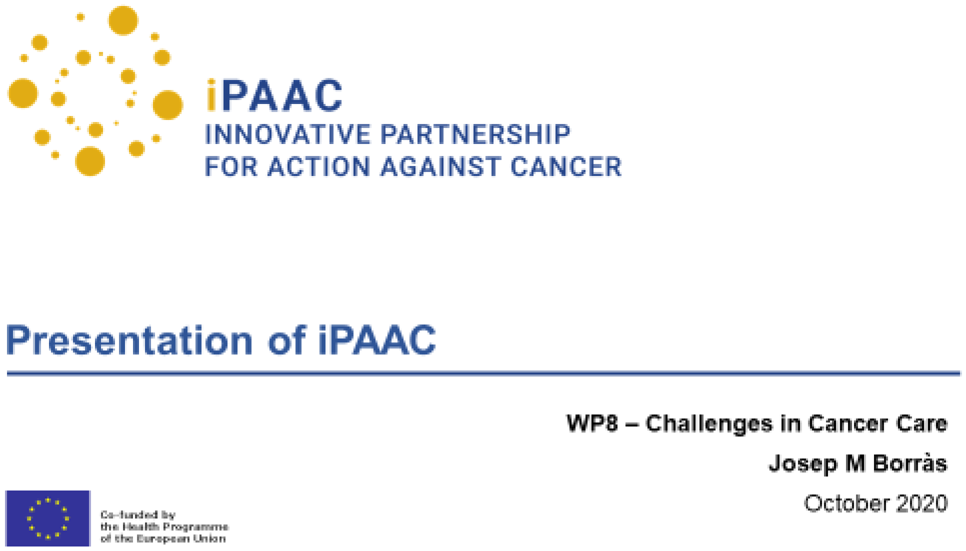
Vanbutsele G, Van Belle S, Surmont V, De Laat M, Colman R, Eecloo K, Naert E, De Man M, Geboes K, Deliens L, Pardon K. The effect of early and systematic integration of PCin oncology on quality of life and health care use near the end of life: A randomised controlled trial. Eur J Cancer. 2020 Jan;124:186-193. doi: 10.1016/j.ejca.2019.11.009. Epub 2019 Dec 5. PMID: 31812934.

Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. J Clin Oncol 2004;22(4):714–724.

World Health Assembly. Resolution WHA67.19 Strengthening of PCas a component of comprehensivecare throughout the life course. 2014. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (last accessed December 4, 2020).

Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leighl N, Oza A, Moore M, Rydall A, Rodin G, Tannock I, Donner A, Lo C. Early PCfor patients with advanced cancer: a cluster-randomised controlled trial. Lancet. 2014 May 17;383(9930):1721-30. doi: 10.1016/S0140-6736(13)62416-2. Epub 2014 Feb 19. PMID: 24559581.

7 Appendix 1



iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Presentation of iPAAC

WP8 – Challenges in Cancer Care
Josep M Borràs
October 2020

Co-funded by
the Health Programme
of the European Union

WORK PACKAGES – IPAAC

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Innovative Partnership for Action Against Cancer (iPAAC) is the third consecutive Joint Action dedicated to cancer control.

iPAAC WORK PACKAGES:

WP 1 – Coordination
National Institute of Public Health of Slovenia (NIJZ)

WP 2 – Dissemination
Institute of Health Information and Statistics of the Czech Republic (UZIS)

WP 3 – Evaluation
Croatian National Institute of Public Health (HZJZ)

WP 4 – Integration in National Policies and Sustainability
Belgian Cancer Centre, Sciensano (SC)

Co-funded by
the Health Programme
of the European Union

WORK PACKAGES – IPAAC

WP 5 – Prevention and Screening
Cancer Society of Finland (CSF)

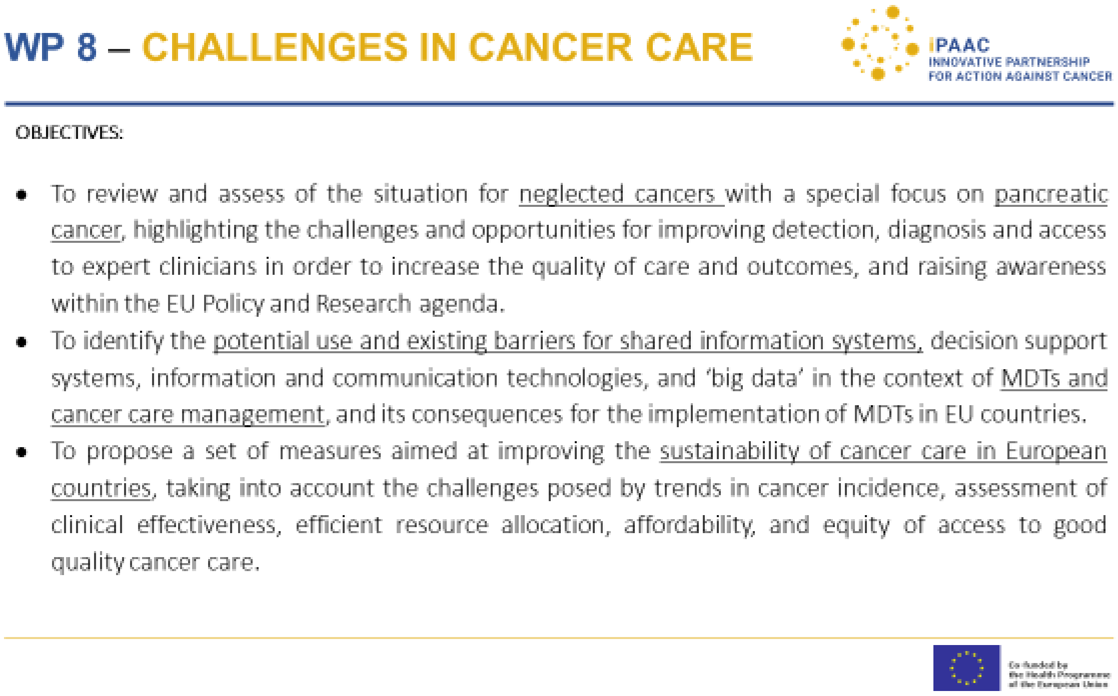
WP 6 – Genomics in Cancer Control and Care
Belgian Cancer Centre, Sciensano (SC)

WP 7 – Cancer Information and Registration
Italian National Institute of Public Health (ISS)

WP 8 – Challenges in Cancer Care
Catalan Institute of Oncology (ICO)

WP 9 – Innovative Therapies in Cancer
French National Institute of Cancer (INCa)

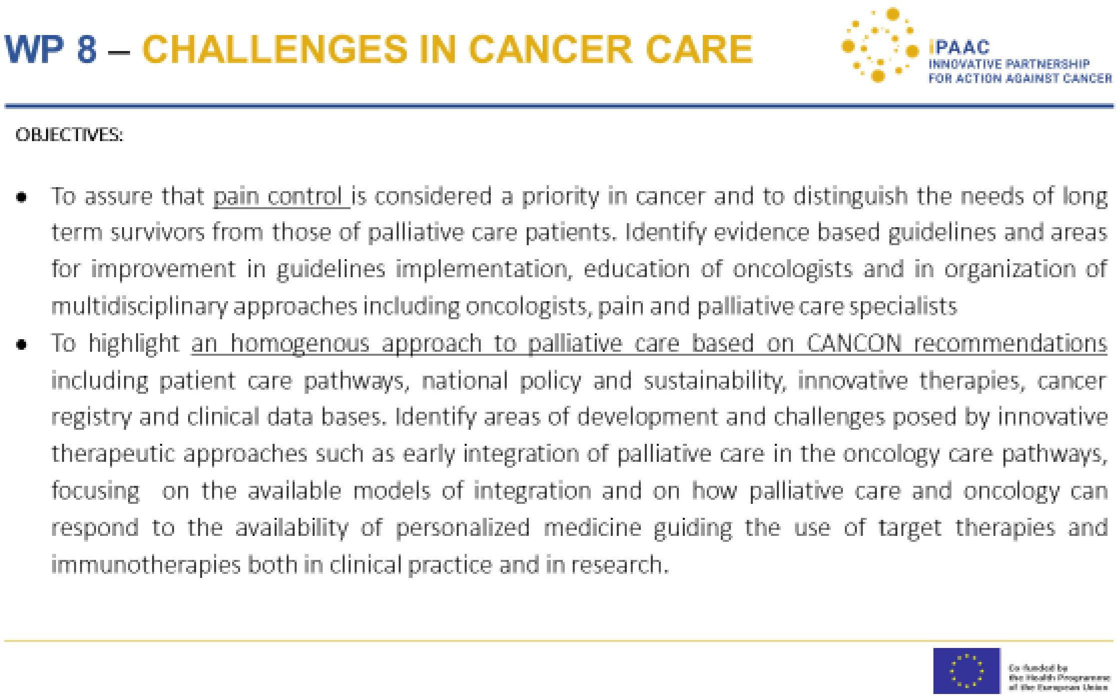
WP 10 – Governance of Integrated and Comprehensive Cancer Care
German Federal Ministry of Health and German Cancer Society (DKG)



WP 8 – CHALLENGES IN CANCER CARE

OBJECTIVES:

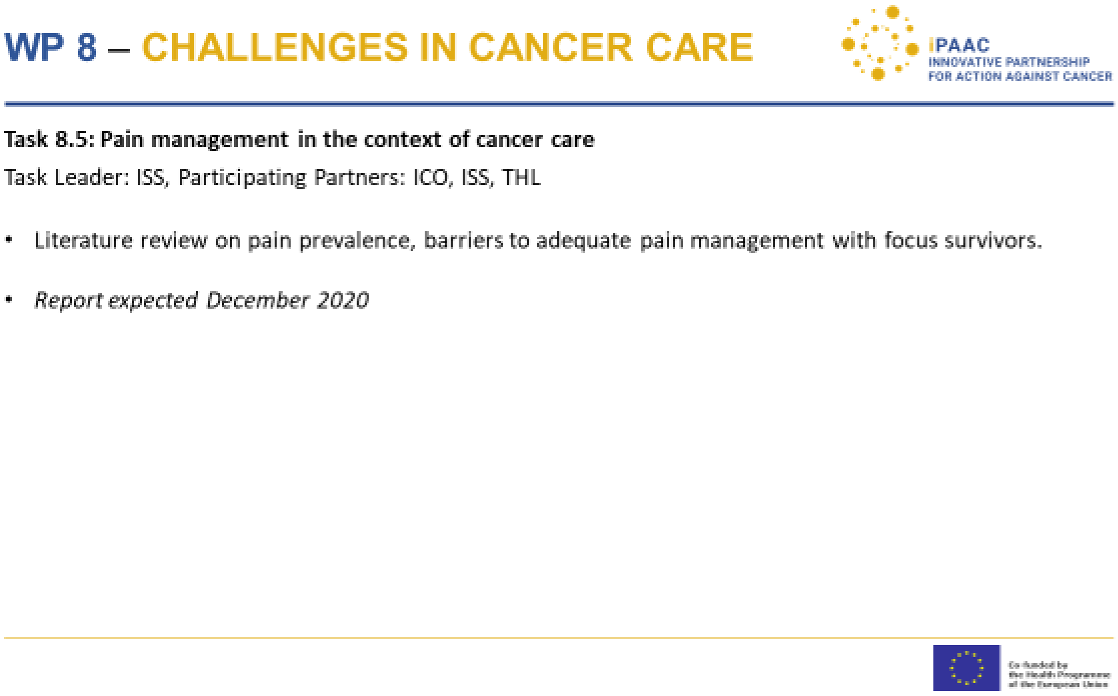
- To review and assess of the situation for neglected cancers with a special focus on pancreatic cancer, highlighting the challenges and opportunities for improving detection, diagnosis and access to expert clinicians in order to increase the quality of care and outcomes, and raising awareness within the EU Policy and Research agenda.
- To identify the potential use and existing barriers for shared information systems, decision support systems, information and communication technologies, and 'big data' in the context of MDTs and cancer care management, and its consequences for the implementation of MDTs in EU countries.
- To propose a set of measures aimed at improving the sustainability of cancer care in European countries, taking into account the challenges posed by trends in cancer incidence, assessment of clinical effectiveness, efficient resource allocation, affordability, and equity of access to good quality cancer care.



WP 8 – CHALLENGES IN CANCER CARE

OBJECTIVES:

- To assure that pain control is considered a priority in cancer and to distinguish the needs of long term survivors from those of palliative care patients. Identify evidence based guidelines and areas for improvement in guidelines implementation, education of oncologists and in organization of multidisciplinary approaches including oncologists, pain and palliative care specialists
- To highlight an homogenous approach to palliative care based on CANCON recommendations including patient care pathways, national policy and sustainability, innovative therapies, cancer registry and clinical data bases. Identify areas of development and challenges posed by innovative therapeutic approaches such as early integration of palliative care in the oncology care pathways, focusing on the available models of integration and on how palliative care and oncology can respond to the availability of personalized medicine guiding the use of target therapies and immunotherapies both in clinical practice and in research.

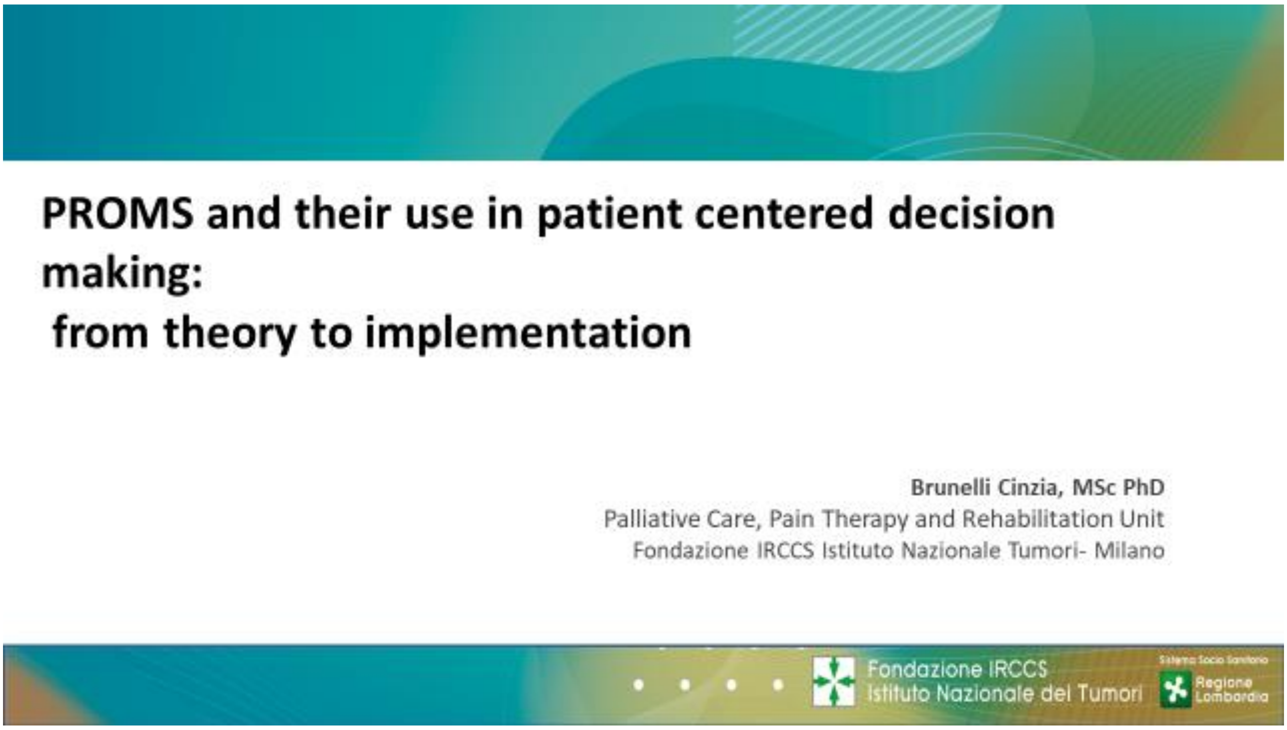


WP 8 – CHALLENGES IN CANCER CARE

Task 8.5: Pain management in the context of cancer care

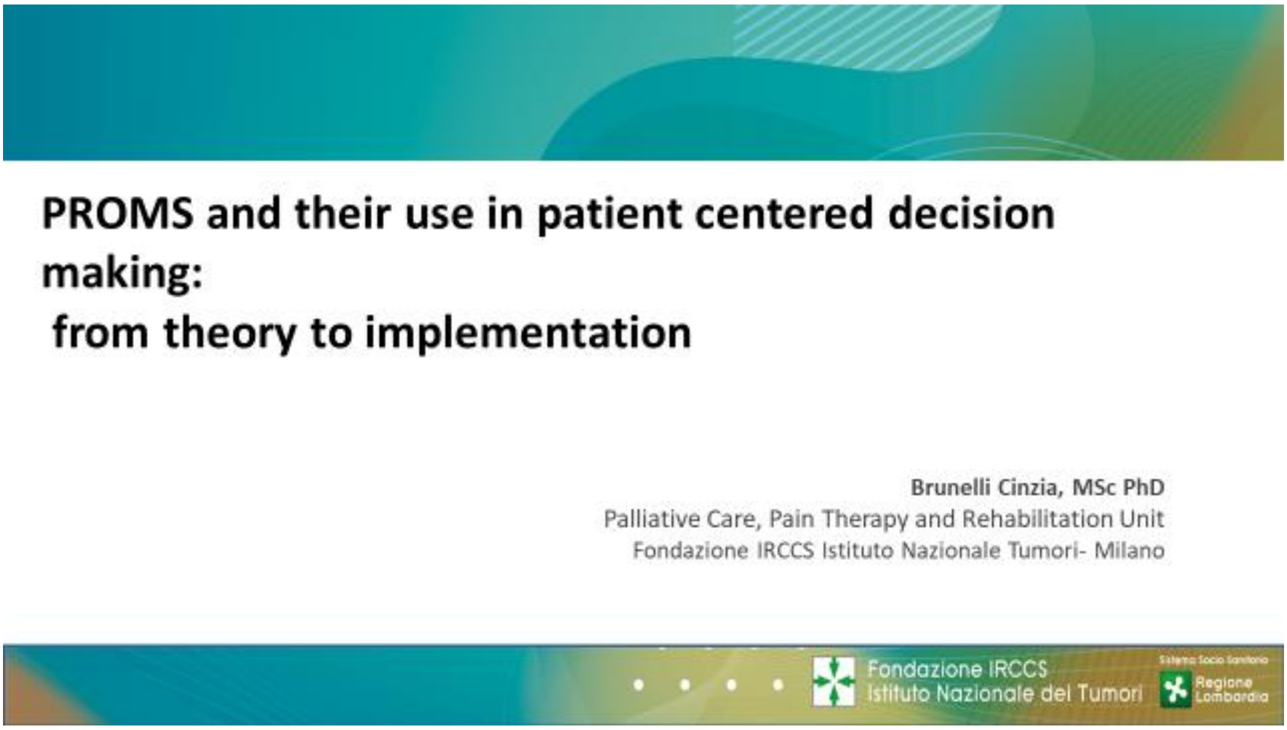
Task Leader: ISS, Participating Partners: ICO, ISS, THL

- Literature review on pain prevalence, barriers to adequate pain management with focus survivors.
- *Report expected December 2020*



PROMS and their use in patient centered decision making:
from theory to implementation

Brunelli Cinzia, MSc PhD
Palliative Care, Pain Therapy and Rehabilitation Unit
Fondazione IRCCS Istituto Nazionale Tumori- Milano



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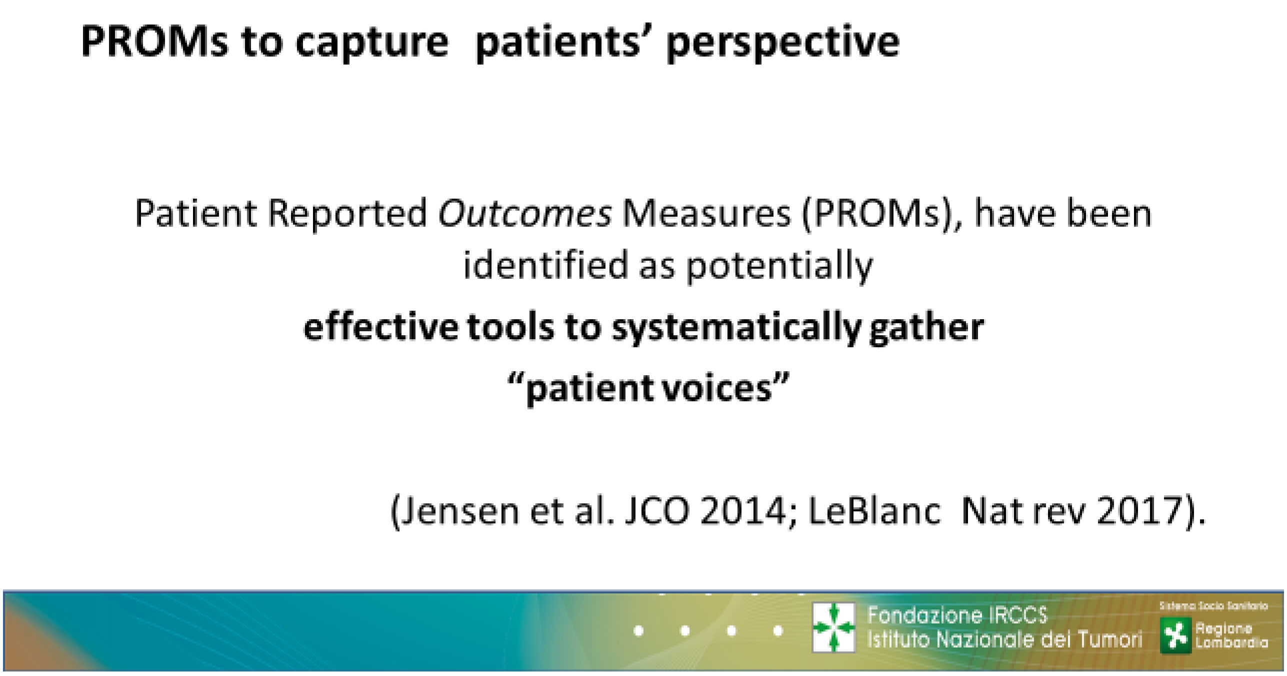
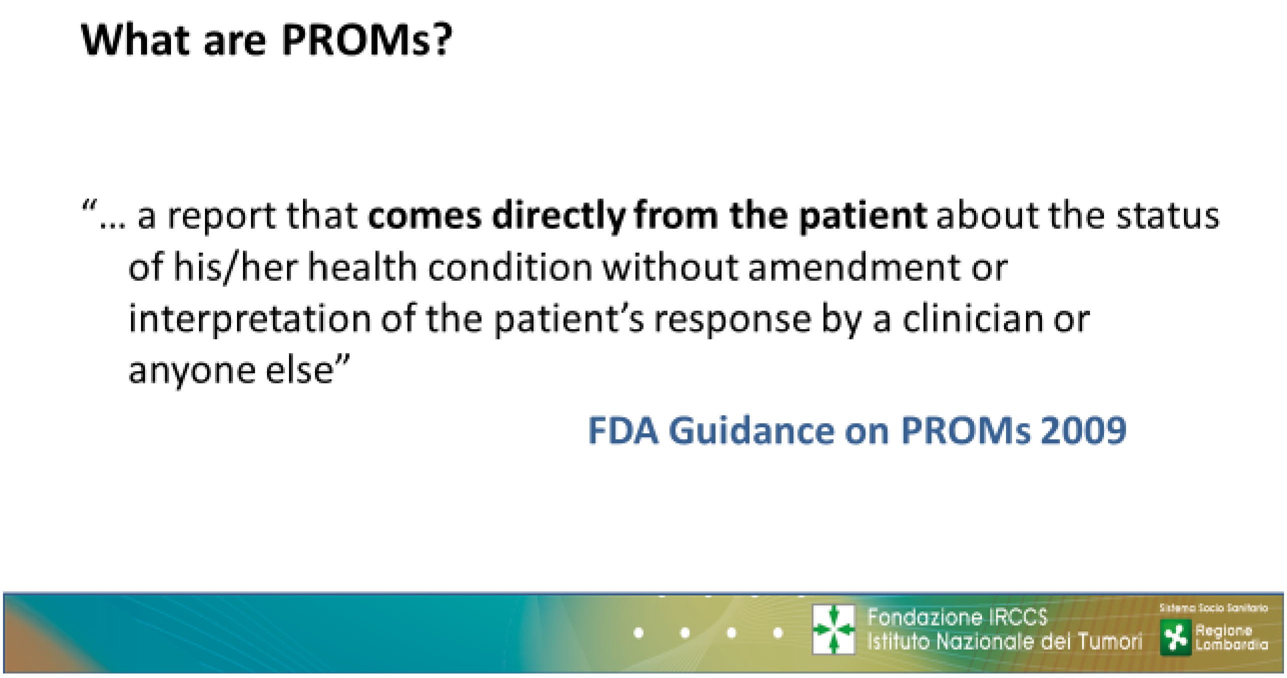


