

# Cancerworld

## Moving towards efficiency in cancer care: Examples

Adriana Albini / 8 February 2021

The graphic features a light blue background with a white grid of 10 icons, each representing a principle of the European Code of Cancer Practice. The icons are arranged in two rows of five. The top row includes: 1. Equal Access (scales), 2. Information (person with speech bubble), 3. Quality, Expertise & Outcomes (award), 4. Specialised Multidisciplinary Care (group of people), 5. Shared Decision-Making (two people with arrows). The bottom row includes: 6. Research & Innovation (DNA helix), 7. Quality of Life (hands holding a heart), 8. Integrated Supportive & Palliative Care (hands holding a heart), 9. Survivorship & Rehabilitation (person with arms raised), 10. Reintegration (group of people). To the right of the grid is the European Cancer Organisation logo, a blue circle with the text 'european cancer ORGANISATION'. Below the grid are the hashtags '#cancerpatientrights #codeofcancerpractice' and the website 'europeancancer.org/code'.

### European Code of Cancer Practice

YOU HAVE A RIGHT TO:

1. EQUAL ACCESS
2. INFORMATION
3. QUALITY, EXPERTISE & OUTCOMES
4. SPECIALISED MULTIDISCIPLINARY CARE
5. SHARED DECISION-MAKING
6. RESEARCH & INNOVATION
7. QUALITY OF LIFE
8. INTEGRATED SUPPORTIVE & PALLIATIVE CARE
9. SURVIVORSHIP & REHABILITATION
10. REINTEGRATION

#cancerpatientrights #codeofcancerpractice europeancancer.org/code

## Improving Efficiency in Cancer Care”- 2nd event

The series of webinars called “Spotlights on Improving Efficiency in Cancer Care” and including 11 monthly meetings from December 2020 to October 2021 is going forward. The [Second SPCC Webinar](#) is entitled “Moving towards efficiency in cancer care: Examples”.

The introduction was conducted by Andreas Charalambous, Department Chair, Associate Professor of Oncology and Palliative care at the Cyprus University of Technology, Adjunct Professor at the University of Turku in Finland, President Elect of the European Cancer Organization, and member of the SPCC Scientific Advisory Board. He has acquired specialised skills in the development and review of nursing educational programmes, both clinical and academic.

In his words he summarized the mission of the SPCC webinars and reminded to the audience that efficient cancer care can not be only a synonym of cost containment but rather it refers to the delivery of the best possible health outcomes using the human and financial fund structure and technological resources available, with a focus on what really matters to patients.

## The example of PROCHE

Florian Scotté, the first speaker of the session is MD-PhD, is medical oncologist at the European Hospital Georges Pompidou (Paris, France), and head of the SCUPP (Supportive Care in Cancer Unit Pompidou Paris). He is General Secretary of the AFSOS (French Speaking Association for Supportive Care in Cancer).

Teaching at several universities, and being coordinator of the inter-university diploma of supportive care, he is involved in training both medical and para-medical personnel.

He presented an innovative way to monitor patients at home, delving into supportive care. “The patient can be seen with different approaches – he states – by the surgeon, by the medical oncologist, by the nurses, by the dieticians, by many people in health care”. What is innovative in supportive care is to combine those different approaches in order to see the patient under this global vision.

Dr Scotté reported that author Ethan Basch in 2010 presented in the [New England Journal of Medicine](#), the difference between the professional perception and the patient feeling concerning the different side effects and toxicities, related to the cancer itself or its treatments. Fatigue, appetite loss, nausea, vomiting, constipation, all are symptoms that the patient perceives in a personal way, and often there is a gap between the perception of the patient and the one of the professional health care. The Perspective article in NEJM had the provocative title “The Missing Voice of Patients in Drug-Safety Reporting”.

