Hosted by

EUROPEAN UNION

Committee of the Regions

Cancer Control Joint Action Policy Conference

"Cancer Survivorship: a Policy Dialogue"

13 May 2015 in Brussels

Report

Co-funded by the Health Programme of the European Union

The first Cancer Control (CanCon) Joint Action Policy Conference "Cancer Survivorship: a Policy Dialogue" was hosted by the Committee of the Regions in Brussels and organized by the Association of European Cancer Leagues and Cancer Society of Finland and took place on the 13 May 2015 in Brussels.

Opening the conference**, Mr Markku Markkula**, the President of the European Committee of the Regions (CoR) welcomed participants to the Committee of the Regions. He outlined the role of the CoR, a political assembly of holders of a regional or local electoral mandate serving the cause of European integration. The CoR provides institutional representation for all the European Union's territorial areas, regions, cities and municipalities. Mr Markkula also outlined the importance of such a policy event on cancer, as everyone has some experience of cancer and the devastation it can cause.

Mr Martin Seychell, Deputy Director General for Health and Food Safety, European Commission, informed participants of the role of the European Commission in cancer control. The Commission has been active in cancer policy for 30 years. As cancer survivorship rates have increased, he stressed that we must aim at increasing the quality of life of patients and survivors. Survivorship policies must include reintegration, palliative care, and all health policy actions should aim at decreasing health inequalities. Despite our efforts, inequalities in survival rates still exist across Europe, and patients do not always get timely access to treatment. The Commission aims to reduce these inequalities so that best practices become common practices. The Joint Action on Cancer Control (CanCon) is a key initiative to achieve this. The Commission also coordinates the expert group on cancer control, who have been asked to work on the issue of cancer survivorship. The Commission has worked on cancer policy and initiatives since 1985, and this will continue to remain high on the policy agenda.

Mr Alojz Peterle, Member of European Parliament, President of MEPs Against Cancer (MAC) in the European Parliament, outlined the importance of regional authorities in contributing to cancer control. The opinions given by the Committee of the Regions to the European Parliament initiatives help them to shape their policies. Mr Peterle urged that there was a lack of health literacy among politicians, where the political focus is often on the financial means or the lack of them. For example, disease prevention is not given enough attention or financial investment. We should aim for an ambitious interpretation of the Lisbon Treaty to ensure health is integrated in all policies.

Mr Peterle informed the participants that MAC had resumed their activities in the Eighth Legislative term of the European Parliament. Priorities this term will be centred on reducing cancer incidence by promoting prevention, reducing mortality by ensuring equitable access to high quality treatment and care and ensuring a good quality of life for cancer patients and survivors. Mr Peterle told participants that his vision as President of MAC is to form MAC groups in National Parliaments across the 28 EU Member States.

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Dr Sakari Karjalainen, Secretary General of Cancer Society of Finland and CanCon Dissemination Leader, welcomed the participants on behalf of the organizers of the meeting, ECL and the Cancer Society of Finland, the only two organizations representing the NGO community in the CanCon project as associated partners, and important stakeholders for dissemination of the results of CanCon. The Cancer Society of Finland is the biggest patient and public health organization in the country, maintains a Finnish cancer registry which is responsible for development and dissemination of cancer screening in Finland. It leads the CanCon work packages on dissemination and on screening.

He explained the aim of the work package on dissemination, which is to inform governments and experts and to engage European citizens (the public, stakeholder networks and different partners) to set cancer control firmly on the European agenda and to foster networking across different fields of science. The European Guide on Quality Improvement in Comprehensive Cancer Control is the key document to be communicated.

Dr Karjalainen also briefed the delegates about the second network meeting, which was held in the morning (the same day) with over 20 participants discussing how to best disseminate the guide. All stakeholders agreed it will be a challenge for the CanCon. Dr Karjalainen concluded by stating this conference clearly demonstrates that all the CanCon stakeholders are expecting major improvements in cancer control and that the CanCon joint action will make a significant contribution to that change.

Ms Joan Kelly, President of the Association of European Cancer Leagues (ECL) spoke about *Perspective on Cancer Control and Advocacy.* She briefly introduced the ECL as a pan–European, non profit, non governmental umbrella organization created in 1980, with members being cancer organization at national and regional levels across wider Europe.