PROMs to capture patients' perspective

Patient Reported *Outcomes* Measures (PROMs), have been identified as potentially

effective tools to systematically gather
"patient voices"

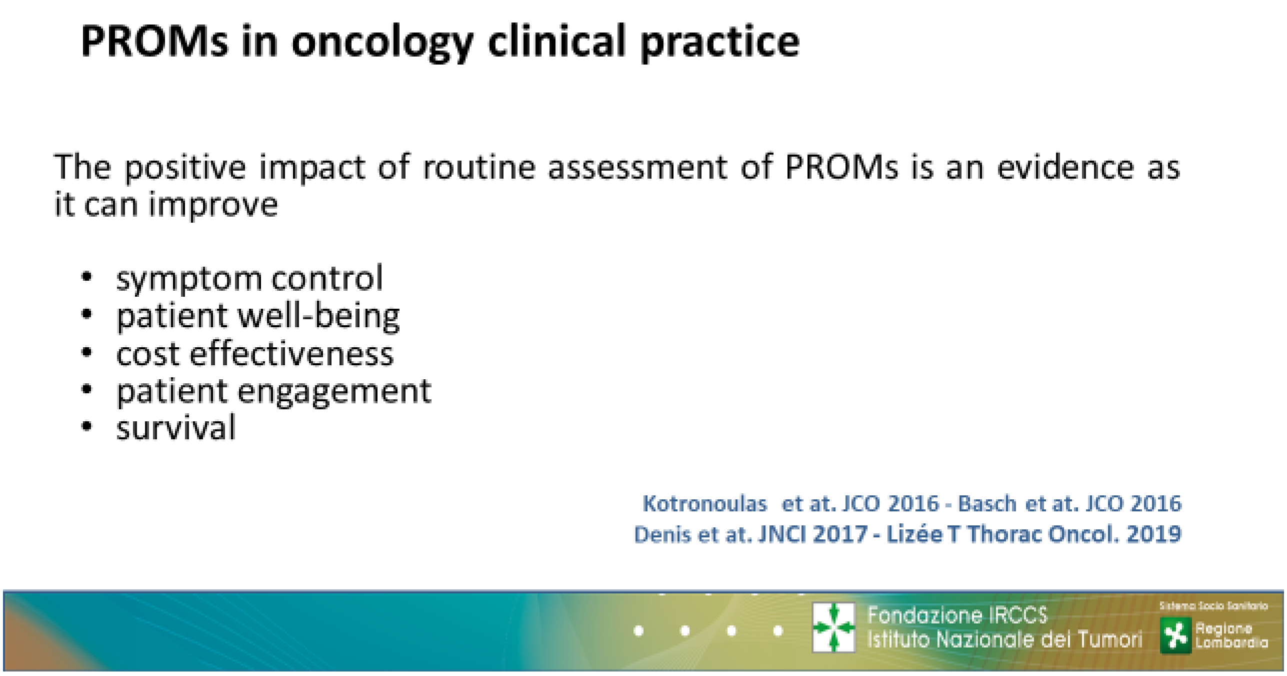
(Jensen et al. JCO 2014; LeBlanc Nat rev 2017).



What are PROMs?

"… a report that **comes directly from the patient** about the status of his/her health condition without amendment or interpretation of the patient's response by a clinician or anyone else"

FDA Guidance on PROMs 2009



PROMs in oncology clinical practice

The positive impact of routine assessment of PROMs is an evidence as it can improve

- symptom control
- patient well-being
- cost effectiveness
- patient engagement
- survival

Kotronoulas et at. JCO 2016 - Basch et at. JCO 2016
Denis et at. JNCI 2017 - Lizée T Thorac Oncol. 2019

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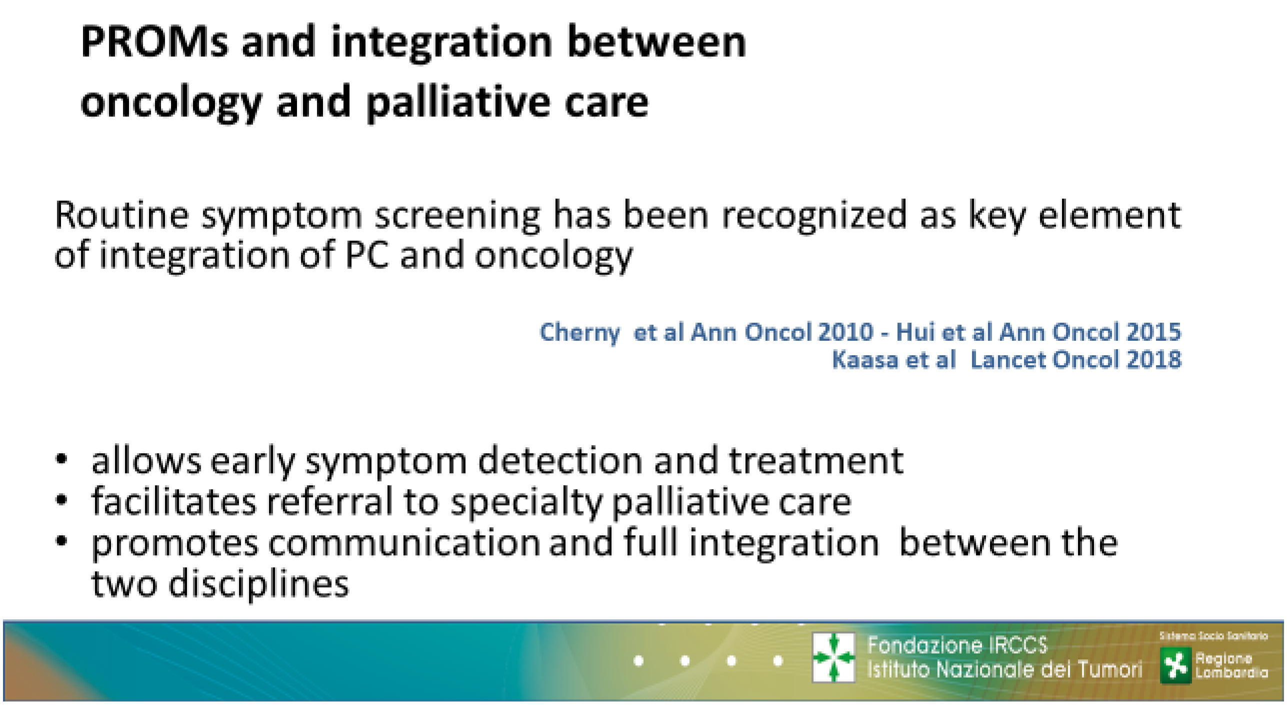

PROMs and integration between oncology and palliative care

Routine symptom screening has been recognized as key element of integration of PC and oncology

Cherny et al Ann Oncol 2010 - Hui et al Ann Oncol 2015
Kaasa et al Lancet Oncol 2018

- allows early symptom detection and treatment
- facilitates referral to specialty palliative care
- promotes communication and full integration between the two disciplines

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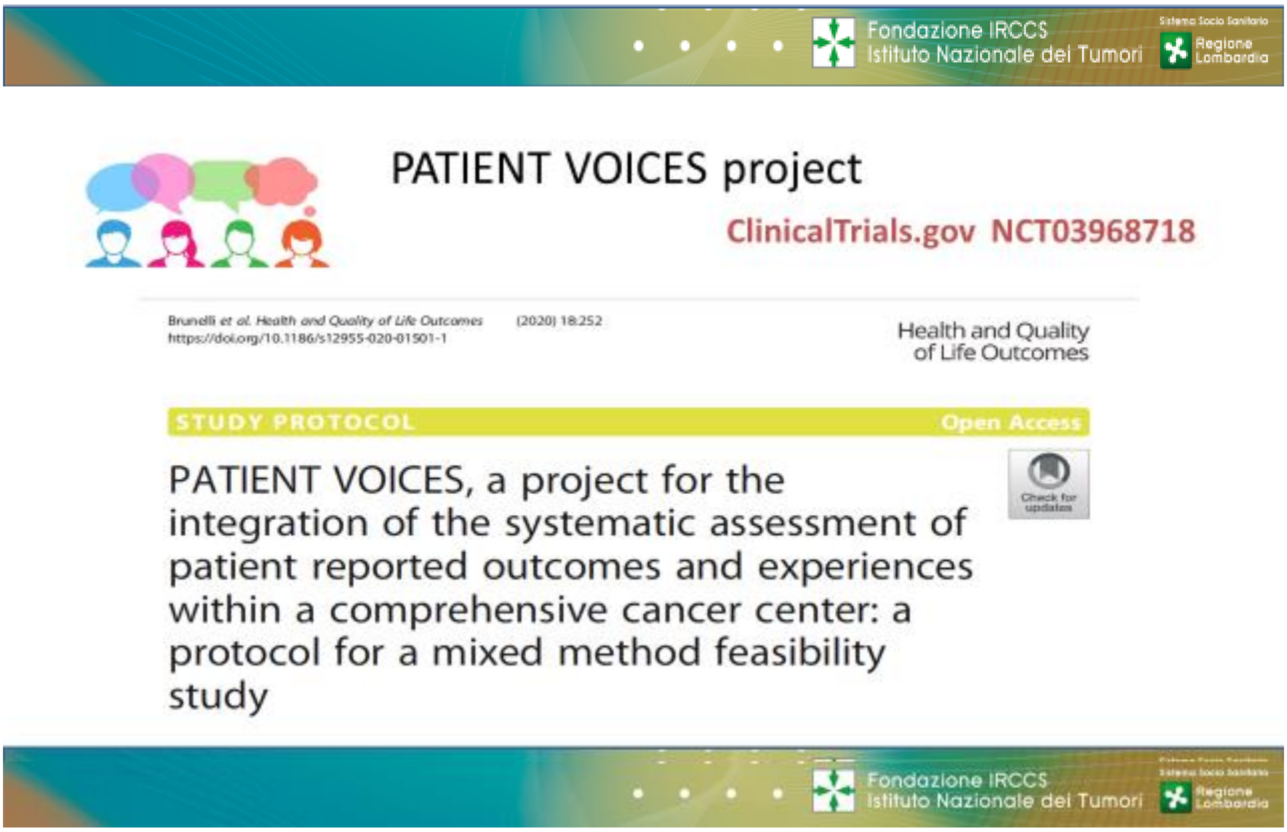
PROMs in routine clinical care

Due to barriers at various levels, ***systematic PROM collection is not widely implemented in routine oncology practice*** for use at individual patient care



PATIENT VOICES project

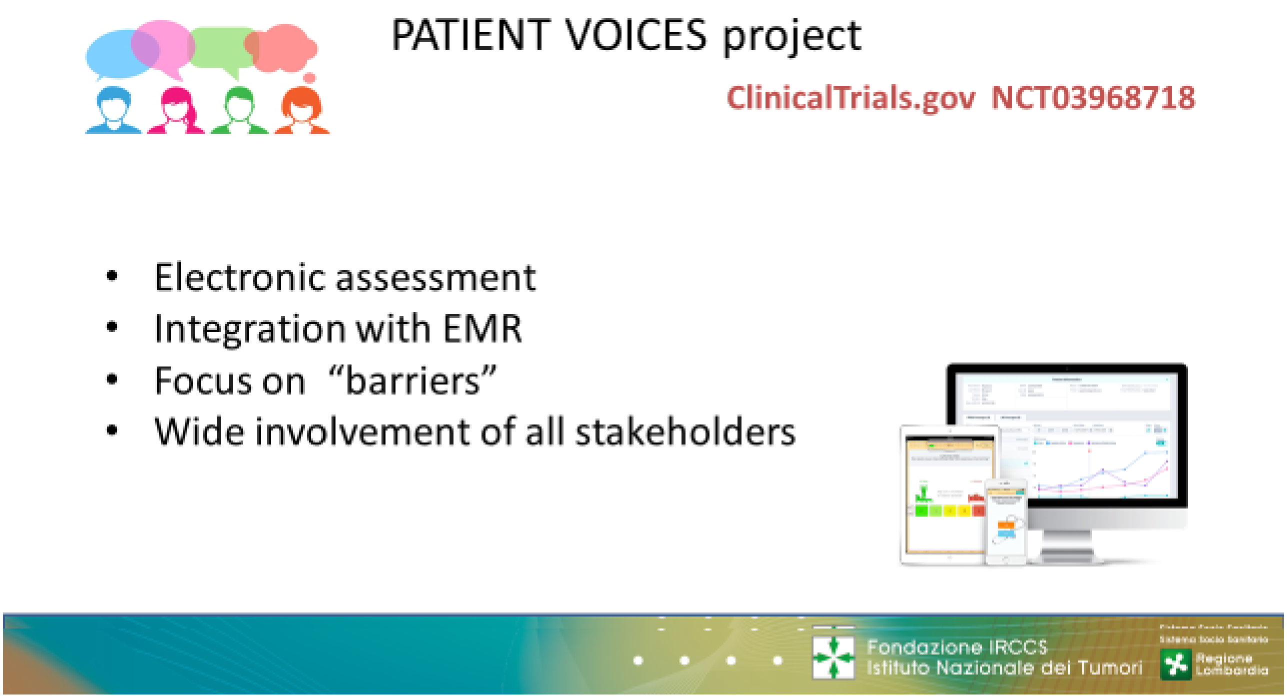
ClinicalTrials.gov NCT03968718

Brunelli *et al. Health and Quality of Life Outcomes* (2020) 18:252
https://doi.org/10.1186/s12955-020-01501-1

Health and Quality of Life Outcomes

STUDY PROTOCOL Open Access

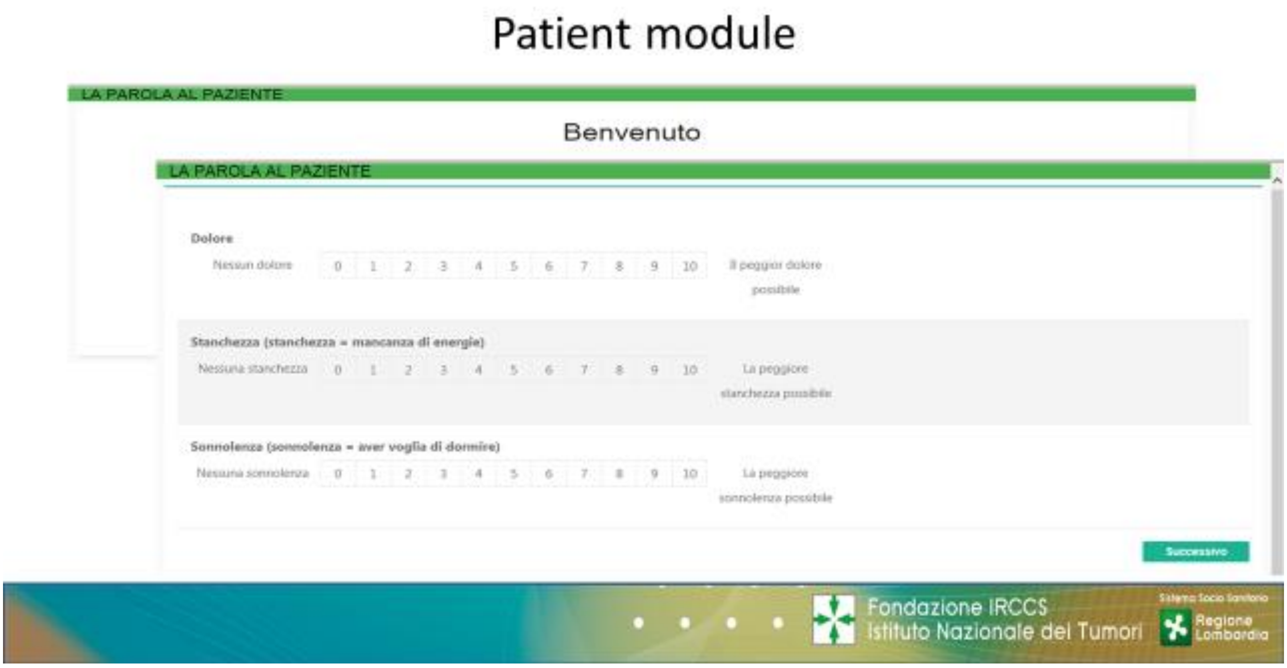
PATIENT VOICES, a project for the integration of the systematic assessment of patient reported outcomes and experiences within a comprehensive cancer center: a protocol for a mixed method feasibility study



PATIENT VOICES project

ClinicalTrials.gov NCT03968718

- Electronic assessment
- Integration with EMR
- Focus on "barriers"
- Wide involvement of all stakeholders



Patient module

LA PAROLA AL PAZIENTE

Benvenuto

LA PAROLA AL PAZIENTE

Dolore
Nessun dolore 0 1 2 3 4 5 6 7 8 9 10 Il peggior dolore possibile

Stanchezza (stanchezza = mancanza di energie)
Nessuna stanchezza 0 1 2 3 4 5 6 7 8 9 10 La peggiore stanchezza possibile

Sonnolenza (sonnolenza = aver voglia di dormire)
Nessuna sonnolenza 0 1 2 3 4 5 6 7 8 9 10 La peggiore sonnolenza possibile

Clinician module

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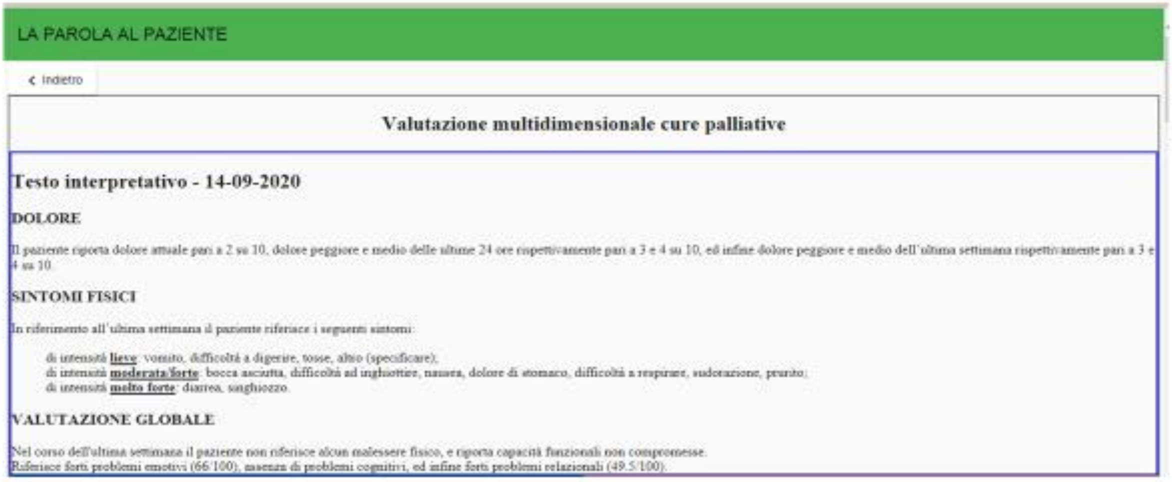
Clinician module



Valutazione multidimensionale cure palliative

Testo interpretativo - 14-09-2020

DOLORE

Il paziente riporta dolore attuale pari a 2 su 10, dolore peggiore e medio delle ultime 24 ore rispettivamente pari a 3 e 4 su 10, ed infine dolore peggiore e medio dell'ultima settimana rispettivamente pari a 3 e 4 su 10.

SINTOMI FISICI

In riferimento all'ultima settimana il paziente riferisce i seguenti sintomi:

di intensità **lieve**: vomito, difficoltà a digerire, tosse, altro (specificare);
di intensità **moderata/forte**: bocca asciutta, difficoltà ad inghiottire, nausea, dolore di stomaco, difficoltà a respirare, sudorazione, prurito;
di intensità **molto forte**: diarrea, singhiozzo.

VALUTAZIONE GLOBALE

Nel corso dell'ultima settimana il paziente non riferisce alcun malessere fisico, e riporta capacità funzionali non compromesse.
Riferisce forti problemi emotivi (66/100), assenza di problemi cognitivi, ed infine forti problemi relazionali (49.5/100).