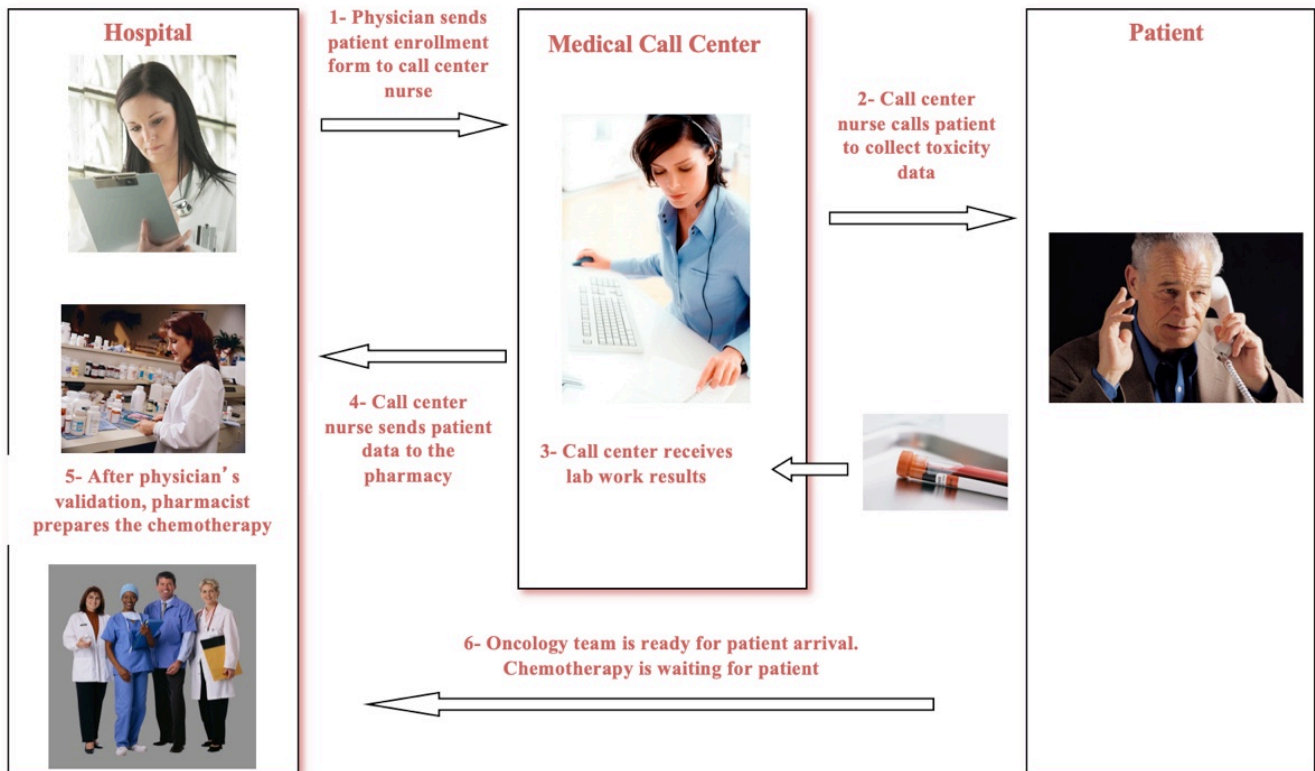
Recent papers of Bash confirmed that better supportive care and monitoring symptoms during treatment increases adherence to therapy and should improve clinical outcomes. He and other groups have demonstrated that the use of patient-reported outcomes (PROs) during treatment represents a way of achieving such results.

A [publication of Dr Scotté](#) himself states that “The advent of new cancer therapies, alongside expected growth and ageing of the population, better survival rates and associated costs of care, is uncovering a need to more clearly define and integrate supportive care services across the whole spectrum of the disease. The current focus of cancer care is on initial diagnosis and treatment, and end of life care.”

In his talk Professor Scotté presented the storytelling of PROCHE program in order to improve efficiency of care in hospitals. PROCHE stays for PRogramme d’Optimisation du circuit CHimiothErapie [Programme for optimisation of the chemotherapy network]) initiative, and it is an innovative oncology-monitoring program designed to reduce patient waiting time and chemotherapy waste, ultimately improving patient care.

The program has the objectives to optimize the oncology day hospital, to enhance the monitoring of patients at home, to propose the right supportive care treatment and approach for the patient, to decrease unnecessary hospitalizations venues to the hospital, and to increase quality of life.

In the studies of the team, side effect data for each patient were collected two days prior to each scheduled in-hospital chemotherapy treatment by nurses through a specialized call centre who contacts patients and completes a questionnaire. Laboratory test results were also entered into the database. According to these data, oncologists confirmed, postponed or cancelled the scheduled treatment the day before. If confirmed, the hospital pharmacy prepared the chemotherapy drugs a day in advance of the visit. Study endpoints included the time between scheduled treatment administration and actual administration (treatment delay) on the day of the visit and patient satisfaction, and were recorded the months prior to, and during, the program.



On one side of the program the professionals could see that there was a decrease of patient-waiting time at the day-hospital, reduced by 50% and that meant a better efficiency of all the day-hospital.

The other part of the study was about improvement in terms of quality of life. Examining the data, a significant decrease of fatigue and pain was achieved thanks to the introduction of the program PROCHE.

In one methodology [presented at ASCO](#), toxicities and their grade reported in medical records for each patient were plotted against time under treatment, to calculate the area under the curve of toxicities (AUCtox) that takes into account both the intensity and duration of toxicities, and the number of events. AUCtox was calculated for any toxicity reported at least once.