Ms Kelly stressed the vital role of cancer leagues in advocacy to raise awareness of cancer related issues and to campaign for policy and legislation that can help save lives and to improve lives of people with cancer as well as establishing and maintaining a dialogue with key policymakers to provide input on cancer issues. ECL, specifically, represents the voice of cancer leagues in Europe and can as such represent members' interests towards EU Institutions. It also facilitates the dialogue and exchange of best practices between its member cancer leagues and can as such help reducing inequalities across Europe. She particularly stressed the vital role ECL plays in disseminating the European Code against Cancer, as an extremely valuable tool not only for cancer patients but for the general public as well. Ms Kelly affirmed that *the European code is a critical piece of information to be delivered in each country, each community, delivered to every individual.*

Dr Tit Albreht, CanCon Project Coordinator from the Slovenian National Institute of Public Health, gave an overview and an update on the first year of CanConl Joint Action, which is now in a very busy period, with a stakeholder forum with 40 participants taking place just a day before the policy conference. CanCon is now in month 15 out of 36, it will finish in February 2017, with a conference hosted under the Maltese EU Presidency which is a great opportunity to stress the political importance of the issue of cancer control – he added that all participants would be welcome to join that conference. All of the technical and coordination activities have been submitted so far as planned. One of the two key deliverables of this Joint action is Guide coordination, it consists of the preparation of a common methodology for Guide chapters, and the activity is coordinated by the Belgium cancer centre. Templates and outlines for chapters are being prepared, as well as a First Quality Assessment Report .There has been a recruitment of experts on the compilation of health policy guides.

Dr Albreht went on to explain the difference between the previous Joint Action, the European Partnership fror Action against Cancer (EPAAC) and Joint Action CanCon: contrary to EPAAC, the set-up is different this time - in EPAAC the Member States had a very important role in monitoring and steering the projects and now in CanCon there is a Member State platform where we it is expected to discuss issues that are not covered by the chapters of a future guide. It has been selected via a vote on specific topics of interest to Members States and these are: National Cancer Control Programmes (run by the National Institute of Public Health in Slovenia), Genomics in Public Health (coordinated by the Belgium Catholic Centre), Disinvestment in Cancer (run by *Catholica University of Rome)* and Cancer Prevention Outcome *(run by La sapienza University in Rome*).

Dr Albreht also outlined the topics of core work packages which are: Integrated cancer control; Community–level Cancer Care; Survivorship and Rehabilitation and Screening.

Community–level Cancer Care, which focuses on after care for patients at primary level, is linked especially to the question of cancer survivorship, notably: what do cancer patients experience after they have received treatment. "*Previously there has been a lot of focus on reducing the mortality, now the focus needs to switch to quality of life of patients*", stressed Dr Albreht. After receiving treatment, cancer patients gradually return to the care of primary care physicians, and this is not always a well prepared transition. Within the work package, following a very successful survey on these issues run among Member States, literature has been prepared and there will be several pilots on mapping and exploring the state of the art of after care of cancer patients at primary level in Slovenia, partly also in Norway and Bulgaria.

In conclusion, Dr Albreht announced that they are preparing a digital information platform for skin cancer which focuses on preventing skin cancer in younger generations, another very important topic.

Prof Michel Coleman from London School of Hygiene and Tropical Medicine delivered a very stimulating keynote presentation, presented cancer survival trends and inequalities across Europe and highlighted the role of European policy. He started by giving clear definitions on what is a distinction between survival and survivorship.

He explained that survival is a key matrix for the success and effectiveness of health care systems, whereas survivorship is the process of living with, though, and beyond cancer.

Pointing to the figures, gleaned from population-based cancer registers all across the world and Europe, and a CONCORD study (Global surveillance of cancer survival) he stressed the wide range in survival/inequality in diagnosis and treatment across countries.

Differences in survival suggest that lessons can be learned, notably from countries with the highest survival rates. The same data also raises questions for further research. One of the key messages stemming out of the study is also that worldwide surveillance is crucial for cancer control policy and cancer registries need political, legislative and financial stability. The latter has been compromised lately with the European Regulation on Data Protection, which brings about several changes related to consent policy and the purpose of processing personal data concerning health for statistical or scientific research purposes. Prof Coleman warned that medical clinical research and disease registries are threatened by insistence on patient consent. European Regulation on Data Protection threatens retrospective clinical research, biobanks and population-based cancer registries. It would not only require patients' informed consent to record their disease in a cancer registry, but it would also require researchers to ask for a patient's specific consent every single time new research is carried out on available data.