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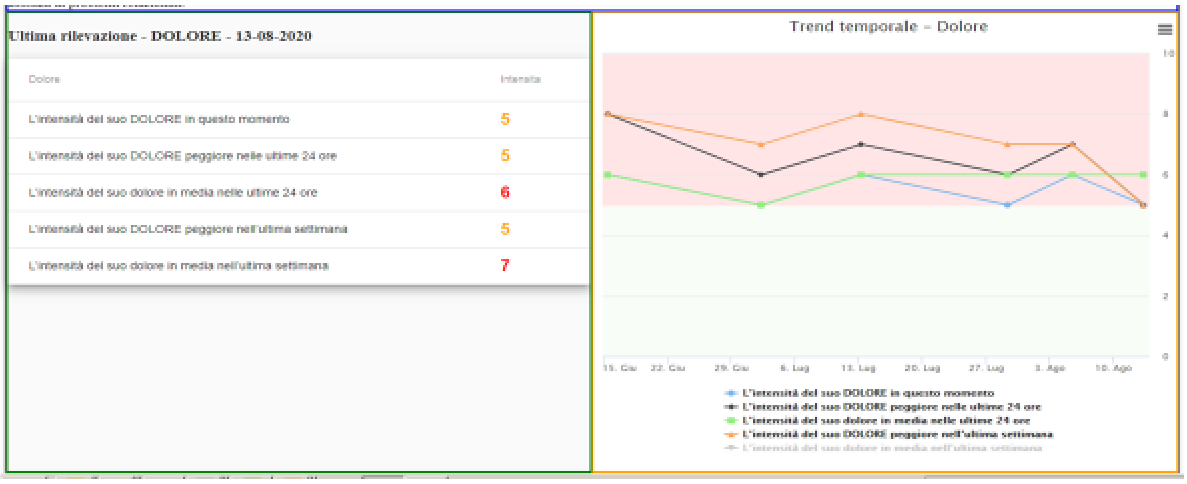
Clinician module



Ultima rilevazione - DOLORE - 13-08-2020

Dolore	Intensità
L'intensità del suo DOLORE in questo momento	5
L'intensità del suo DOLORE peggiore nelle ultime 24 ore	5
L'intensità del suo dolore in media nelle ultime 24 ore	6
L'intensità del suo DOLORE peggiore nell'ultima settimana	5
L'intensità del suo dolore in media nell'ultima settimana	7

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Development of implementation strategies

A multi-disciplinary stakeholder team including

- patients
- oncology clinicians
- researchers
- health informatics professionals
- health system administrators

will be involved in the development of implementation strategies

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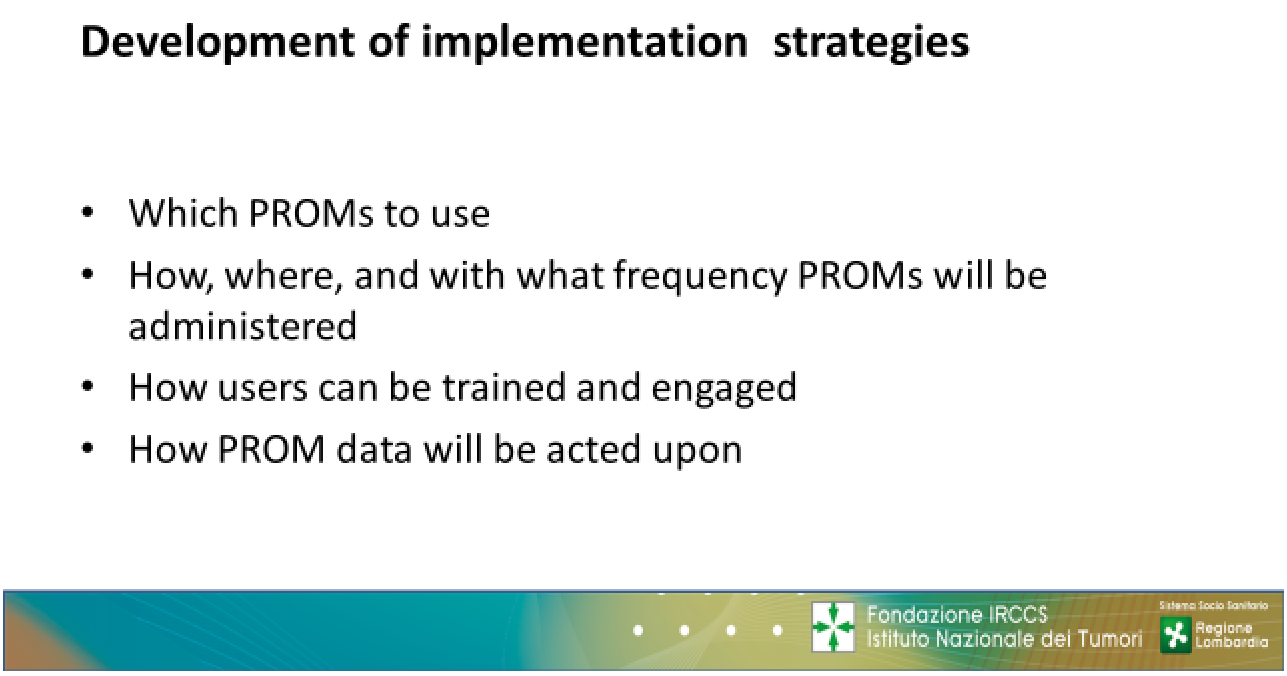
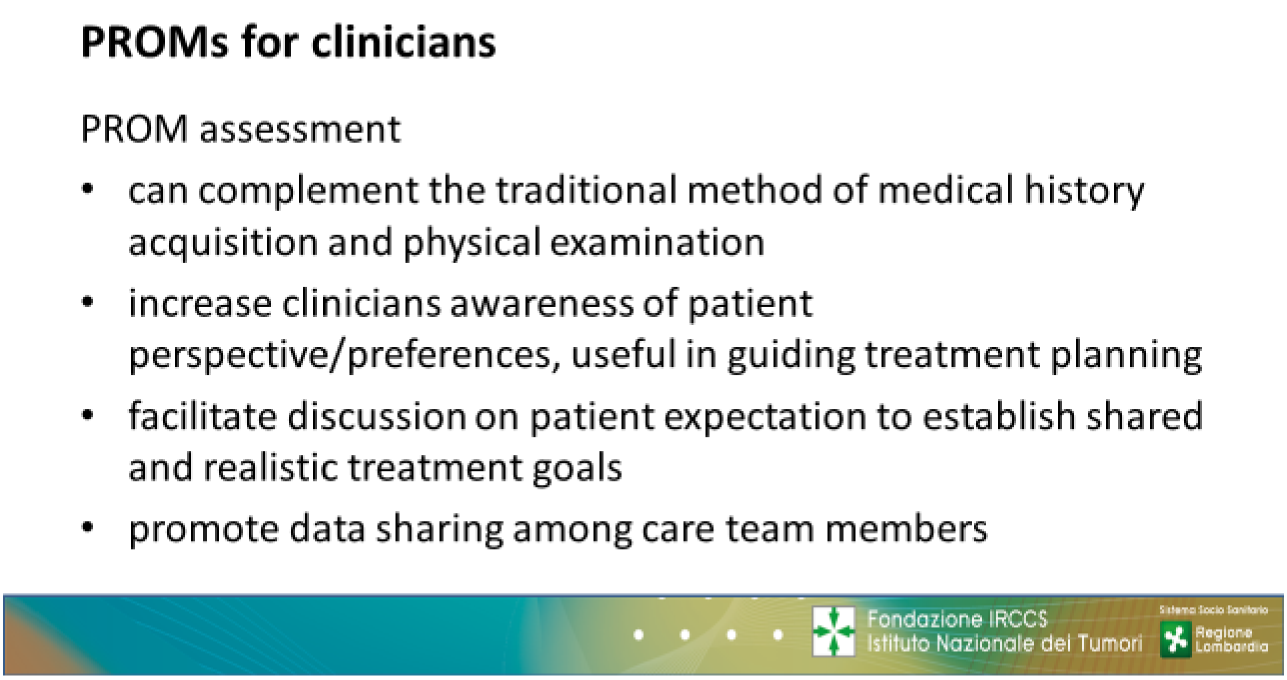


Development of implementation strategies

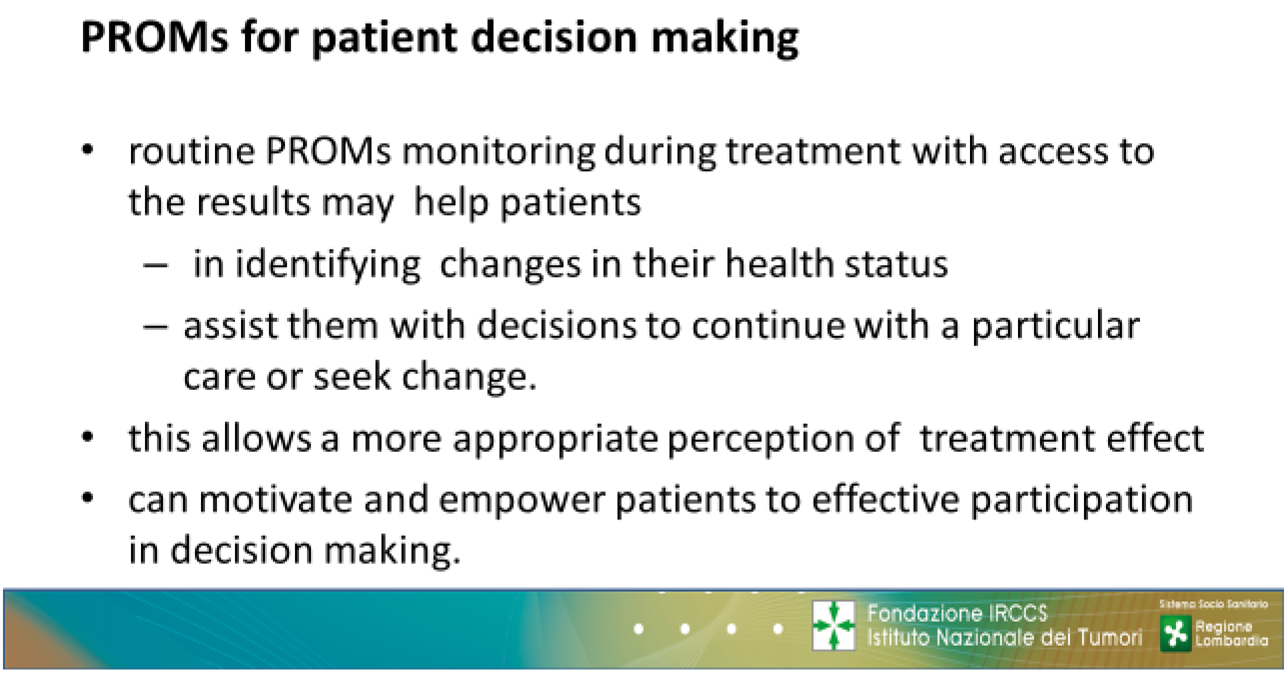
- Which PROMs to use
- How, where, and with what frequency PROMs will be administered
- How users can be trained and engaged
- How PROM data will be acted upon



PROMs for clinicians

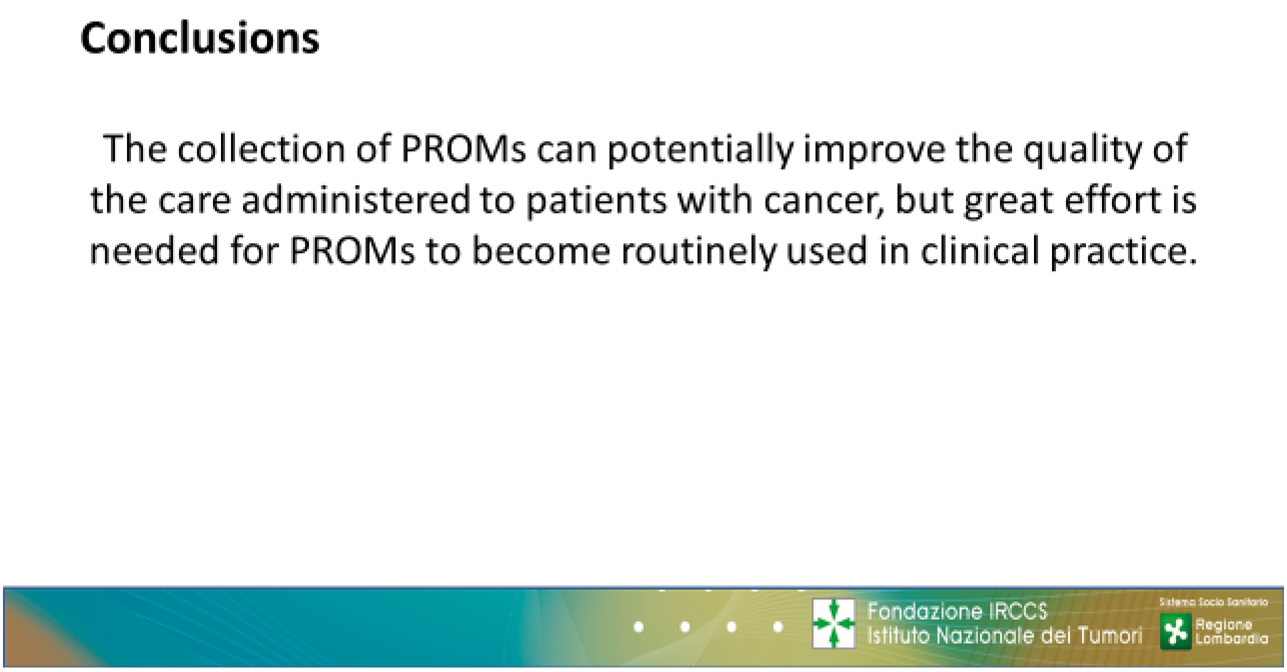
PROM assessment

- can complement the traditional method of medical history acquisition and physical examination
- increase clinicians awareness of patient perspective/preferences, useful in guiding treatment planning
- facilitate discussion on patient expectation to establish shared and realistic treatment goals
- promote data sharing among care team members



PROMs for patient decision making

- routine PROMs monitoring during treatment with access to the results may help patients
  - in identifying changes in their health status
  - assist them with decisions to continue with a particular care or seek change.
- this allows a more appropriate perception of treatment effect
- can motivate and empower patients to effective participation in decision making.



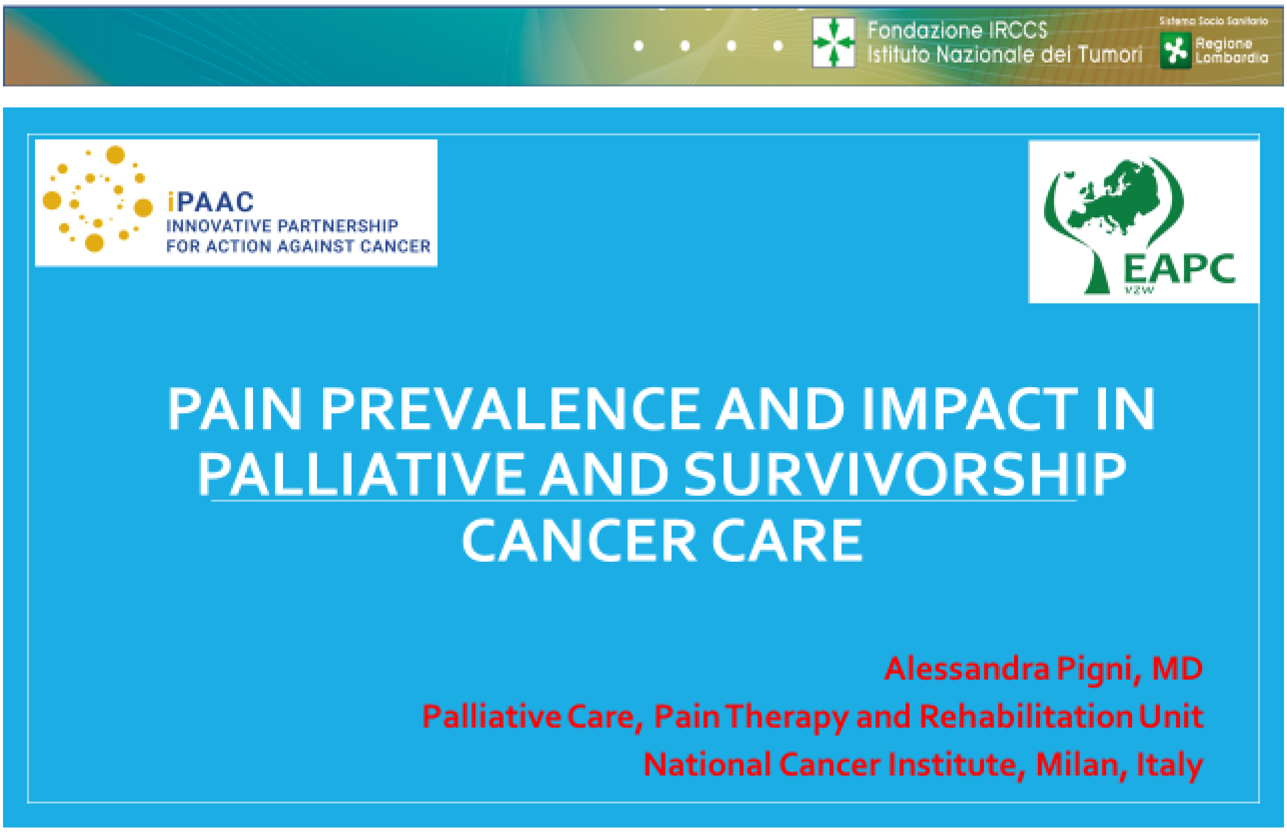
Conclusions

The collection of PROMs can potentially improve the quality of the care administered to patients with cancer, but great effort is needed for PROMs to become routinely used in clinical practice.

Conclusions

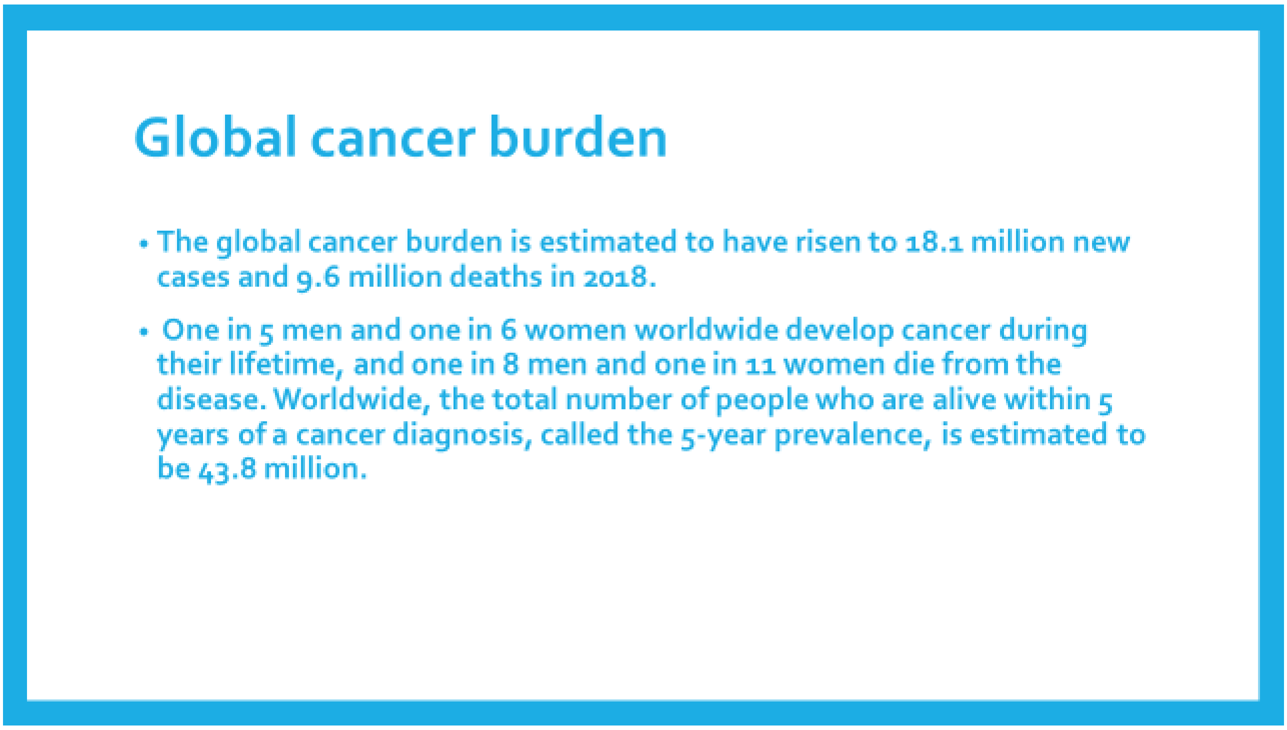
PROMs implementation requires:

- Specific guidance and training of clinical staff
- Specific patient education and motivation
- Appropriate policies
- IT solutions designed for this purpose.