A conclusion of the study presented at ASCO is that a patient monitored by a nurse has a better rate of response by 85%, compared to using a web platform, with a 78%; the study was significant in favour of the nurse monitoring. However, with the web monitoring, there was better information on the low level of severity related to anticancer treatment with more grade 1 and 2, compared to the nurse monitoring. So, both web approach and nurse navigator approach have important roles. Combined approach is probably the best solution, depending the choice of the patient.

Dr Scotté also discussed in the webinar what happens to the patient with pain. The patient with the worst pain curve, has the worst prognosis. While the patient with no pain at the start of the cancer management, and no pain at the end of this management, has the better survival curve. A patient with the highest level of pain at the start and at the end, has the worst survival curve. But for a patients with high level of pain at the start of the anticancer treatment, and not pain at the end there is both an action of the anticancer treatment, and a good accompaniment by the supportive team.

The conclusion was that PROCHE is a Digital- and Human-based program which improves quality of life. This anticipation program also changes in better and more efficient the day-hospital organization.

## **EONS project example - Effectiveness of a Multimodal Education and Support Program for the Prevention of Cancer Related Cachexia for patients and their family caregivers**

Dr Constantina Cloconi was the next presenter. She is a Clinical Research Nurse at the German Oncology Center in Limassol (Lemesos), Cyprus and Teaching Assistant, Cyprus University of Technology, Limassol. She reported on the effectiveness of a multimodal education and support program for the prevention of cancer related cachexia for patients and their family caregivers. The research team includes clinical dietitians, integrative medicine specialists, supervisors, and a medical oncologist.

[SPCC task force](#) raised awareness of malnutrition and cachexia in cancer patients. The task force, held as a virtual meeting in June 2020, with stakeholders from organisations across Europe, which resulted in a call to action for early diagnosis of cancer patients with malnutrition/cachexia, the introduction of practical tools to identify patients, and multimodal supportive care to become an integral part of treatment.

Dr Cloconi explained that cancer related cachexia is a multifunctional syndrome which is characterized by an ongoing loss of skeletal muscle mass, that cannot be fully reversed by conventional nutritional support. This is accompanied by a progressive functional impairment. The pathophysiology is based on a negative protein and energy balance, driven by a various combination of reduced food intake, loss of appetite, because of the treatment and abnormal metabolism. A patient with cancer related cachexia can have high treatment toxicity, high eating related distress, high caregiver burden and can have a lower quality of life both and a worse prognostic score, sometimes even a large difference. An 80% of advanced cancer patients experience cachexia which is the final cause of 20 to 60% of cancer death. Through a systematic review the team reported by Dr Cloconi has approached a non-pharmacological management of cancer related Cachexia. Nutritional support, nutritional supplements, and psychotherapeutic interventions, like relaxation, exercise, can give patients better outcomes. Patient, caregiver and family education on the nutrition related stress reduction is another critical aspect. The team run a randomized control trial to evaluate the effectiveness of a multimodal education and support program for the prevention of cancer related Cachexia syndrome for patients and also for family caregivers during cancer treatment.

The study includes 60 cancer patients, 30 patients for each group and one caregiver for each patient. It is taking place at German Oncology center in Limassol Cyprus. The control group receives the usual care, another group has a guideline of 10 steps for better nutrition through the treatment and a telephone support.

The intervention group is provided with the usual care plus a multimodal education and a support program which includes the oncologist, the cancer nurse, the clinician and the integrative medicine doctor.

Patients recruited have solid tumours, breast, colorectal, stomach, pancreas and lung, chosen because cancer related cachexia is often present in these types of cancer. They are patients subjected to intravenous chemotherapy or immunotherapy or hormone therapy, since the toxicity is superior than the in radiation therapy which is less systemic. Participants are zero or pre-cachexia stage.

Cancer related cachexia assessment focuses on a protocol which has three stages: Precachexia, Cachexia, Refractory.

The first stage which is Precachexia is represented by weight loss less than 5%, anorexia and metabolic changes. The second stage is cachexia, which is more than 5% weight loss or BMI less than 20 and so on, and the Refractory stage, which is the most severe status and is characterized by a variable degree of cachexia. To measure cancer related Cachexia is a complex process, the team uses a medical scale implemented in the German Oncology Center, and it can calculate the BMI, the muscle mass, the fat mass, oedema, sarcopenia, protein levels, to help the patient to decrease symptoms, improve the quality of life.