In a response as to what is the role for Europe, Prof Coleman gave a few concrete suggestions. He called the MEPs to explain to the public why, despite the underlying principle of consent for data collection, identifiable data must for some purposes be collected without consent, for public health research that harms no-one and potentially benefits everyone. He also suggested the European Commission could survey public attitudes to cancer registration, promote cancer to become a reportable disease as well as to endorse registries as a key instrument in cancer control and to develop a European Cancer Information System.

He proposed that the European Union could reconsider one-time consent for retrospective observational research and arrange derogations from consent for disease registries and public health research, as well as to ensure that registries remain public agencies with public oversight.

In conclusion Prof Coleman championed the idea of creating a new European Centre for Cancer Control, following the example of European Centre for Disease Prevention and Control (ECDC) in Sweden.

Mr Julien Tognetti from the National Institute of Cancer in France, spoke about cancer survivorship in France as a national example, guiding the delegates first through the history of political commitment to cancer control in France with the launch of strongly supported French National Cancer Plans in 2003, 2009 and 2014. Every year, the French National Cancer Institute (INCa), scientific and sanitary agency in charge of coordination of cancer control actions, has to report on the progress achieved to the French President of the Republic.

Major progress was achieved in France with the introduction of the personalized survivorship programme including social and professional rehabilitation in the 3rd National Cancer Plan (2014-2019).

The 3rd Cancer Plan meets ambitious health care objectives, namely to: cure more people, preserve the continuity and quality of life, invest in prevention and research, and optimize the monitoring and the organizations operating in cancer control. Particular attention is given to children and adolescents diagnosed with cancer and their families. Survivorship is specially addressed within the objective of preserving the continuity and quality of life with ensuring integrated and personalized “health pathways” (moving from care pathways to health pathways), taking into account all patients’ and relatives’ needs, starting with the diagnosis, including the adapting of announcement measures and personalized care and survivorship programmes, and later a formal exchange phase at the end of active oncological treatment when the patient continues care with the GP. Special attention is also given to ensuring easier life at home and offering adapted housing solutions, such as improving access to home help, developing housing solutions close to treatment. Empowering of patients with accessible and adapted information and self-management programmes has also been stressed.

In order to reduce risks of long term effects and secondary cancer, preservation of fertility and systematic long term follow up of children and adolescents needs to be ensured. To help people diagnosed to maintain healthy preventative lifestyle, systematic support to wean people off tobacco and better manage alcohol intake and promote physical activity is being encouraged. Another priority has been given to ensure “professional pathways”- enabling the continuation of studies and employment and return to work. There is interesting data for France on how many people lost their job after cancer diagnosis and how many then managed to find work after cancer.

The target for 2020 is to increase by 50% the chances to return to work 2 years after a cancer diagnosis. There is also interesting data for insurance in France for cancer survivors and to improve access to insurance and loans. A memorandum of understanding on the “right to be forgotten” (*droit à l’oubli*) has been signed by the French government and health stakeholders to assist access to loans and insurance.

In conclusion, Mr Tognetti presented survivorship at European level as reflected in the CanCon work package 8, led by INCa. The objective is to develop a European Framework for high-quality cancer survivorship care and rehabilitation that could be promoted at the EU level, including a list of European recommendations, namely on personalized rehabilitation and survivorship care plans. He noted that there is a lot of mutual thinking reflected from the French 3rd National cancer plan in CanCon and vice versa, and that WP8 in CanCon mirrors expectations of the National Cancer Plan. This is the reason Mr Tognetti sees CanCon WP8 as a real opportunity to install a policy dialogue between actions implemented at national level and the recommendations at EU level, a concrete dialogue exercise to improve the implementation of the cancer plan.

Question & Answers Session

During the **question & answers session**, after the keynote speeches**, Prof Francesco de Lorenzo** from the European Cancer Patient Coalition congratulated France on the signing of the Memorandum of Understanding on “the right to be forgotten” and called for the right to be forgotten to be brought at the European level. He also offered his support to Prof Coleman to work together on the issue of how Italy will implement regulation on data protection.