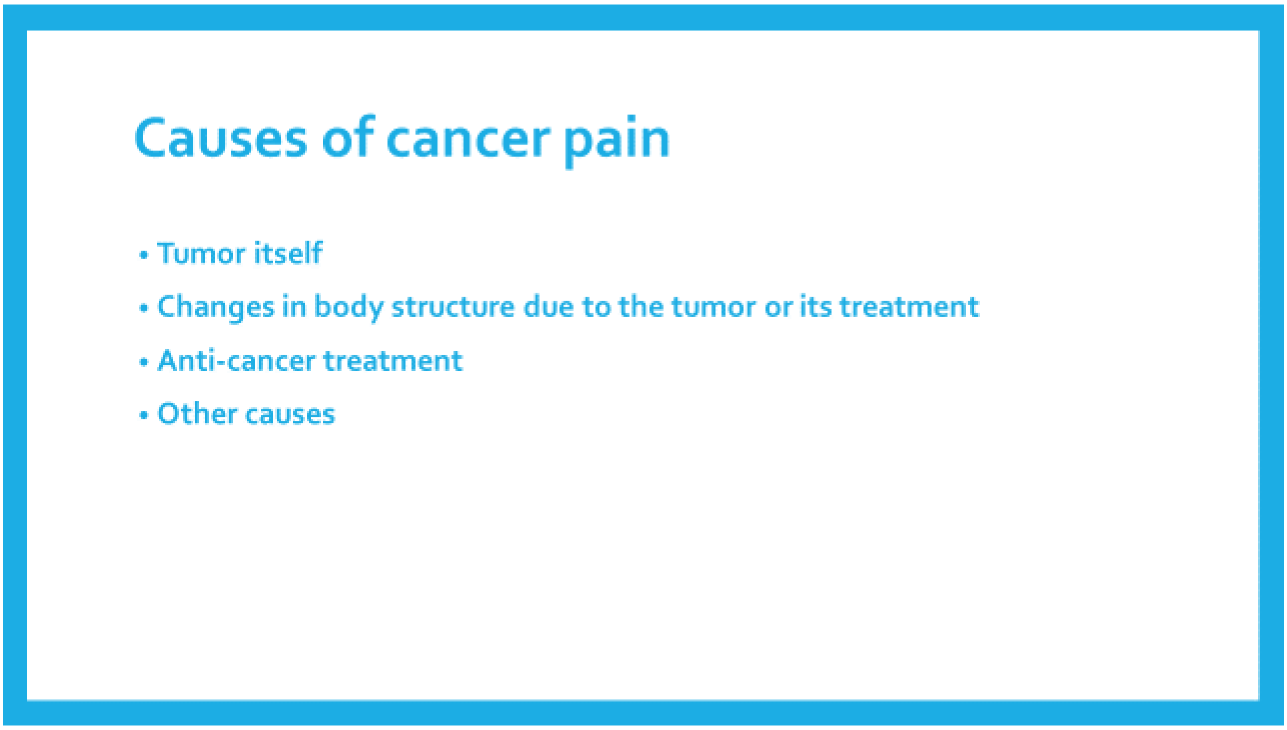
PAIN PREVALENCE AND IMPACT IN PALLIATIVE AND SURVIVORSHIP CANCER CARE

Alessandra Pigni, MD
Palliative Care, Pain Therapy and Rehabilitation Unit
National Cancer Institute, Milan, Italy



Global cancer burden

- The global cancer burden is estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018.
- One in 5 men and one in 6 women worldwide develop cancer during their lifetime, and one in 8 men and one in 11 women die from the disease. Worldwide, the total number of people who are alive within 5 years of a cancer diagnosis, called the 5-year prevalence, is estimated to be 43.8 million.

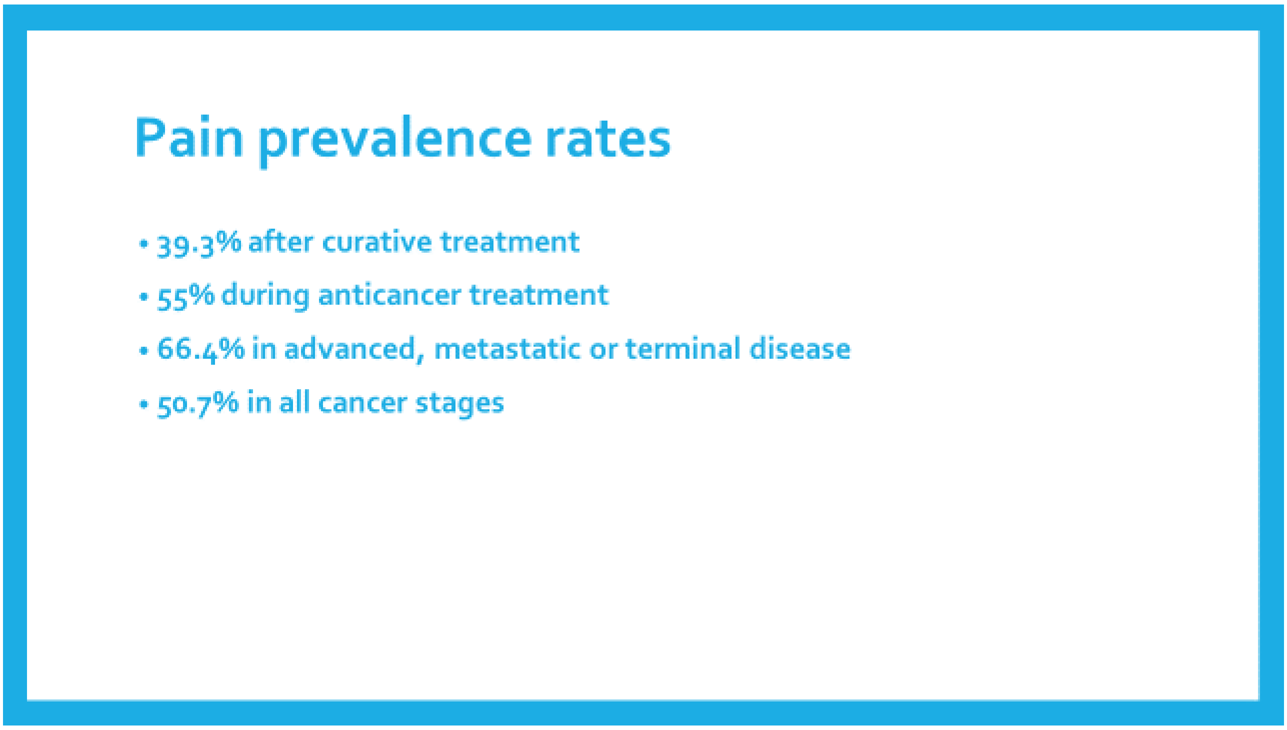


Causes of cancer pain

- Tumor itself
- Changes in body structure due to the tumor or its treatment
- Anti-cancer treatment
- Other causes

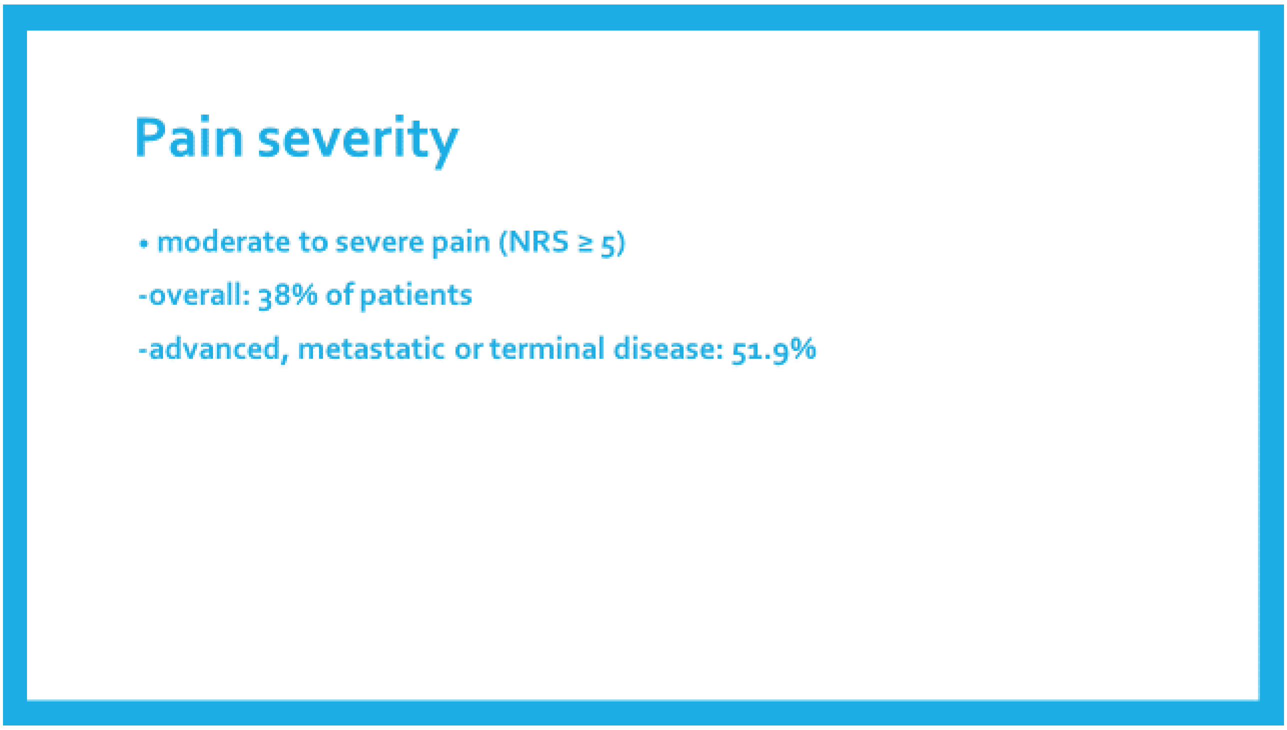
Pain prevalence in cancer patients

van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ. Update on Prevalence of Pain in Patients With Cancer: Systematic Review and Meta-Analysis. J Pain Symptom Manage. 2016;51(6):1070-1090



Pain prevalence rates

- 39.3% after curative treatment
- 55% during anticancer treatment
- 66.4% in advanced, metastatic or terminal disease
- 50.7% in all cancer stages

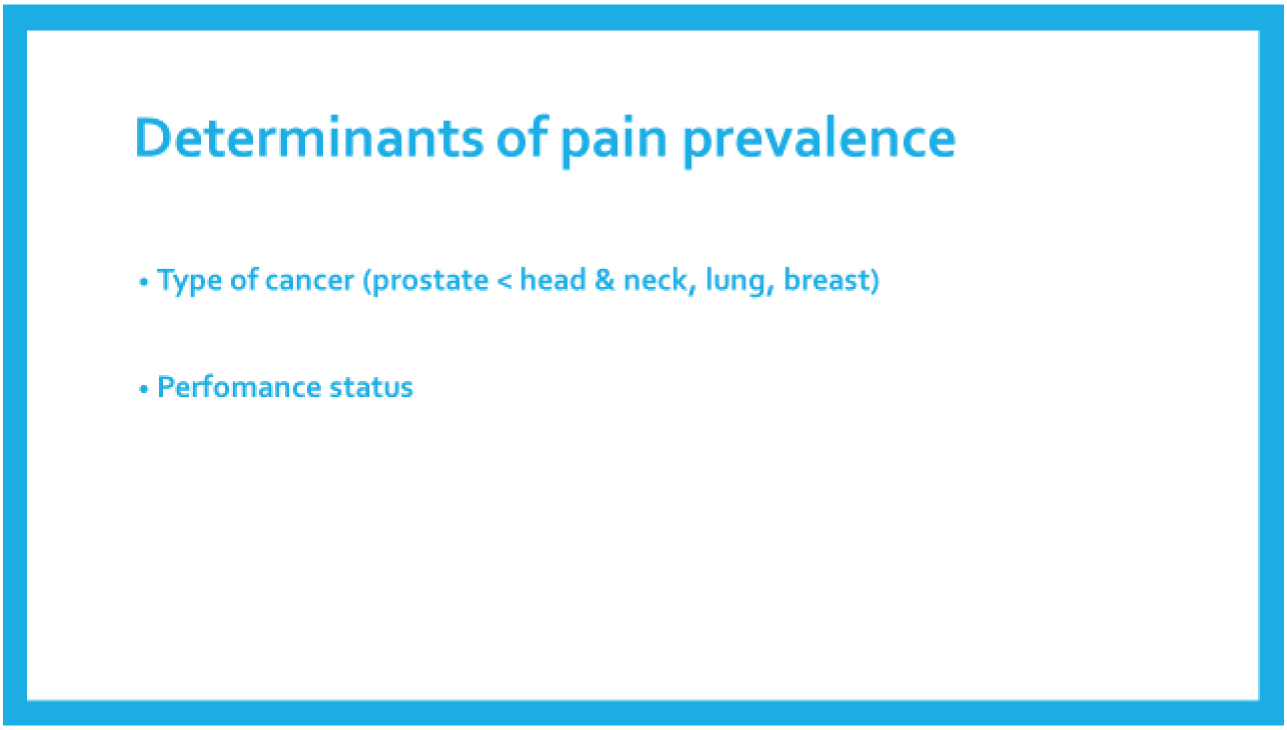


Pain severity

- moderate to severe pain (NRS ≥ 5)

-overall: 38% of patients

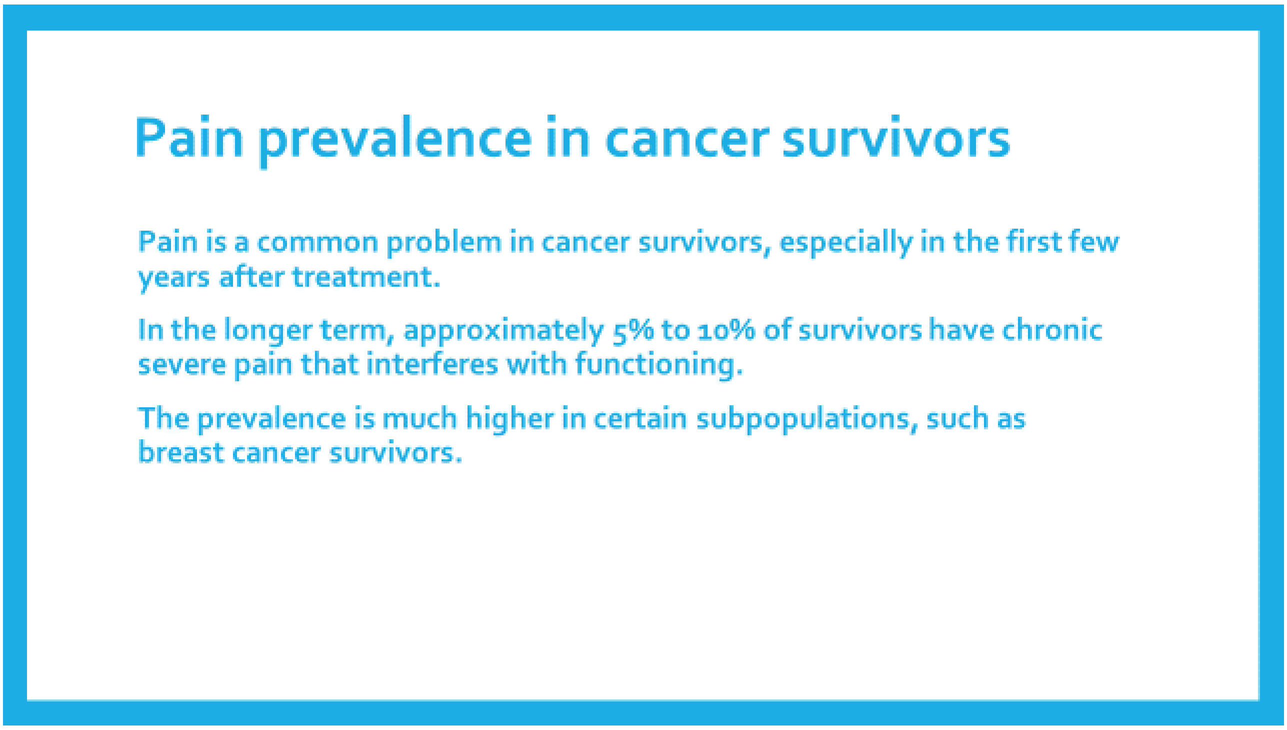
-advanced, metastatic or terminal disease: 51.9%



Determinants of pain prevalence

- Type of cancer (prostate < head & neck, lung, breast)

- Perfomance status



Pain prevalence in cancer survivors

Pain is a common problem in cancer survivors, especially in the first few years after treatment.

In the longer term, approximately 5% to 10% of survivors have chronic severe pain that interferes with functioning.

The prevalence is much higher in certain subpopulations, such as breast cancer survivors.

The impact of opioid therapy

- With competent management, cancer pain can be controlled in 80% to 90% of cases
- Nearly 50% of cancer patients in the developed world receive less than optimal care.

Barriers

❑Patient-related barriers

❑Physician-related barriers

❑Institutional barriers

Opioids long-term consequences

➢Tolerance

➢Dipendence

➢Addiction

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Integration of palliative care with oncology within a patient centred decision making approach

Augusto Caraceni

Direttore SC Cure Palliative Terapia del dolore e Riabilitazione Fondazione IRCCS
Istituto Nazionale dei Tumori di Milano

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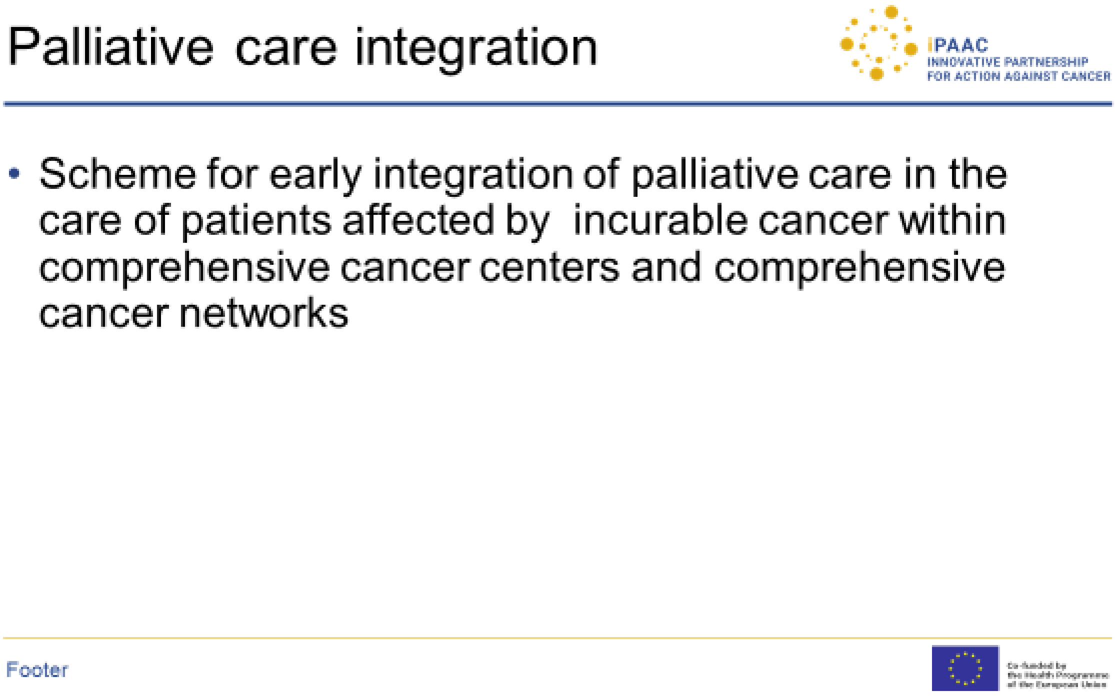
dei Tumori

Sistema Sanitario Regione Lombardia

EAPC
EAPC Research Network



Palliative care integration

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FOR ACTION AGAINST CANCER

- Scheme for early integration of palliative care in the care of patients affected by incurable cancer within comprehensive cancer centers and comprehensive cancer networks

Footer

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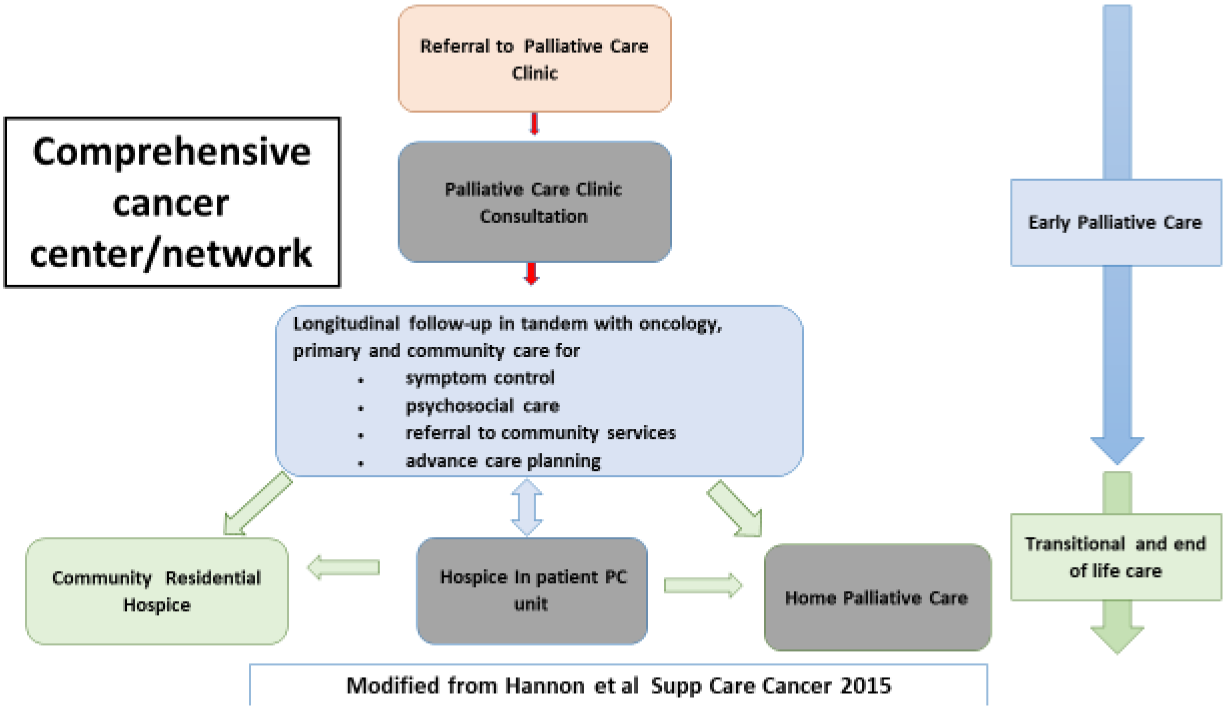


Comprehensive cancer center/network

Referral to Palliative Care Clinic

Palliative Care Clinic Consultation

Longitudinal follow-up in tandem with oncology, primary and community care for
- symptom control
- psychosocial care
- referral to community services
- advance care planning