If the patient consents, then, the nurse will assist him patient for cancer related cachexia. If the patient is in normal or precachexia stage, then in the study it is asked to introduce a family caregiver. There are four visits for the patient and their caregiver with the oncology nurse, and few times with the clinical dietician and the integrative medicine doctor. The team monitor and ask them how many kilos they lost, and if they lost them during the last month, the last three months, last six months. So, they use the functional assessment of anorexia for the quality of life and the eating related distress scale. Sometimes patients are fasting or avoiding meat or avoid other foods which are important for their diets, just because distress or for consulting "google" instead of a doctor. They are also assessed on the Memorial Symptom Scale to record the symptoms before the treatment. The family caregiver must fill the social-demographic form, the Burden Interview and the Quality of Life questionnaire. The last appointment is the follow-up, where there are assessments for everything again, for the Quality of Life, for the blood test, for the body composition, for the eating-related distress scale. In summary: at the baseline appointment patients and their family caregivers are educated on how to deal with the symptoms to help them to improve their diet and daily routine. They have to change their whole nutrition routine and they receive a booklet. They can read information regarding to the symptom, like changing of taste, nausea, vomiting, diarrhoea, constipation, dry mouth, or mucositis or fatigue.

## Non Pharmacological Management of Cancer Related Cachexia



Nutritional intervention, like honey, lemons, spices consumption can help them for alleviating constipation, nausea, and other discomfort. Some patients have problems with lactose or they have diabetes, or they have high blood pressure or they have other problems. There is a special focus on each of them, since they are all different. Patients can call the oncology nurse for questions, during the multimodal program. The aim is to incorporate a routine assessment of cancer related cachexia

in clinical practice from: the healthcare providers, the medical oncologist, the nurses, to provide and standardize a pathway for the management of cancer related cachexia to increase patient's quality of life. The team aims to support the patient centric version of care, with the help of caregivers, to improve the cancer treatment outcome and to reduce the eating related distress and burden, finally also to reduce the social inequalities to have equal education about diet, and treatment. So, the project aims to reduce the inefficiency in cancer care related to cachexia. Prevention of this complication should be promoted and assessed. The healthcare providers must support and educate their patients and their family caregivers. The take-home message is that all cancer patients are at risk of malnutrition. They can be even if they are in obesity. Sometimes patients in cachexia do not have enough muscle-mass to care for themselves. So, early recognition of cancer related cachexia can save lives and affect patients' quality of life, and prevention is the key.

## **Improving cancer care through a patient focused lens: The European Code of Cancer Practice and a European Cancer Dashboard**

Professor Mark Lawler closed the panel presentations. He is Associate Pro-Vice-Chancellor, Professor of Digital Health, and Chair in Translational Cancer Genomics at Queen's University Belfast (QUB) and a member of the Board of the European Cancer Organisation. He further elaborated on how we must improve cancer care through a more data-enabled patient focused lens. Prof Lawler updated on recent work at the European Cancer Organization.

He highlighted the significant challenges over the last 12 months, due to the impact of the pandemic on cancer patients and cancer services. However, he also emphasised the significant opportunities that exist, due to a number of key developments over the last 15 months. The new European Parliament clearly has identified health as an EU priority, and we have seen significant increase in the health budget in the EU (EU for Health)

The new European Commissioner for Health and Food Safety, [Stella Kyriakides](#) has emphasised that there needs to be a strong cancer focus.

The Europe Beating Cancer Plan, the EU Cancer Mission, and the Lancet Oncology European Cancer Groundshot Commission (led by Lawler) all emphasise the need to enhance cancer research in Europe and improve cancer outcomes

A significant development for the European Cancer Organisation has been the European Code of Cancer Practice, which Lawler and colleagues launched in Brussels (virtually) on the 23rd of September 2020 by Commissioner Stella Kyriakides. who has been a strong supporter of cancer patients throughout Europe.

For all the opportunities indicated above, it is important that they are realized for all of Europe - we need to close the cancer inequality divide that unfortunately exists in Europe. In this regard, the East West Divide is an important component of the European Cancer Organisations Inequalities Focussed Network.

# European Code of Cancer Practice

## YOU HAVE A RIGHT TO:



#cancerpatientrights #codeofcancerpractice

[european-cancer.org/code](http://european-cancer.org/code)

Addressing inequalities must be a key focus of what we do together, both in relation to cancer control and cancer research efforts. Developing and applying cancer intelligence has to be the driver for initiatives to combat cancer inequalities. We have seen significant improvements in relation to national cancer control plans, across Central and Eastern Europe (CEE), however unfortunately, we see that total healthcare spending falls in general, below the EU average. It must be underlined that funding and money are not the complete solution to the problem. For example, Lawler presented data on the economic burden of colorectal cancer in 33 European countries which showed that certain CEE countries are spending a significantly larger amount of their pharmaceutical budget than it would be expected on colorectal cancer, but that this excess spend is not reflected in an improved colorectal cancer survival in these same countries. In relation to the topic of the SPCC seminar, this is an example of real inefficiency in the spending of precious resources.