EORTC epidemiologist Ms Lifang Liu echoed the concern of the potentially devastating effect that that the EU Data Protection Regulation would have on cancer registries. Her work is to look into implementation of the drug and to conduct research and since only cancer registries cover real world populations, they are absolutely vital for cancer survivorship support.

Mr Martin Seychell from the European Commission said he was glad to hear data protection issues had been raised as this is one issue that will determine public health in EU in the future. Member States have to take difficult decisions on which health priorities will set in the future. To do so, we need good data on what to prioritise in terms of investment. The health sector is very responsible in the usage of data compared to others.

Ms Joan Kelly from ECL also noted that all the advancements made in cancer control in Ireland, would never have been made without data. Data helps all actors understand the magnitude of what needs to be done, “If *you do not know the size of the problem, how would you fix it.”**

Ms Isabelle Lebrocquy, a cancer survivor from the audience, shared her experience as an initiator of a social legislation in the Netherlands, concerning job loss and long term unemployment of cancer patients. She has set up online surveys to prove the scope of the problem. She fully endorsed the importance of giving up a little privacy to get much needed data and figures, which are necessary to pressure governments to consider changing any policy.

Ms Anastassia Negrouk from EORTC reminded the participants of the public consultation launched by Directorate General Employment of the European Commission concerning long term unemployment. There is no specific reference to cancer, but she invited everybody to respond to the public consultation to raise awareness on this issue.

A Panel Discussion on improving the quality of life of patients and survivors followed, with panelists representing the voice of cancer patients, the European Parliament, cancer leagues and employers.

Prof Francesco de Lorenzo, President of the European Cancer Patients Coalition (ECPC) stressed that rehabilitation and return to “normal life” is a key word in cancer survival.

ECPC has been working hard to convince governments and regions to prioritize rehabilitation for cancer patients, which is different to rehabilitation from other diseases.

Ms Isabelle Lebrocquy, founder of NGO Opuce explained her experience as a cancer patient, she lost her job due to cancer, living in Belgium, The Netherlands and France and experiencing different health and social systems.

She is now preparing an intervention in Holland with two scientists how to help employers and cancer patients. She believes the government should set a good example as an employer and called the European Community to be a role model for employers.

Dr Charles Tannock, Member of the European Parliament (MEP) and Vice President of MEPs Against Cancer stressed that the way identifiable data is gathered, analyzed and used for the proven benefit to individuals and society in disease prevention, protection and effectiveness is a very helpful illustration for anti-EU audiences of how the European Union is adding value in their lives.

His plea as a politician and medical doctor would be to call for every Member State to have a cancer registry.

Mr Hedwig Verhaegen, from “Kom op tegen Kanker “(Stand up to Cancer), the Flemish cancer society, stressed the need for cancer survivors to have access to private insurance and flexibility to return to work. He explained about a campaign his cancer league organised in Flanders to return to work. He noted how essential it is for cancer survivors to return to work, to again regain their place in society. He pointed at the issue of workplace arrangements, and inflexibility of employers when survivors are still struggling with long term effects of cancer treatment. They need to come back to work in stages and not necessarily full time immediately.

Dr. Ulrike Helbig from the German Cancer Society, noted that despite there being 70,000 cancer patients in Germany, there is no existing data on survivors, nor is there a definition on what a cancer survivor is. It is also difficult to agree what are the right questions to ask cancer survivors as well as what is the goal to be achieved. Psycho oncological methods need to be addressed, for example, on how can a patient go back to the doctor ten years after cancer treatment with a problem related to past cancer treatment.

Mr Dimitri Stoquaart, CEO and entrepreneur of a private SME company, shared his own personal battle as a cancer patient himself and as an employer of a young cancer patient, where he does not feel equipped to help his employee to successfully balance rehabilitation and return to work. He stressed that in particular SMEs, which do not have the extensive human resources services that big multinational companies do, need a lot of support themselves to be able to support their employees as much as they would want to.

Key Policy Messages and Recommendations:

- Cancer registries and data collection need to be supported
- Legislation at different levels needs to be addressed, notably on data protection to enable data availability for research in public health
- Politicians need to recognize the added value of investments with clear social and economic added value, which can be facilitated if statistics are available and awareness is raised
- Awareness notably needs to be raised among employers and patients
- SMEs need additional support when helping cancer survivors
- EU can play a key role in leading the way in health policy where important national divergences persist