Community Residential Hospice

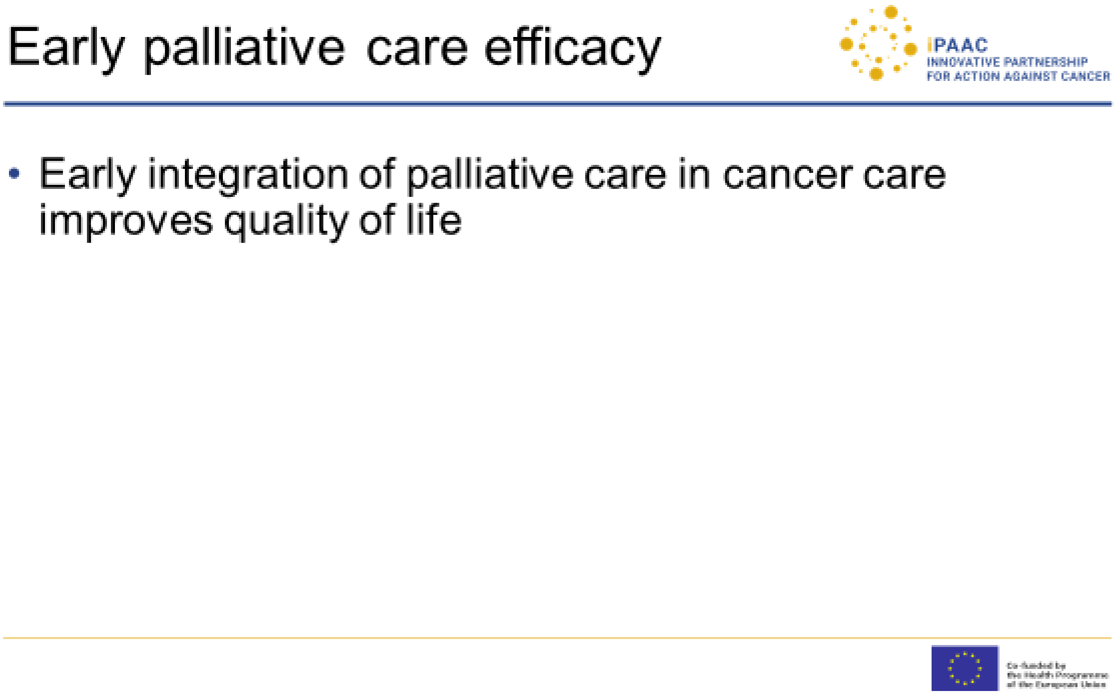
Hospice In patient PC unit

Home Palliative Care

Early Palliative Care

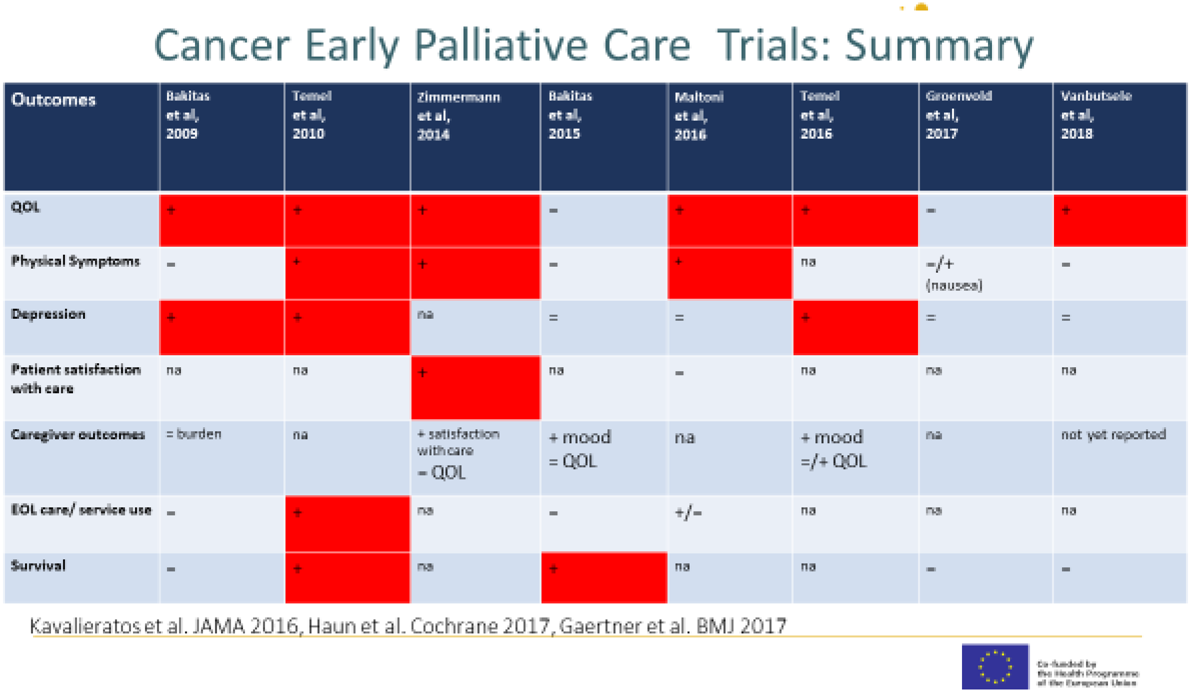
Transitional and end of life care

Modified from Hannon et al Supp Care Cancer 2015



Early palliative care efficacy

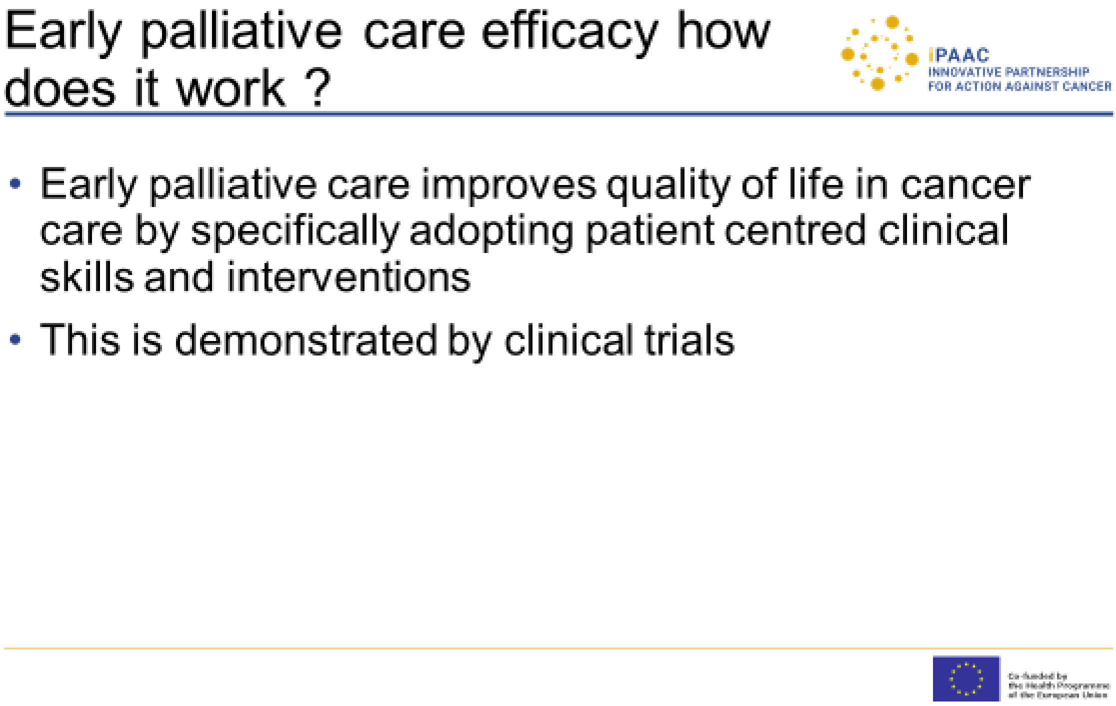
- Early integration of palliative care in cancer care improves quality of life



Cancer Early Palliative Care Trials: Summary

Outcomes	Bakitas et al, 2009	Temel et al, 2010	Zimmermann et al, 2014	Bakitas et al, 2015	Maltoni et al, 2016	Temel et al, 2016	Groenvold et al, 2017	Vanbutsele et al, 2018
QOL	🟥 +	🟥 +	🟥 +	–	🟥 +	🟥 +	–	🟥 +
Physical Symptoms	–	🟥 +	🟥 +	–	🟥 +	na	–/+ (nausea)	–
Depression	🟥 +	🟥 +	na	=	=	🟥 +	=	=
Patient satisfaction with care	na	na	🟥 +	na	–	na	na	na
Caregiver outcomes	= burden	na	+ satisfaction with care – QOL	+ mood = QOL	na	+ mood =/+ QOL	na	not yet reported
EOL care/ service use	–	🟥 +	na	–	+/–	na	na	na
Survival	–	🟥 +	na	🟥 +	na	na	–	–

Kavalieratos et al. JAMA 2016, Haun et al. Cochrane 2017, Gaertner et al. BMJ 2017



Early palliative care efficacy how does it work ?

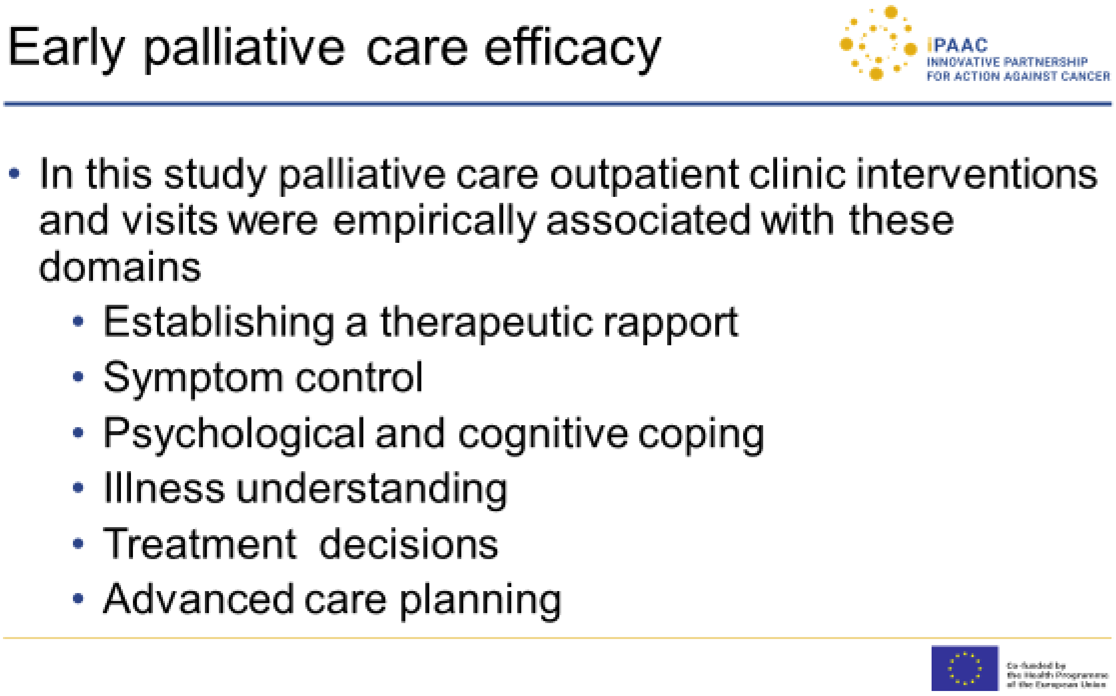
- Early palliative care improves quality of life in cancer care by specifically adopting patient centred clinical skills and interventions
- This is demonstrated by clinical trials

VOLUME 36 · NUMBER 11 · APRIL 10, 2018

JOURNAL OF CLINICAL ONCOLOGY — ORIGINAL REPORT

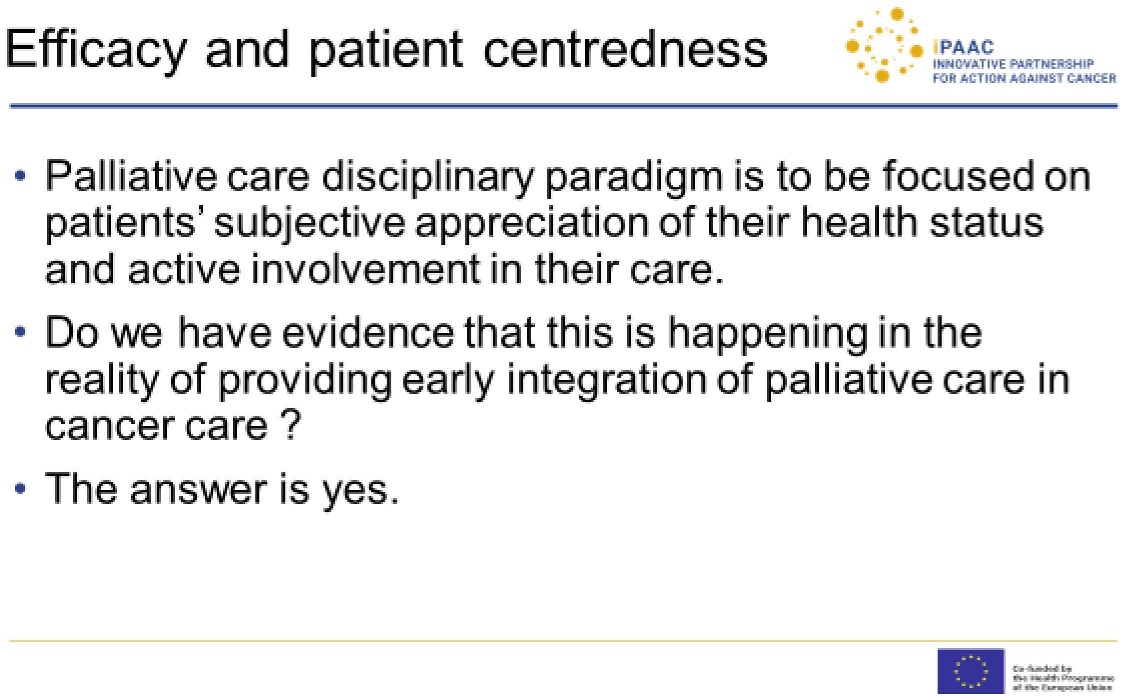
Defining the Elements of Early Palliative Care That Are Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care

Michael Hoerger, Joseph A. Greer, Vicki A. Jackson, Elyse R. Park, William F. Pirl, Areej El-Jawahri, Emily R. Gallagher, Teresa Hagan, Juliet Jacobsen, Laura M. Perry, and Jennifer S. Temel



Early palliative care efficacy

- In this study palliative care outpatient clinic interventions and visits were empirically associated with these domains
  - Establishing a therapeutic rapport
  - Symptom control
  - Psychological and cognitive coping
  - Illness understanding
  - Treatment decisions
  - Advanced care planning



Efficacy and patient centredness

- Palliative care disciplinary paradigm is to be focused on patients' subjective appreciation of their health status and active involvement in their care.
- Do we have evidence that this is happening in the reality of providing early integration of palliative care in cancer care ?
- The answer is yes.

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
2017, Vol. 31(1) 72–81
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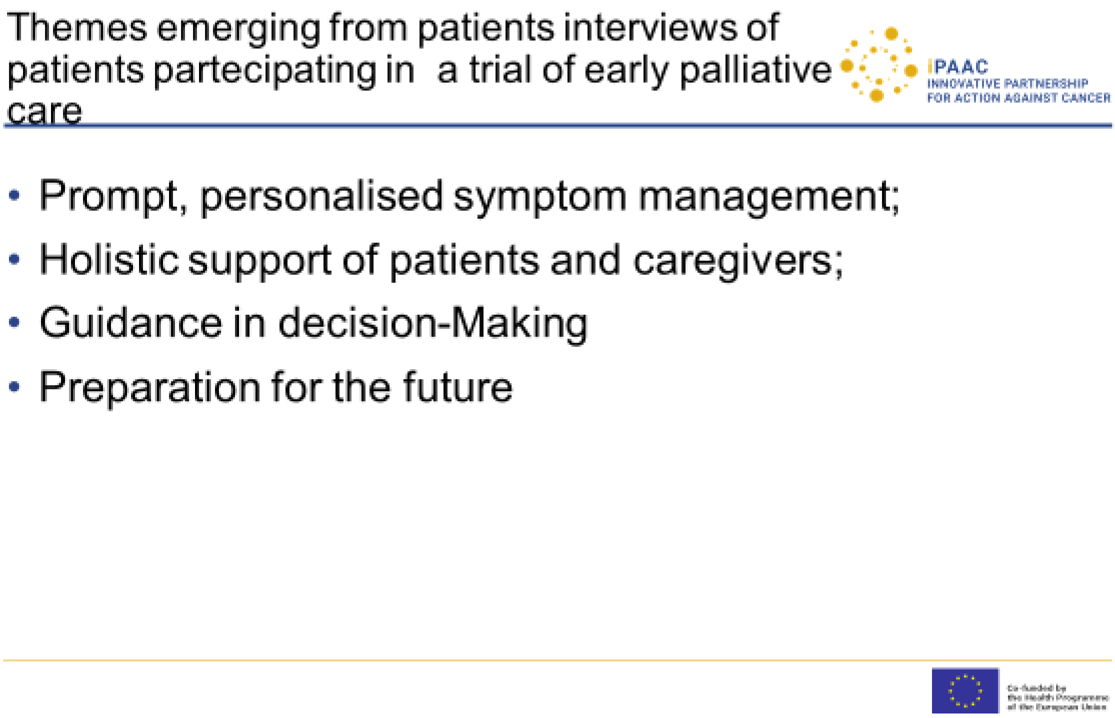
DOI: 10.1177/0269216316649126
pmj.sagepub.com
SAGE

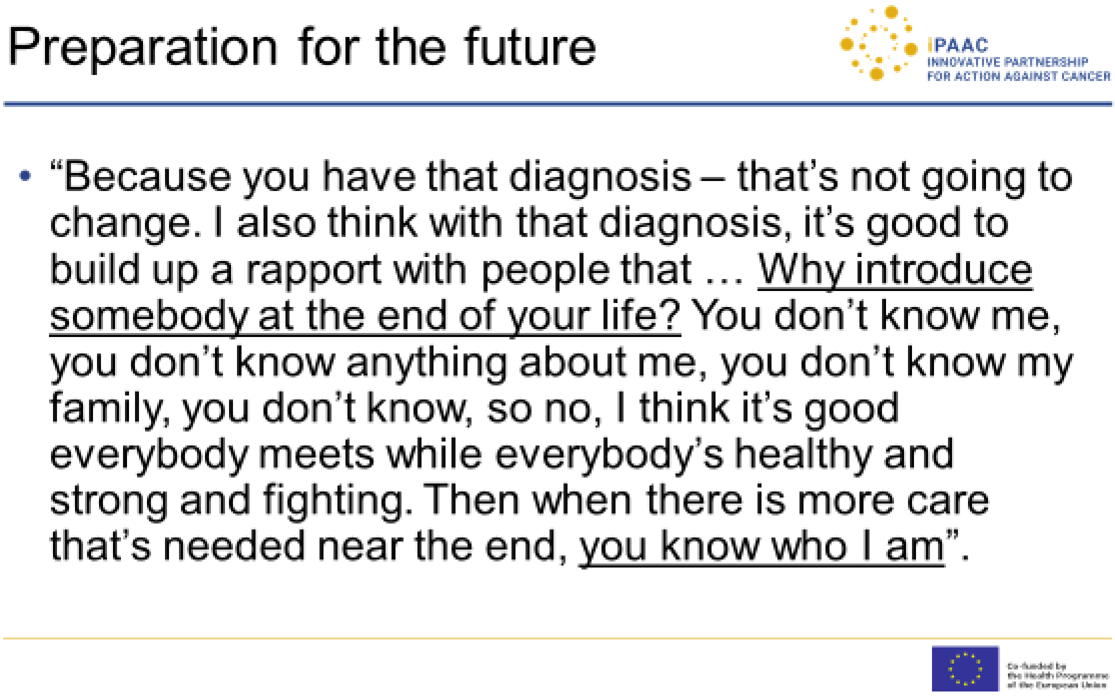
Experiences of patients and caregivers with early palliative care: A qualitative study

Breffni Hannon[1,2], Nadia Swami[2], Gary Rodin[2,3,4], Ashley Pope[2] and Camilla Zimmermann[1,2,3,4]



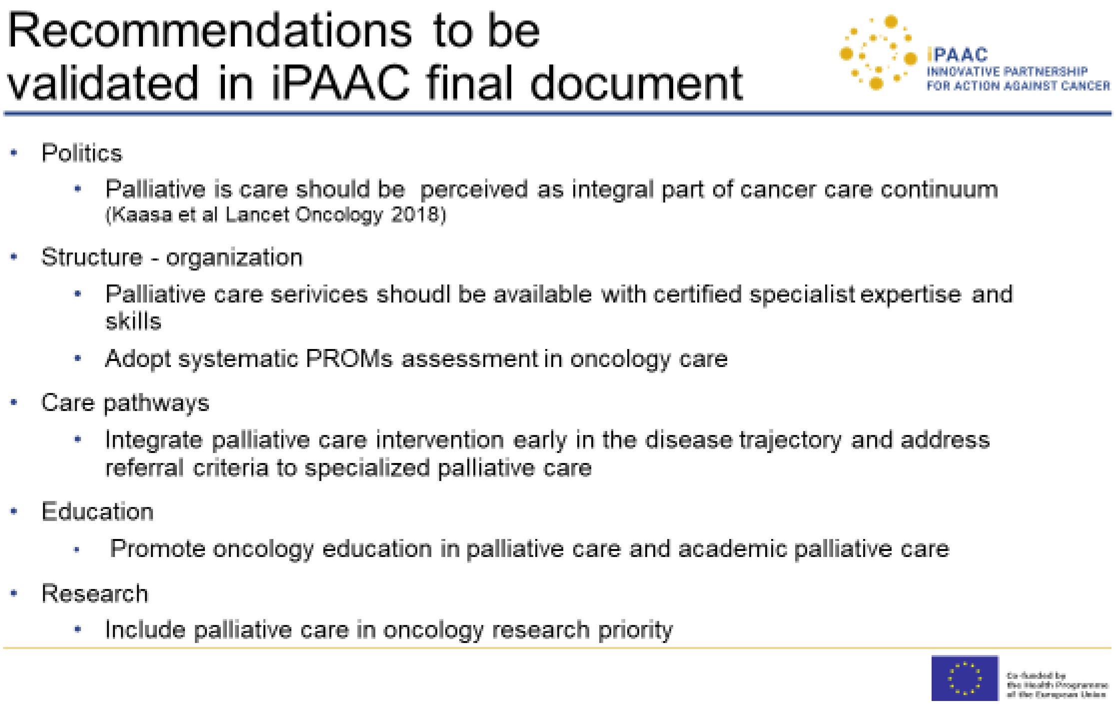
Themes emerging from patients interviews of patients partecipating in a trial of early palliative care

- Prompt, personalised symptom management;
- Holistic support of patients and caregivers;
- Guidance in decision-Making
- Preparation for the future



Preparation for the future

- “Because you have that diagnosis – that’s not going to change. I also think with that diagnosis, it’s good to build up a rapport with people that … Why introduce somebody at the end of your life? You don’t know me, you don’t know anything about me, you don’t know my family, you don’t know, so no, I think it’s good everybody meets while everybody’s healthy and strong and fighting. Then when there is more care that’s needed near the end, you know who I am”.