The European Code of Cancer Practice can help to address many of these issues. It is a co-creation between patients and cancer health professionals. It represents a Manifesto of the core requirements for good clinical cancer practice that should actually improve outcomes, not just for certain parts of Europe but for all of Europe.

“The European Code of Cancer Practice will empower European citizens to survive cancer and live longer, healthier and more productive lives,” declared Mark Lawler in his role for Co-chair of the European Code of Cancer Practice initiative, as reported in a previous [article on Cancer World](#) .

The European Code of Cancer Practice has its origins in the European Cancer Patient’s Bill of Rights which Lawler launched with colleagues in the European Parliament on World Cancer Day in 2014. It is also linked to the European Cancer Organizations Essential Requirements for Quality Cancer Care. The European Code of Cancer Practice champions 10 rights that patients must have from their health system in order to ensure the best possible cancer care and control for patients right across Europe will be provided. It is designed to empower citizens through 10 key ‘overarching’ rights and to reduce cancer care inequalities across Europe.

According to the European Code of Cancer Practice the patient has a right to:

1. EQUAL ACCESS
2. INFORMATION
3. QUALITY OF CARE, EXPERTISE AND BEST OUTCOMES

4. SPECIALISED MULTIDISCIPLINARY CARE
5. SHARED DECISION-MAKING
6. RESEARCH AND INNOVATION
7. QUALITY OF LIFE
8. INTEGRATED SUPPORTIVE AND PALLIATIVE CARE
9. SURVIVORSHIP AND REHABILITATION
10. REINTEGRATION

Besides the apparently most obvious one “survivorship”, these 10 rights relate to pivotal issues such as integrated supportive and palliative care, rehabilitation and reintegration into society. Information is a key right, and also resonates with rights to multidisciplinary care and in shared decision-making. The patient moves from being a passive recipient to being an active participant in his/her/their own care.

These 10 key overarching rights represents signposts that patients should expect from their health system, and they should be delivered in order to achieve the best possible outcomes.

We must facilitate patients and citizens to be able to read, understand and pretend implementation of the European Code of Cancer Practice, to bring it forward when they go to see their healthcare professionals. The Code has been translated into 28 different European languages, facilitating its dissemination and its use will improves efficiencies within their health system.

Lawler also talked about Central and Eastern European Cancer Action Group (CEECAG), an initiative that was established over 3.5 years ago, involving again a multi-stakeholder group bringing together patient-advocates, clinicians, researchers, cancer systems, experts, and industry. Initially, seven countries were involved but now this has expanded to 16 countries.

A key aim of CEECAG has been how to turn information into intelligence to capture the cancer landscape in Central and Eastern Europe and to develop new tools to help to collect, but also to monitor cancer intelligence that will help to improve cancer care in in the region. An evidence-based approach to decision-making and policy, is underpinned by a series of “cancer country dashboard” for each of the 16 countries participating in the initiative and has been very instructive. Key areas of focus in CEE countries controlling that affordable high quality equitable cancer control can be delivered include the availability of accurate actionable data, investment in research, education and training, particularly to retain cancer professionals in their home country, innovative ways to develop and standardize the patient pathway so that the quality of care can be achieved right across that continuum from diagnosis to treatment to end of life.

The dashboard helps to develop a cancer “learning environment” that benefits and informs cancer policy in CEE by highlighting key challenges and inequalities across the region, it ensures that evidence becomes an effective enabler of action for stakeholder and it leverages key cancer policy indicators to measure progress over time and provide a benchmark for best practice sharing across the region

The cancer country dashboard therefore provides a way to optimize the use of European resources and to measure progress over time. The European Cancer Organisation will support the development of cancer country dashboards which should be evolving and facilitating the accumulation of cancer intelligence to instruct cancer policies and to measure the effectiveness and impact of targeted interventions.

The European Code of Cancer Practice and the cancer country dashboards should help providing the input to empower governments in providing better options for cancer patients in Europe and



particularly in Central and Eastern Europe. Intelligence is key to illuminating the path that has to be taken.

The cancer country dashboards would provide not only evidence, but a constantly evolving snapshot of what is happening across Europe, allowing to monitor the current landscape and the impact of timely interventions locally, nationally and regionally. A learning environment such as this would benefit the entire Europe, and enable efficiency in cancer care.