Recommendations to be validated in iPAAC final document

- Politics
  - Palliative is care should be perceived as integral part of cancer care continuum (Kaasa et al Lancet Oncology 2018)
- Structure - organization
  - Palliative care serivices shoudl be available with certified specialist expertise and skills
  - Adopt systematic PROMs assessment in oncology care
- Care pathways
  - Integrate palliative care intervention early in the disease trajectory and address referral criteria to specialized palliative care
- Education
  - Promote oncology education in palliative care and academic palliative care
- Research
  - Include palliative care in oncology research priority

What matters to patients at the end of their life?

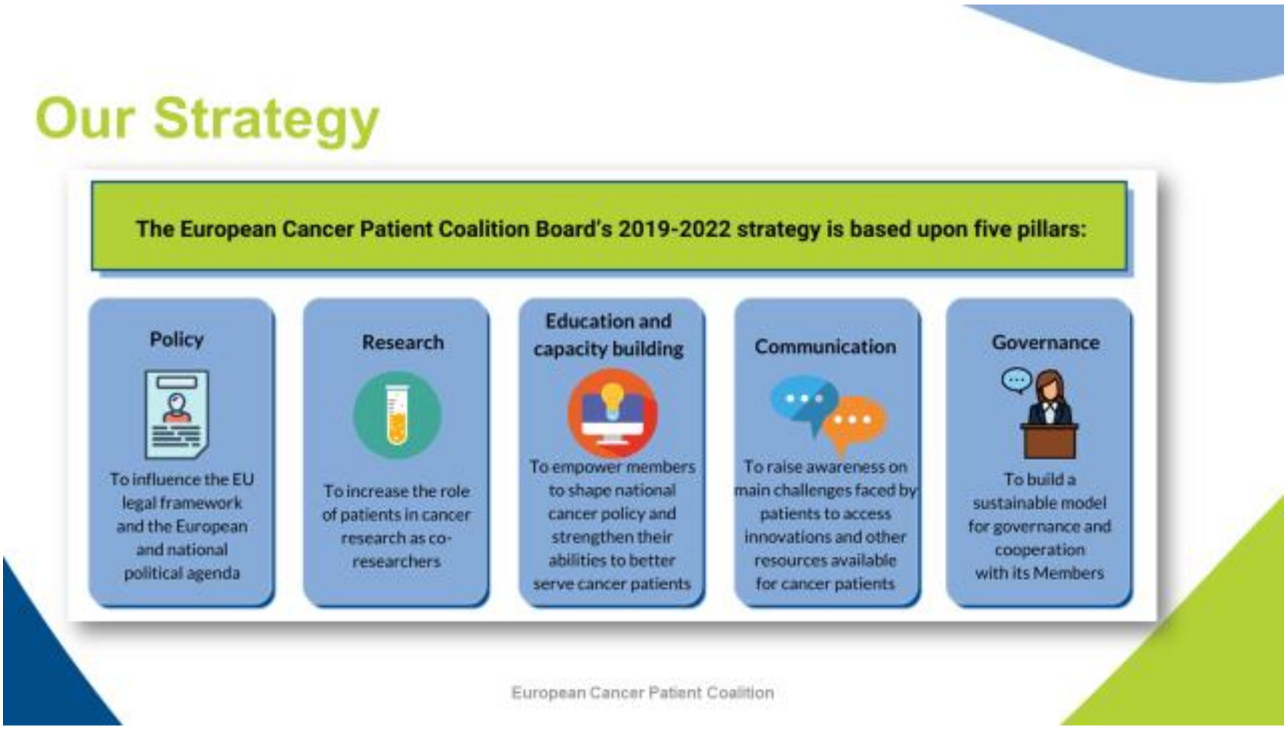
EAPC Congress2020

Jacqueline Daly, ECPC Board Member

Who we are?

- largest European cancer patients' umbrella organisation established in 2003
- +450 member organizations in EU 27 Member States and beyond
- advocate for patients to be acknowledged as equal partners & co-creators of their own health
- we work for a Europe of equality, where all Europeans with cancer have timely & affordable access to the best treatment and care available, throughout their life

European Cancer Patient Coalition

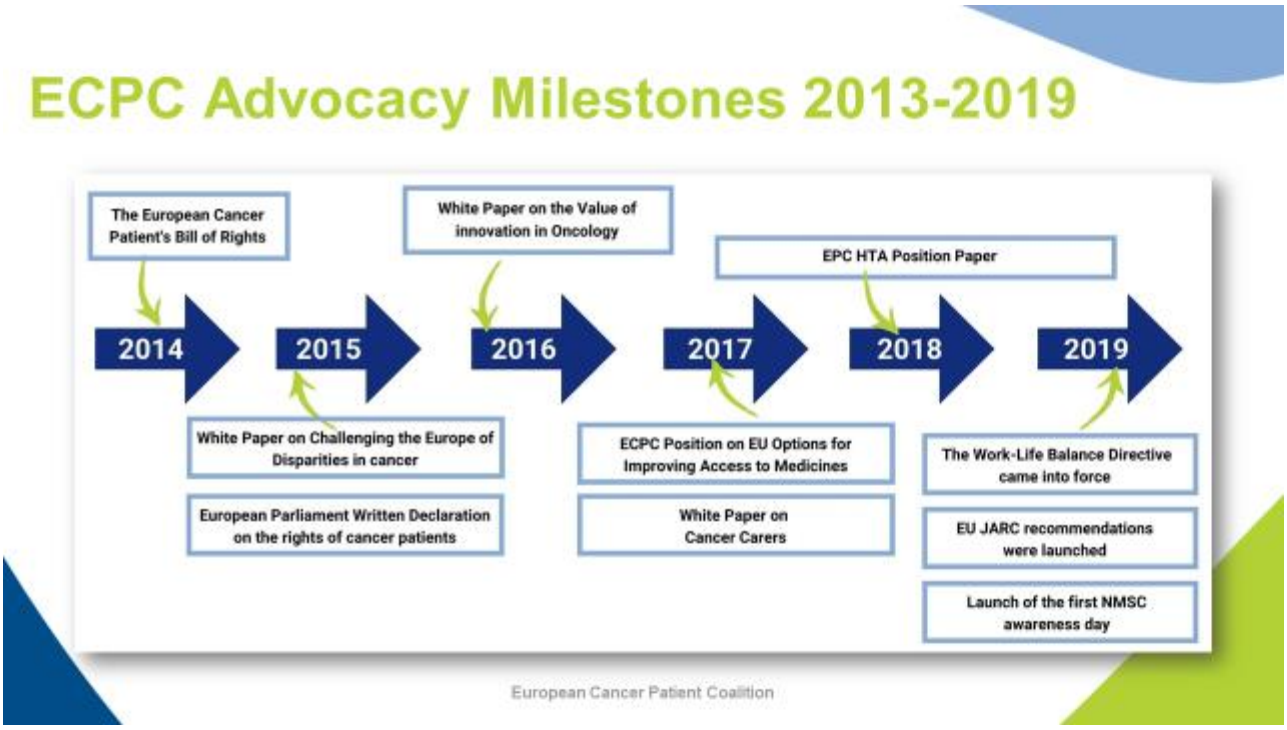


Our Strategy

The European Cancer Patient Coalition Board's 2019-2022 strategy is based upon five pillars:

Policy	Research	Education and capacity building	Communication	Governance
To influence the EU legal framework and the European and national political agenda	To increase the role of patients in cancer research as co-researchers	To empower members to shape national cancer policy and strengthen their abilities to better serve cancer patients	To raise awareness on main challenges faced by patients to access innovations and other resources available for cancer patients	To build a sustainable model for governance and cooperation with its Members

European Cancer Patient Coalition



ECPC Advocacy Milestones 2013-2019

2014
- The European Cancer Patient's Bill of Rights

2015
- White Paper on Challenging the Europe of Disparities in cancer
- European Parliament Written Declaration on the rights of cancer patients

2016
- White Paper on the Value of innovation in Oncology

2017
- ECPC Position on EU Options for Improving Access to Medicines
- White Paper on Cancer Carers

2018
- EPC HTA Position Paper

2019
- The Work-Life Balance Directive came into force
- EU JARC recommendations were launched
- Launch of the first NMSC awareness day

European Cancer Patient Coalition

ECPC leads capacity building in cancer research

ECPC increases the capacity of its members to understand and partake in innovative research by leading communication and dissemination activities in a number of EU-funded research projects.

ECPC is integrating patient views and build the capacity of patients across Europe in the following projects:

- LEGACy
- DIAdIC
- Palliative Sedation
- H2020MM04 Denim
- PREFER
- BDB40 PIONEER
- Immune Image
- Transcan-2
- ELBA
- PREDICT

Funded by the Horizon 2020 Framework Programme of the European Union

European Cancer Patient Coalition

ECPC's Strategic Alliances

My personal experience

It was estimated by the European Commission that in 2020, 1.3 million people will die because of cancer.

While visiting patients in my local hospice in Ireland I noticed patients have mostly simple wishes:

- be with their loved-ones
- to have access to their pets
- be able to communicate till the very end
- a "pain-free" dying and death
- not loosing their dignity
- still want to look their best
- to have an input on how to leave

European Cancer Patient Coalition

Best practices from Ireland

"Writing for the Future"

- For adults
- Patients are offered to record stories for their children and families for future special occasions

We also offer them complimentary therapies so they can find their inner peace.

European Cancer Patient Coalition

Palliative care improves the quality of life of patients and their family members who are facing challenges linked with advanced cancer or other life-threatening illness.

Support can be physical, psychological, social or spiritual.

Key facts:*

- an estimated **40 million people** are in need of palliative care (not only cancer patients)

- **78%** of these people live in low- and middle-income countries

- worldwide, only about **14%** of people who need palliative care currently receive it

- palliative care improves the quality of life of caregivers too

- the majority of adults in need of palliative care have chronic diseases:
cardiovascular diseases (38.5%), **cancer (34%),** chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%)

European Cancer Patient Coalition

* WHO: publishe

Palliative care: more than opioid drugs

We strongly believe that palliative care should fulfil a varied set of needs of cancer patients and their carers. It should be introduced very early, not only as a pain reliever, but as mechanism to help patient and family wellness and coping with cancer.

! ! ! access to adequate palliative care is not systemic or similar within EU countries
! ! ! no coordination at national level
! ! ! allocation of funds for palliative care is generally insufficient and it does not encourage development of new palliative centre services
! ! ! gaps in research on palliative care are still very wide

European Cancer Patient Coalition

Patients can play a fundamental role in addressing care pathways.

We call for full **recognition of cancer patients' rights** to access **timely and adequate palliative care**, during and after the acute treatment phase in all parts of the European Union.

It is a fundamental component of the cancer patient's journey, but it is often neglected.

European Cancer Patient Coalition

PROJECT: Palliative Sedation Scientific, Clinical and Ethical Advisory Board

ECPC is part of the board encouraging policy-makers, researchers, doctors and industry to recognise cancer patients as co-creators of their own health.

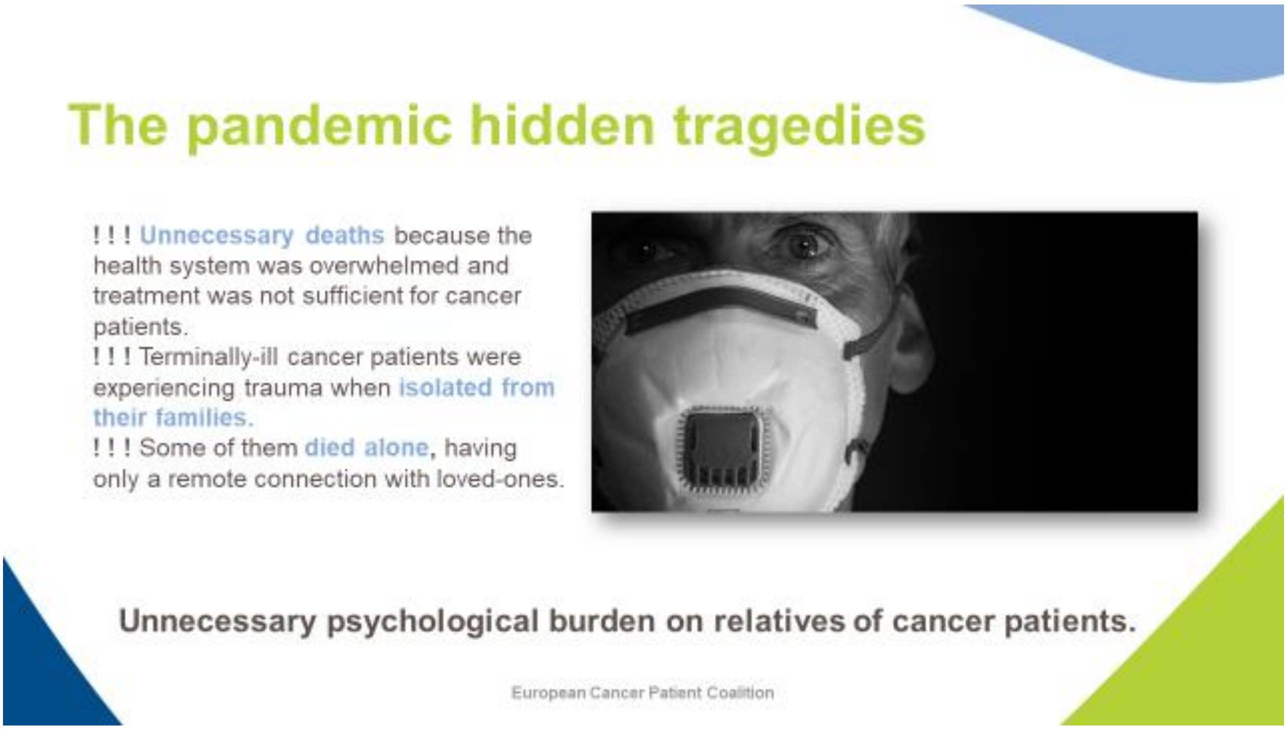
ECPC directly engages with expert patient representatives to ensure research is designed and adapted to better respond to patient needs.

Through its members, ECPC contributes to a PS country survey and supportive interviews that reveal the level of integration of clinical sedation guideline recommendations in healthcare practice across Europe.

ECPC also supports the revision of the current European Association for Palliative Care (EAPC) framework for PS, and the design of the PS educational programme and e-book containing clinical and ethical guidance that can adopted for PS.

European Cancer Patient Coalition

Funded by the Horizon 2020 Framework Programme of the European Union



The pandemic hidden tragedies

! ! ! Unnecessary deaths because the health system was overwhelmed and treatment was not sufficient for cancer patients.
! ! ! Terminally-ill cancer patients were experiencing trauma when isolated from their families.
! ! ! Some of them died alone, having only a remote connection with loved-ones.

Unnecessary psychological burden on relatives of cancer patients.

European Cancer Patient Coalition

8 Appendix 2

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Workpackage 8

Palliative care
Integration with oncology
The case of Early-phase clinical trials

Augusto Caraceni

Direttore SC Cure Palliative Terapia del dolore e Riabilitazione Fondazione IRCCS Istituto Nazionale dei Tumori di Milano

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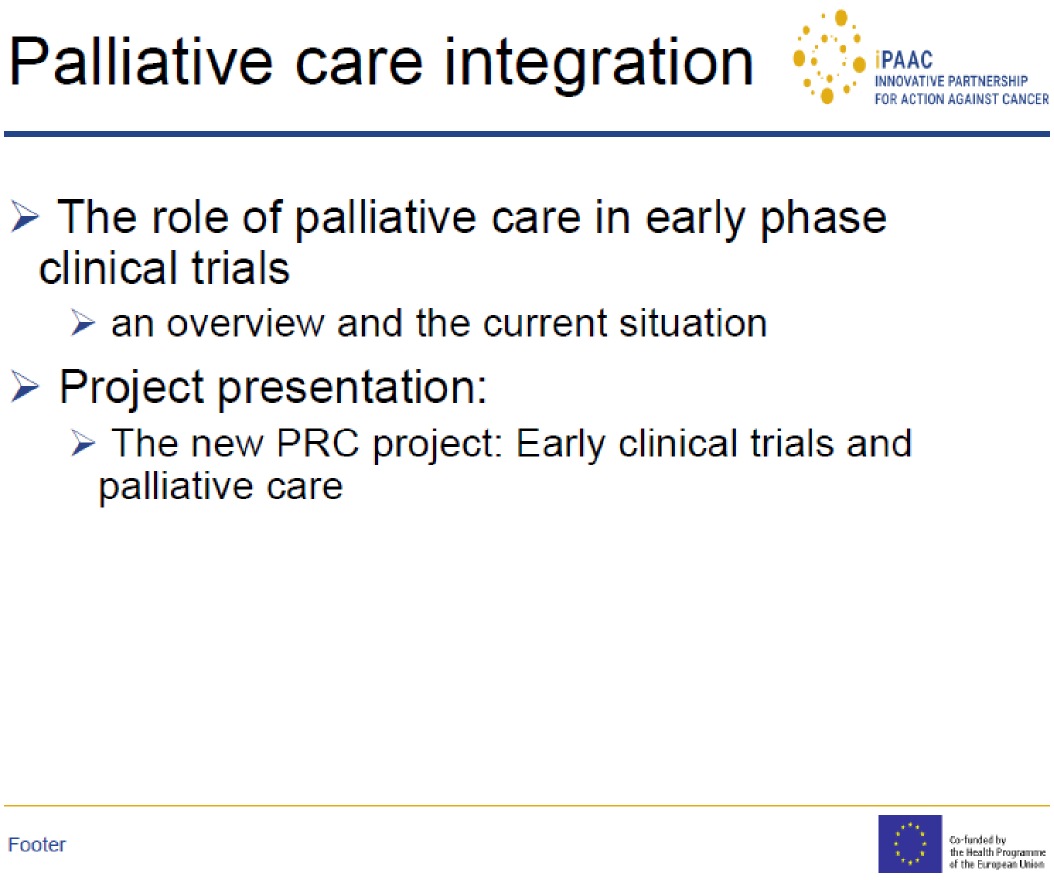
Fondazione IRCCS
Istituto Nazionale
dei Tumori

Regione
Lombardia

EAPC
vzw

EAPC Research Network



Palliative care integration

- The role of palliative care in early phase clinical trials
  - an overview and the current situation
- Project presentation:
  - The new PRC project: Early clinical trials and palliative care

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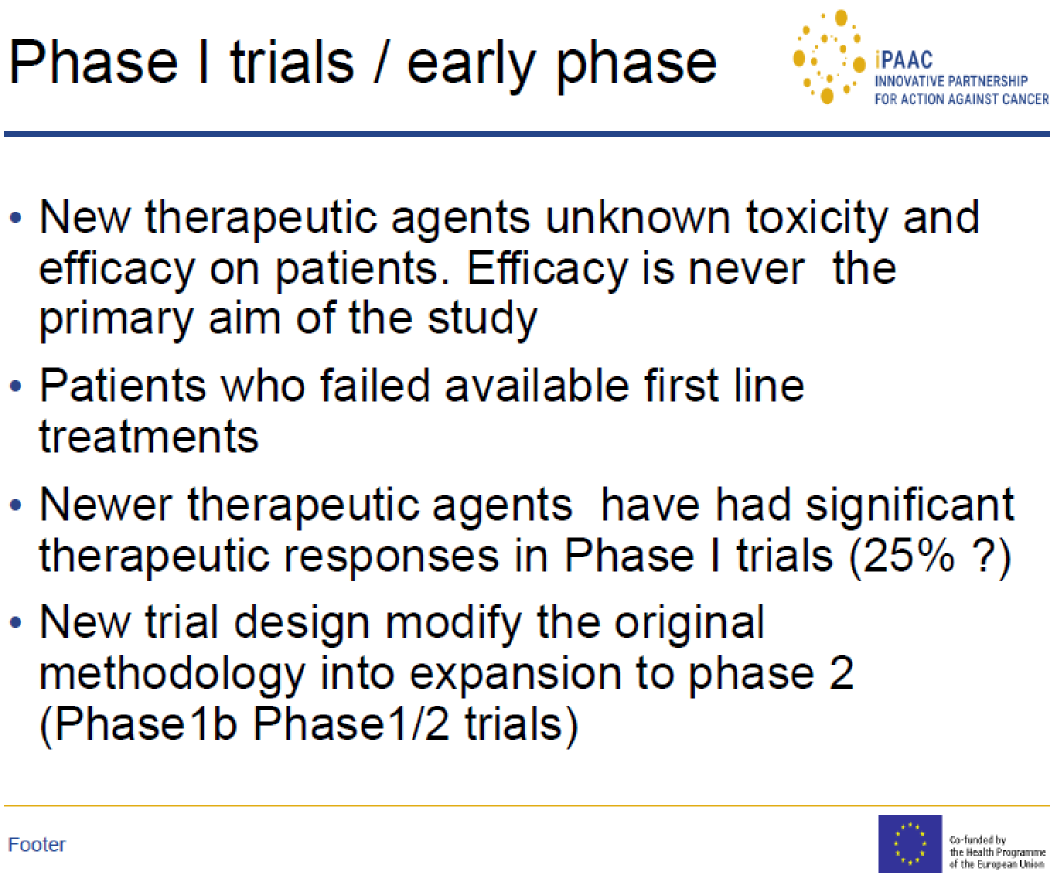

Phase I trials / early phase

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FOR ACTION AGAINST CANCER

- New therapeutic agents unknown toxicity and efficacy on patients. Efficacy is never the primary aim of the study
- Patients who failed available first line treatments
- Newer therapeutic agents have had significant therapeutic responses in Phase I trials (25% ?)
- New trial design modify the original methodology into expansion to phase 2 (Phase1b Phase1/2 trials)

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Literature review

History and Search Details

Search	Actions	Details	Query	Results	Time
#13	•••	›	Search: **#8 AND #12 AND #9** Sort by: **Most Recent**	486	05:45:45
#12	•••	›	Search: **#11 or #7** Sort by: **Most Recent**	18,782	05:44:55
#11	•••	›	Search: **phase 1 clinical studies** Sort by: **Most Recent**	11,128	05:43:54
#9	•••	›	Search: **#2 or #3 or #4 or #5** Sort by: **Most Recent**	956,574	05:33:43
#8	•••	›	Search: **cancer** Sort by: **Most Recent**	4,233,778	05:32:23
#7	•••	›	Search: **phase 1 studies** Sort by: **Most Recent**	15,953	05:31:27
#5	•••	›	Search: **supportive care** Sort by: **Most Recent**	861,426	05:29:39
#4	•••	›	Search: **terminal care** Sort by: **Most Recent**	61,394	05:29:13
#3	•••	›	Search: **end of life care** Sort by: **Most Recent**	87,985	05:28:52
#2	•••	›	Search: **palliative care** Sort by: **Most Recent**	82,794	05:28:31

PRC Milan working group Morena Shkodra, Matteo Duca, Augusto Caraceni

Footer

General topics

- Ethics
  - Optimal palliative care should be available to patients regardless their participation in trials

    (Grunwald HD Cancer Investigations 2007)
- Goals of care discussions

  (Saiki et al J Commun Supp Oncol 2017, Ferrell B et al Clin J Oncol Nurs 2017)
- Informed consent/ Communication

  (Cassel JB et al J Pain Sympt Manage 2016)
  - When palliative care should be discussed ? Is this considered in informed consent ?
  - Should Palliative care team be part of informed consent process ?

Footer

Palliative care needs

- Symptom control QOL
- Psychosocial support
  - Caregivers support
  - Emotional distress
- Advanced care planning
- Spiritual care

- Ferrell B et al Asia Pac J Oncol Nurs 2020
- Ferrell B et al Clin J Oncol Nurs 2017
- Ferrell B et al J Palliat Med 2017
- Ferrell B et al Psycooncology 2020
- Sun et al J Palliat Med 2014
- Anwar et al Cancer 2017
- Fu et al JCO 2012

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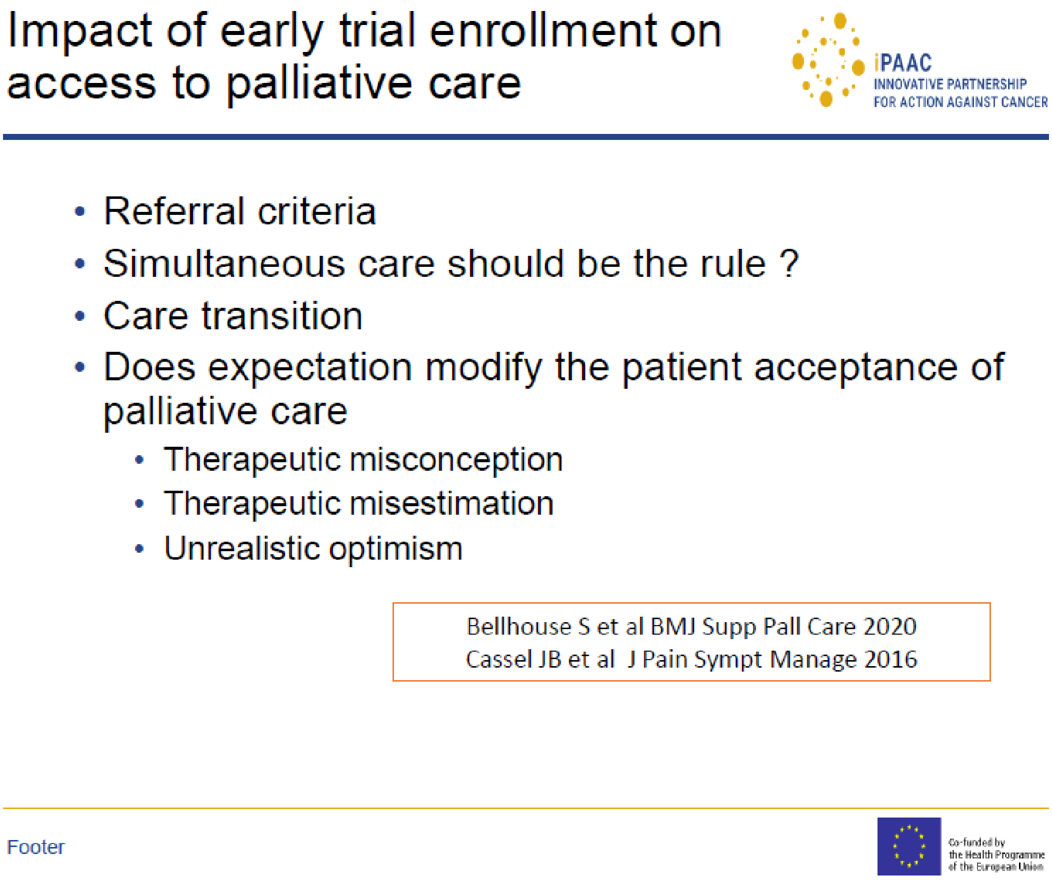

Impact of early trial enrollment on access to palliative care

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FOR ACTION AGAINST CANCER

- Referral criteria
- Simultaneous care should be the rule ?
- Care transition
- Does expectation modify the patient acceptance of palliative care
    - Therapeutic misconception
    - Therapeutic misestimation
    - Unrealistic optimism

Bellhouse S et al BMJ Supp Pall Care 2020
Cassel JB et al J Pain Sympt Manage 2016

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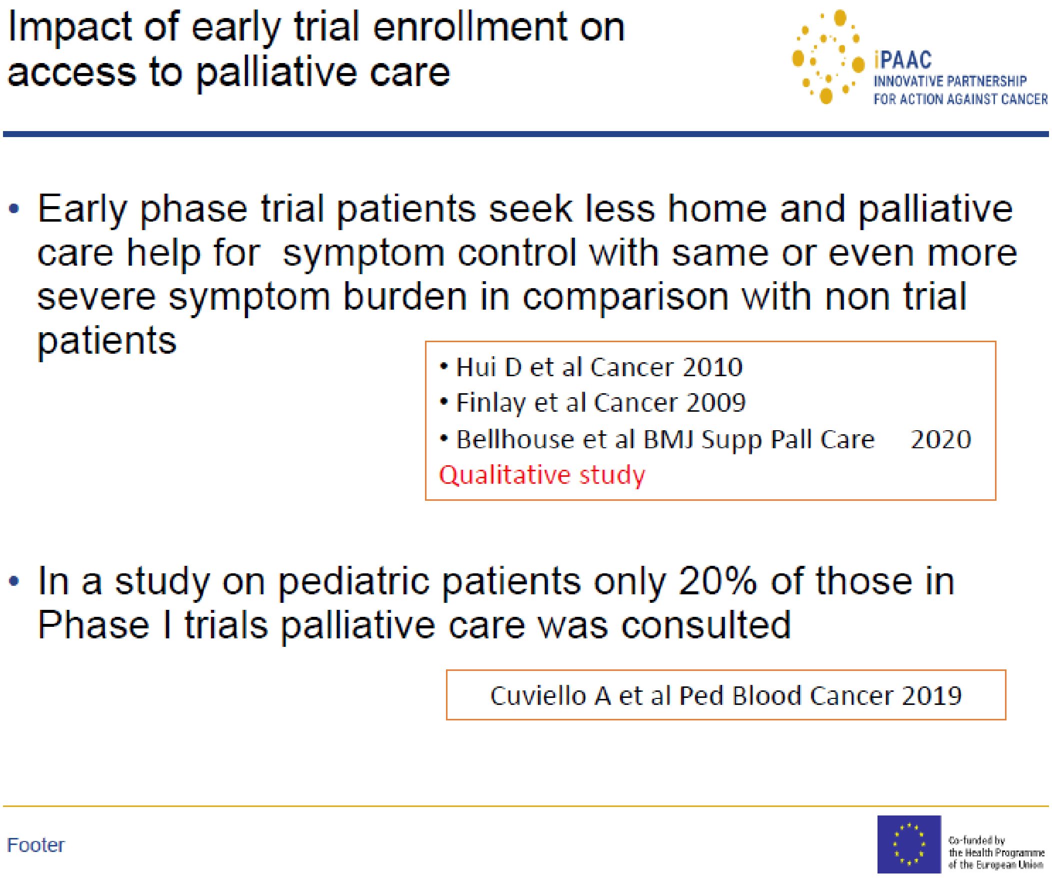

Impact of early trial enrollment on access to palliative care

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

- Early phase trial patients seek less home and palliative care help for symptom control with same or even more severe symptom burden in comparison with non trial patients

- Hui D et al Cancer 2010
- Finlay et al Cancer 2009
- Bellhouse et al BMJ Supp Pall Care 2020

Qualitative study

- In a study on pediatric patients only 20% of those in Phase I trials palliative care was consulted

Cuviello A et al Ped Blood Cancer 2019

Footer

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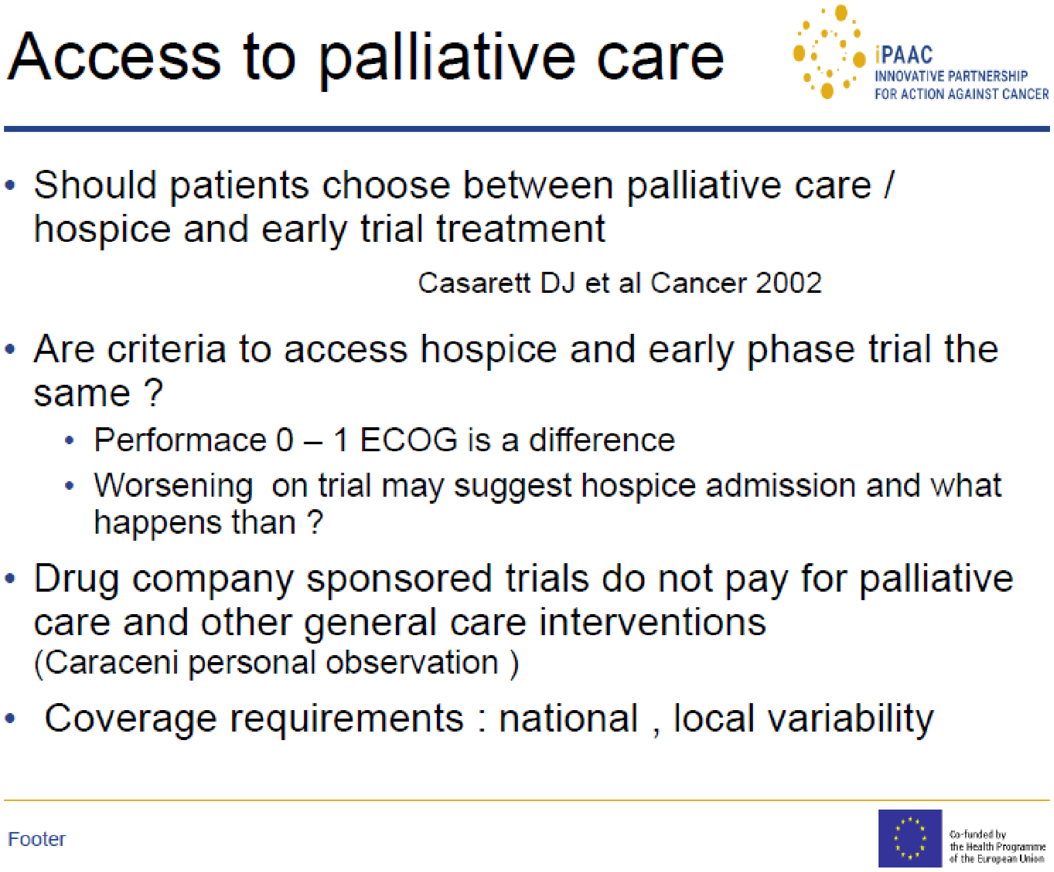

Access to palliative care

- Should patients choose between palliative care / hospice and early trial treatment

  Casarett DJ et al Cancer 2002

- Are criteria to access hospice and early phase trial the same ?
  - Performace 0 – 1 ECOG is a difference
  - Worsening on trial may suggest hospice admission and what happens than ?
- Drug company sponsored trials do not pay for palliative care and other general care interventions
  (Caraceni personal observation)
- Coverage requirements : national , local variability

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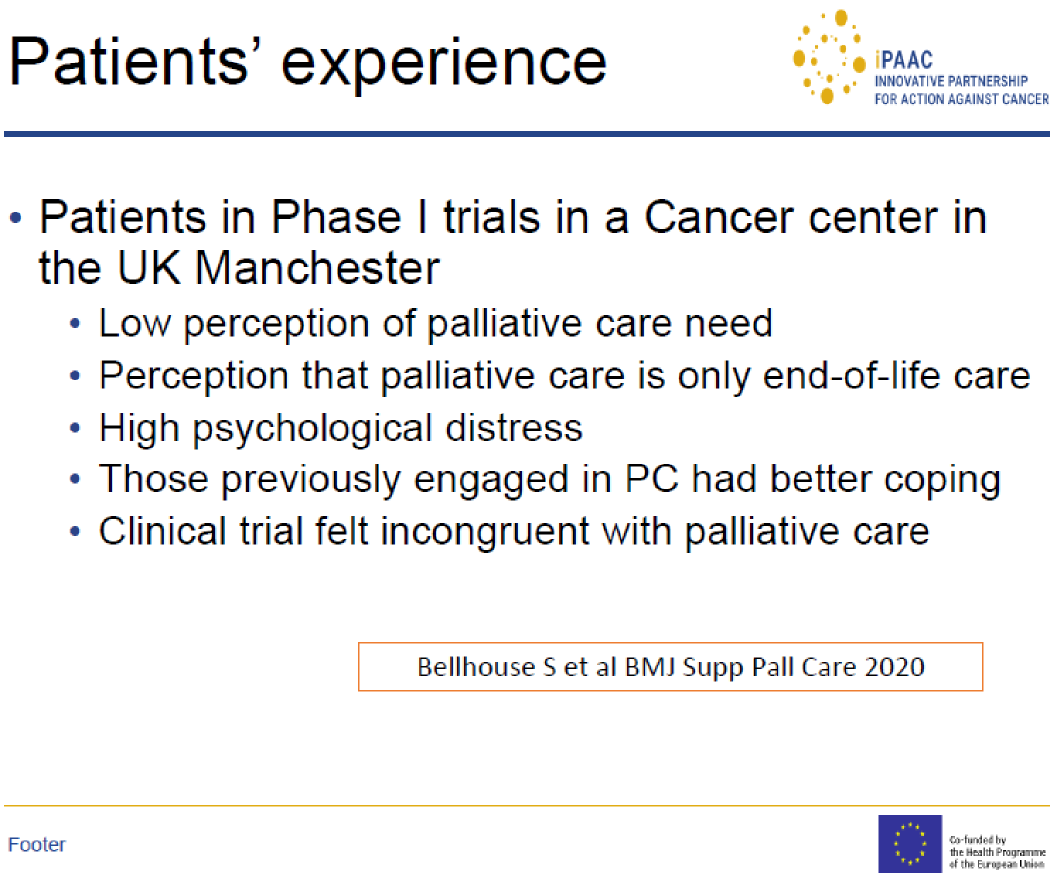

Patients' experience

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- Patients in Phase I trials in a Cancer center in the UK Manchester
    - Low perception of palliative care need
    - Perception that palliative care is only end-of-life care
    - High psychological distress
    - Those previously engaged in PC had better coping
    - Clinical trial felt incongruent with palliative care

Bellhouse S et al BMJ Supp Pall Care 2020

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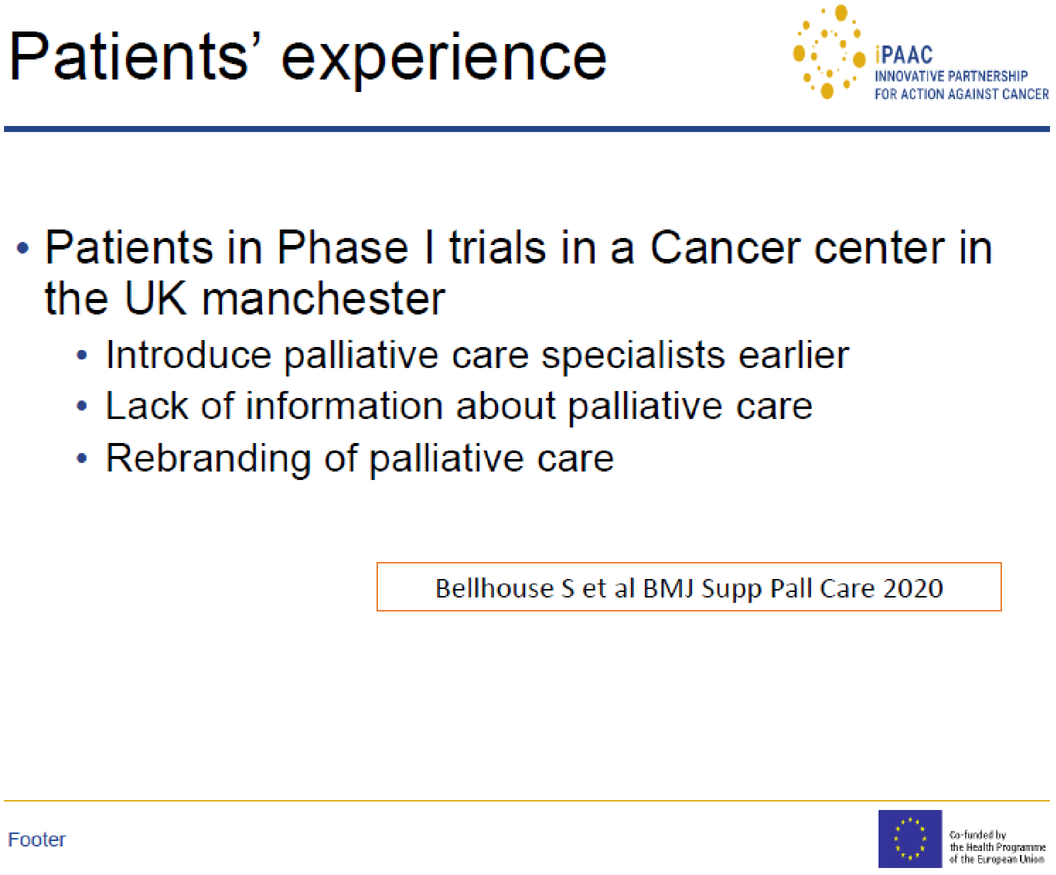

Patients' experience

- Patients in Phase I trials in a Cancer center in the UK manchester
  - Introduce palliative care specialists earlier
  - Lack of information about palliative care
  - Rebranding of palliative care

Bellhouse S et al BMJ Supp Pall Care 2020

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Intervention clinical trials

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- A palliative care intervention for patients on Phase I studies

Ferrell B et al J Pall Med 2020

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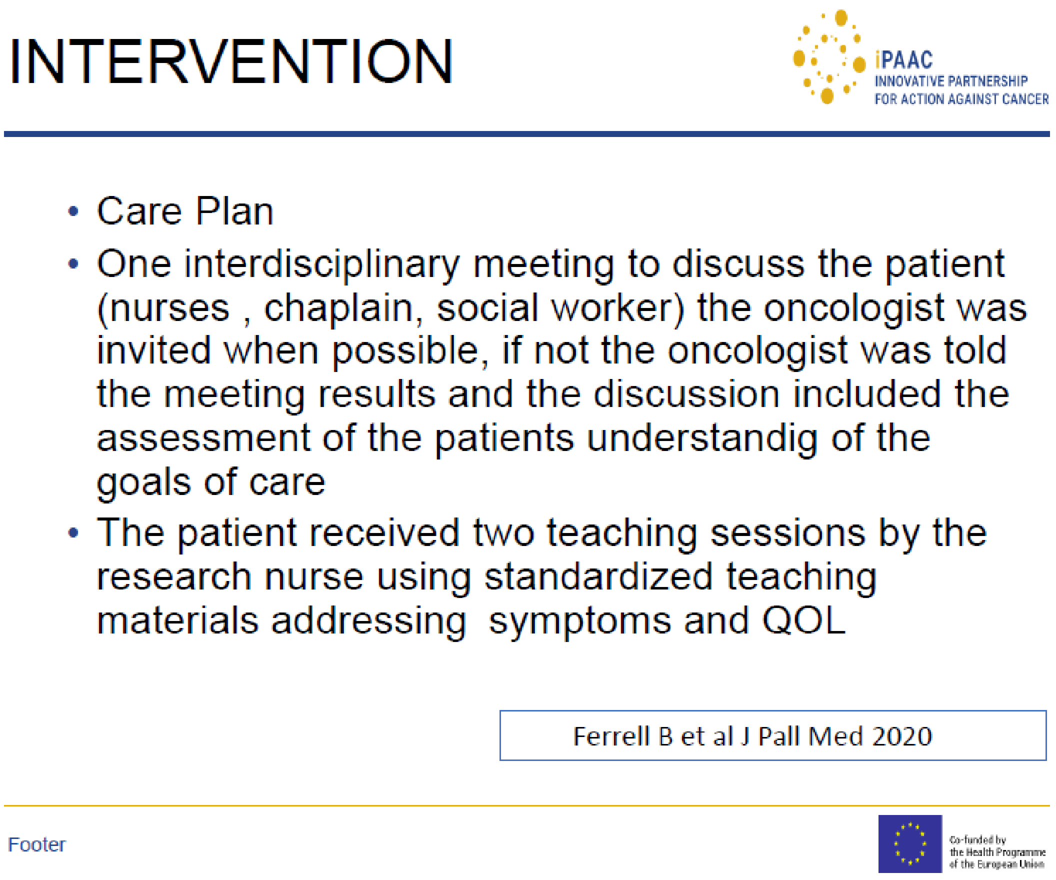

INTERVENTION

- Care Plan
- One interdisciplinary meeting to discuss the patient (nurses , chaplain, social worker) the oncologist was invited when possible, if not the oncologist was told the meeting results and the discussion included the assessment of the patients understandig of the goals of care
- The patient received two teaching sessions by the research nurse using standardized teaching materials addressing symptoms and QOL

Ferrell B et al J Pall Med 2020

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Patients in trial

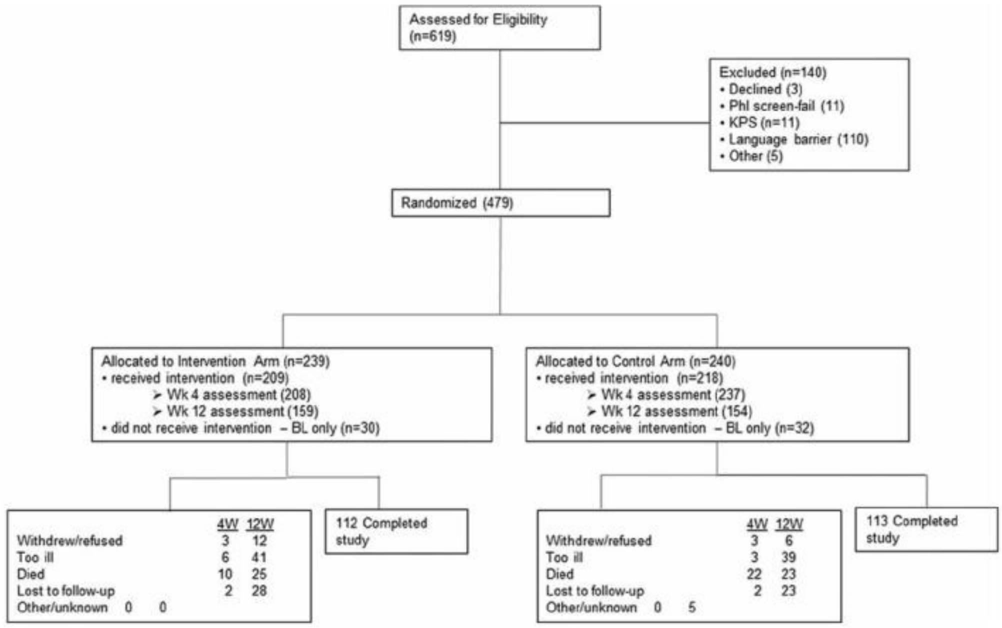
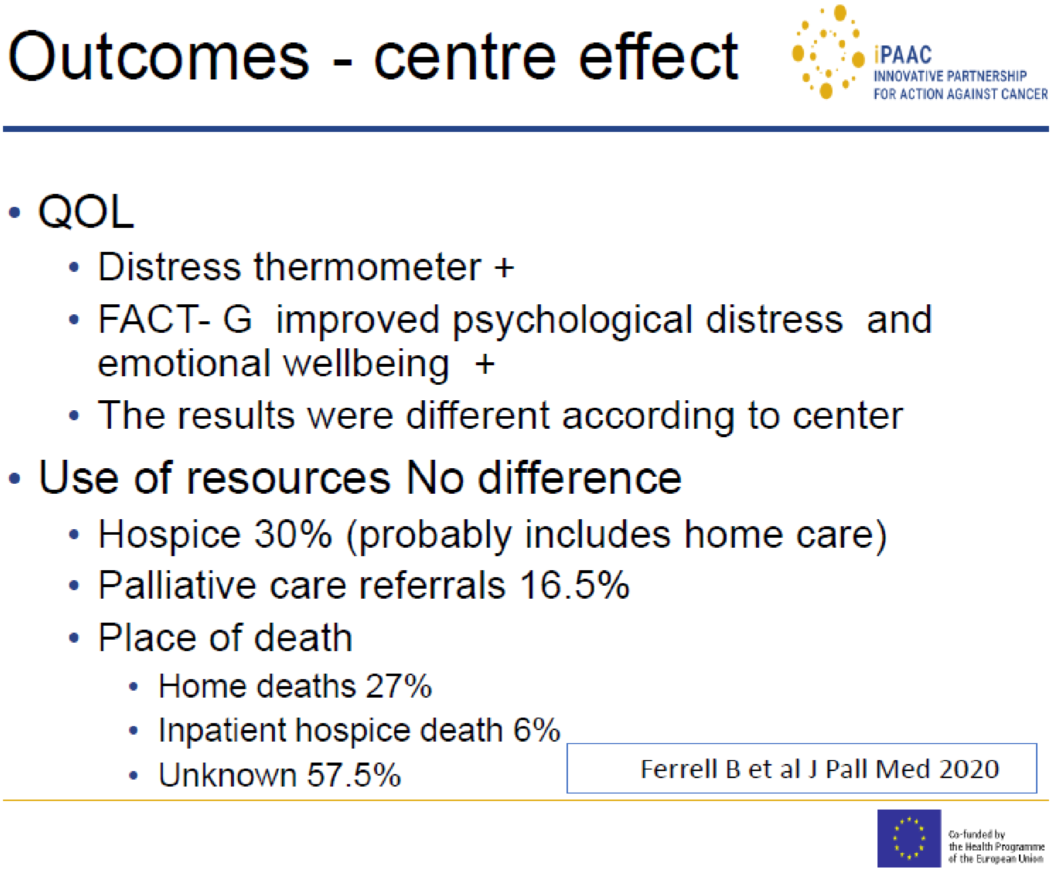


FIG. 1. Consort Diagram.

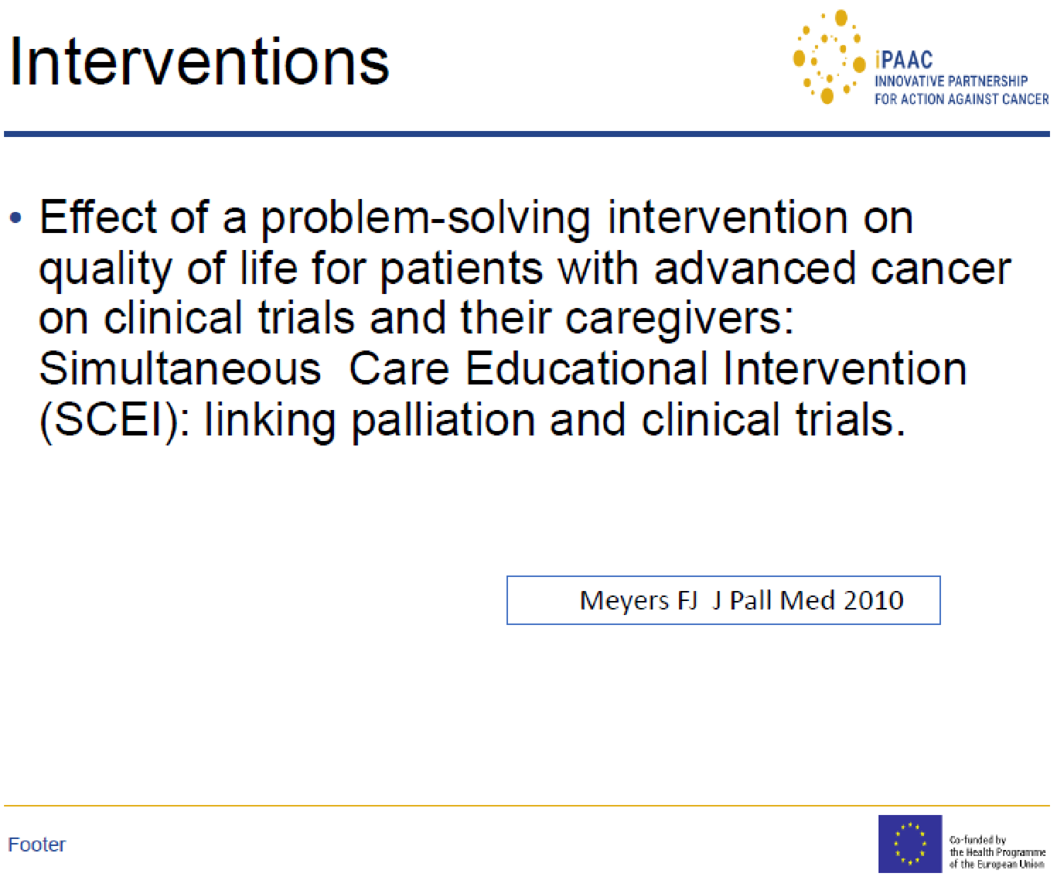
Ferrell B et al J Pall Med 2020



Outcomes - centre effect

- QOL
  - Distress thermometer +
  - FACT- G improved psychological distress and emotional wellbeing +
  - The results were different according to center
- Use of resources No difference
  - Hospice 30% (probably includes home care)
  - Palliative care referrals 16.5%
  - Place of death
    - Home deaths 27%
    - Inpatient hospice death 6%
    - Unknown 57.5%

Ferrell B et al J Pall Med 2020



Interventions

- Effect of a problem-solving intervention on quality of life for patients with advanced cancer on clinical trials and their caregivers: Simultaneous Care Educational Intervention (SCEI): linking palliation and clinical trials.

Meyers FJ J Pall Med 2010

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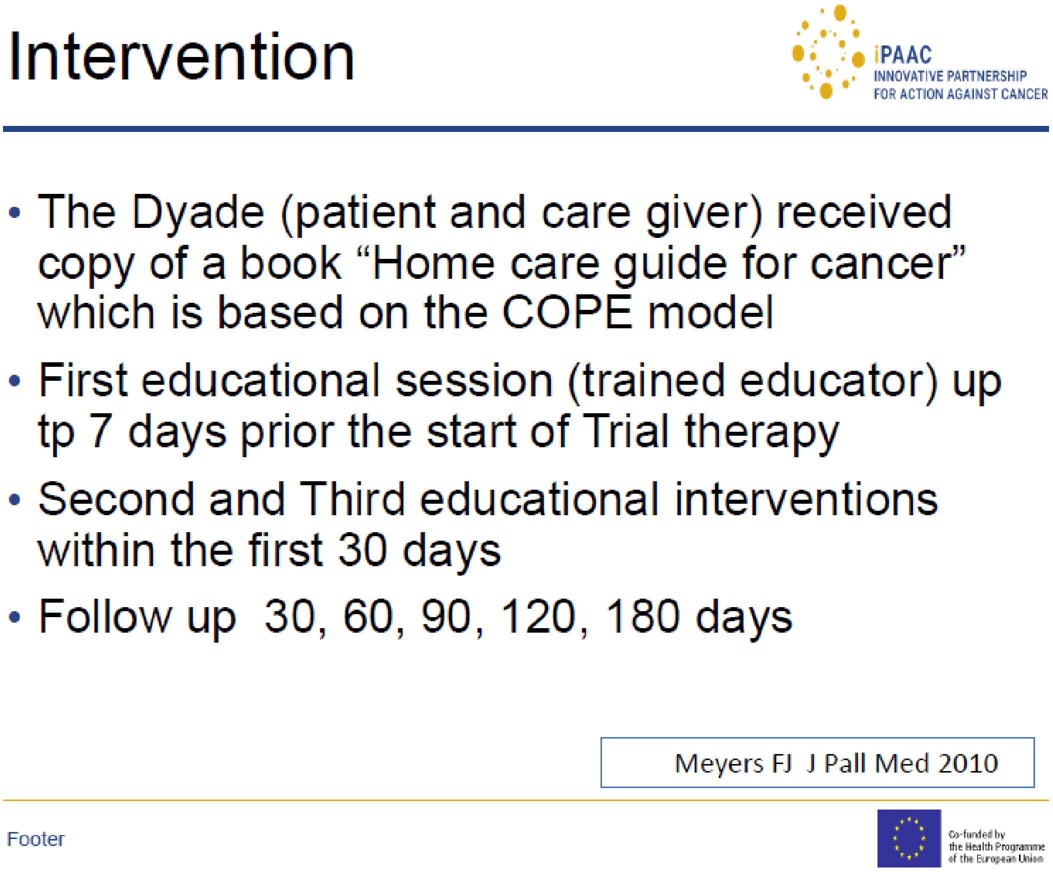

Intervention

- The Dyade (patient and care giver) received copy of a book “Home care guide for cancer” which is based on the COPE model
- First educational session (trained educator) up tp 7 days prior the start of Trial therapy
- Second and Third educational interventions within the first 30 days
- Follow up 30, 60, 90, 120, 180 days

Meyers FJ J Pall Med 2010

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Special Article

Phase I Cancer Trials and Palliative Care: Antagonism, Irrelevance, or Synergy?

J. Brian Cassel, PhD, Egidio Del Fabbro, MD, Tobias Arkenau, MD, PhD,
Irene J. Higginson, BM, BS, BMedSci, PhD, FFPHM, FRCP, Samia Hurst, MD,
Lynn A. Jansen, RN, PhD, Andrew Poklepovic, MD, Annette Rid, MD,
Jordi Rodón, MD, Florian Strasser, MD, ABHPM, and Franklin G. Miller, PhD
Virginia Commonwealth University (J.B.C., E.D.F., A.P.), Richmond, Virginia, USA; Sarah Cannon Research Institute and University College London (T.A.), London, United Kingdom; Cicely Saunders Institute (I.J.H.), King's College London, London, United Kingdom; Institut d'éthique biomedicale (S.H.), Centre médical universitaire, Geneva, Switzerland; Oregon Health and Science University (L.A.J.), Portland, Oregon, USA; King's College London (A.R.), London, United Kingdom; Vall d'Hebron Institut d'Oncologia (J.R.), Barcelona, Spain; ABHPM, Kantonsspital St. Gallen (F.S.), St. Gallen, Switzerland; and National Institutes of Health (F.G.M.), Bethesda, Maryland, USA

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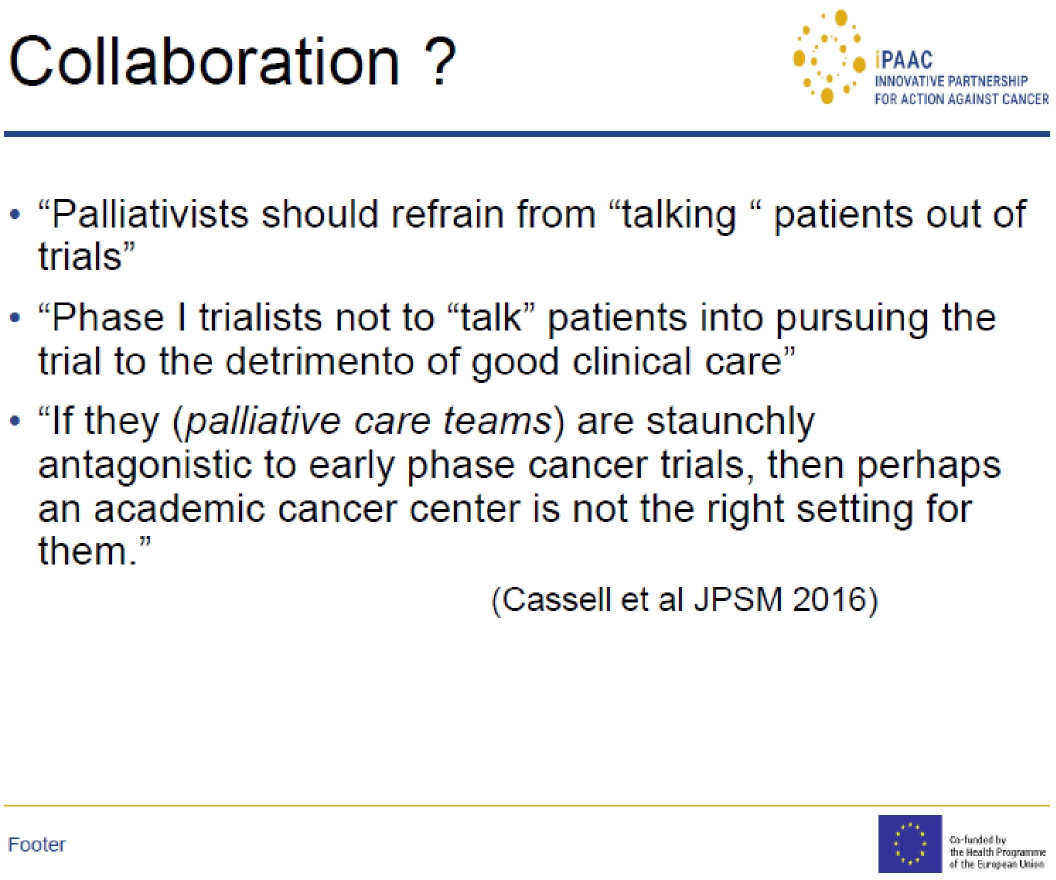

Collaboration ?

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- “Palliativists should refrain from “talking “ patients out of trials”
- “Phase I trialists not to “talk” patients into pursuing the trial to the detrimento of good clinical care”
- “If they (*palliative care teams*) are staunchly antagonistic to early phase cancer trials, then perhaps an academic cancer center is not the right setting for them.”

(Cassell et al JPSM 2016)

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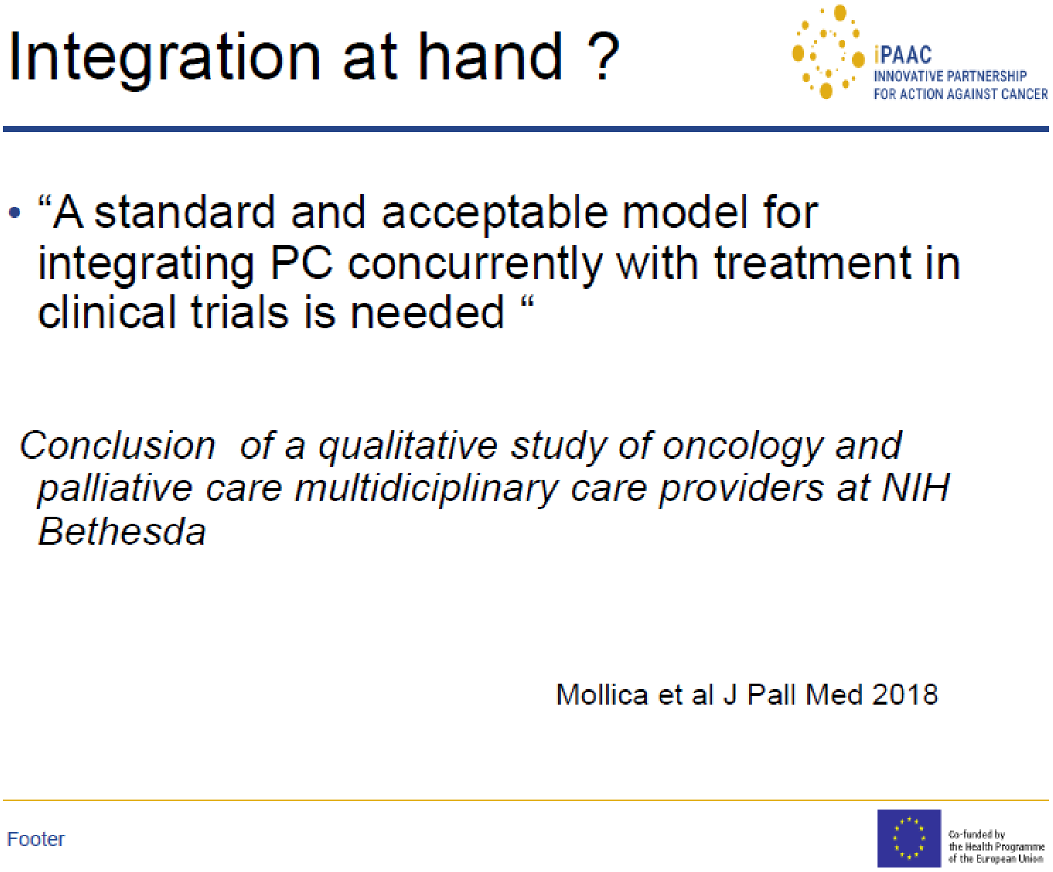

Integration at hand ?

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- “A standard and acceptable model for integrating PC concurrently with treatment in clinical trials is needed “

Conclusion of a qualitative study of oncology and palliative care multidiciplinary care providers at NIH Bethesda

Mollica et al J Pall Med 2018

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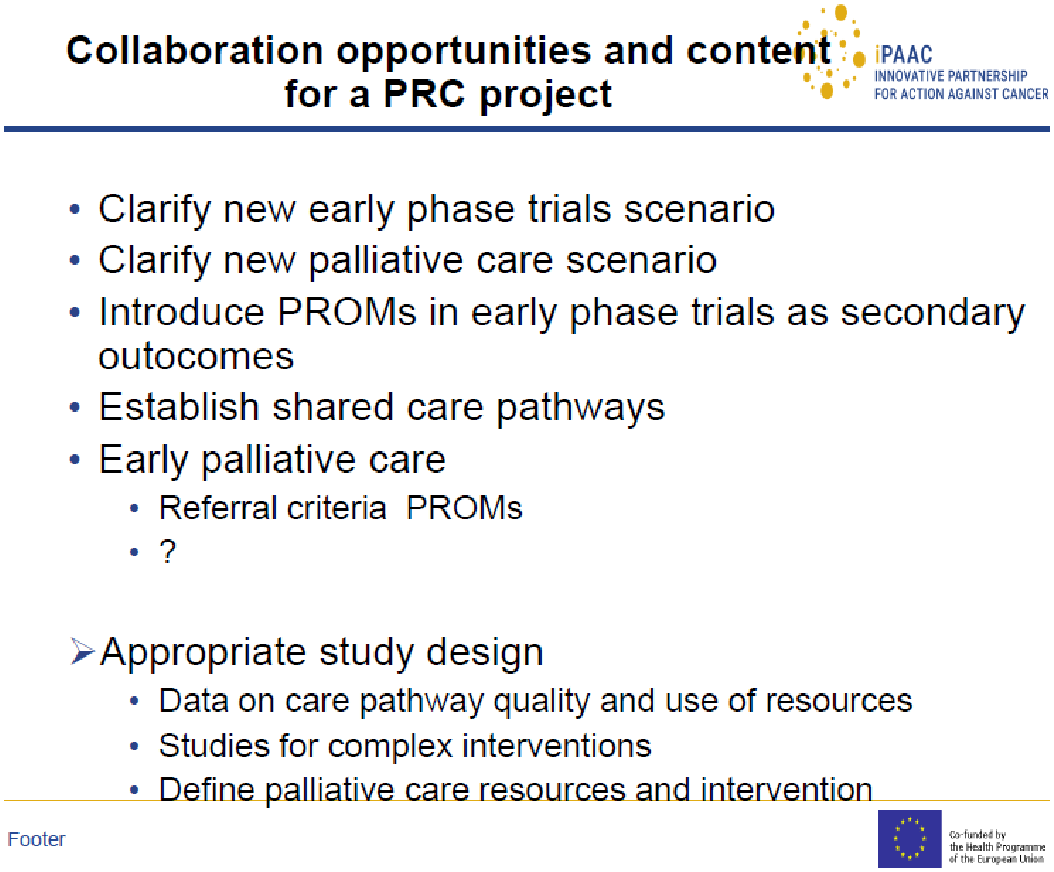

Collaboration opportunities and content for a PRC project

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- Clarify new early phase trials scenario
- Clarify new palliative care scenario
- Introduce PROMs in early phase trials as secondary outocomes
- Establish shared care pathways
- Early palliative care
  - Referral criteria PROMs
  - ?

➢ Appropriate study design
  - Data on care pathway quality and use of resources
  - Studies for complex interventions
  - Define palliative care resources and intervention

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PRC new project

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- PRC Working group
  - Morena Shkodra PhD Student
  - Matteo Duca Phase I trialist
  - Stein Kaasa
  - Phase I trialist Oslo
  - ??
- Systematic literature review (ongoing)
- Proposal for collaboration with
  - ESMO Designated centres for integration of oncology and palliative care
  - Position paper

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