

# A Patient Advocacy Group Summit, Cancer Care in Turkey and The Society of Breast Health

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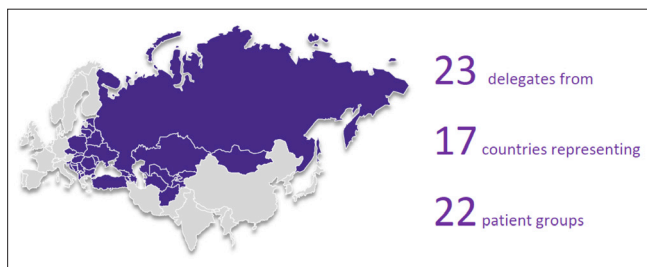
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According to the World Health Organization (WHO), cancer now causes more deaths than all cardiac or all other diseases (1). The number of new cases is expected to rise by about 70% over the next 2 decades. Globally, nearly 1 in 6 deaths is due to cancer, and approximately 70% of deaths from cancer occur in low- and middle-income countries (2). There is a significant disparity in cancer care and outcome of cancer patient results between developed and developing countries. The most important aims of cancer management are prevention, screening, early detection, and effective treatment. In addition to the health care system, patients are the most important stakeholders of cancer care. Patient advocacy groups (PAG) are non-profit, non-governmental (NGO) organizations, and they may play an important role to acquire and protect patients' rights for better cancer management. PAGs can incorporate cancer scientists in a way similar to The Society of Breast Health to perform basic, reliable, and reasonable clinical projects based on the economic, socio-cultural and educational structure of a country. The number of PAGs should be increased and representatives of them should be participated in governmental organizations (such as National cancer Advisory Board, National Cancer Institute, etc.) to advocate and acquire their rights. Their participation absolutely provides integrity in health care systems.

To be a more effective and powerful part of cancer care, PAGs should come together in national and international platforms to share their problems and find solutions. Additionally, expert panelists in this field may explain more useful solutions to increase the benefit of these summits. There was an important patient advocacy group (PAG) summit in Vienna on 15-16, September, 2017. I would like to share my views and opinions about this summit as an invited speaker. Twenty-three delegates from 22 patient-groups representing 17 Central and Eastern European (CEE) countries and seven international experts came together at a first-of-its-kind oncology summit (Figure 1). The aims of the summit were to learn from each other about how to improve cancer care through advocacy in their countries, and to inform, empower and equip patient groups so that they are better able to address the challenges they face. The meeting also encouraged relationship-building and the strengthening of peer-to-peer networks between groups and countries.

The summit objectives were below:

- Bring together the cancer patient community to encourage sharing of experiences and ideas
- Facilitate dialogue and learning about capacity building, communications and effective cancer policy campaigning
- Inform the community about relevant developments in cancer and global standards
- Empower patient advocates to take on old challenges with new insight
- Equip organisation with new skills and knowledge to be more effective.



**Figure 1.** Oncology Collaboration Patient Group Summit brought together 22 patient advocacy groups (PAG) from 17 Central and Eastern Europe Countries in Vienna in September 2017

The summit was designed to support patient groups in the region to share best practice with one another whilst also providing an opportunity to pose questions to an array of oncology and advocacy experts. Survey responses from the attendees highlighted the broad range of skills and experiences the delegates brought to the summit. The delegates were ambitious and passionate about improving cancer outcomes across the Central and Eastern European region. The importance of collaboration became clear through the course of the summit. As did the need for collaboration across patient groups, healthcare professionals, media, government and the pharmaceutical industry to work in partnership towards a common goal.

#### A summit in four sessions

The agenda of the meeting was developed based on the attendee’s feedback, and included four key topics:

- Storytelling and messaging
- Working with social and traditional media
- Engaging with policy influencers
- The power of patient groups

The final session brought the topics together in a workshop where attendees prepared a comprehensive creative campaign to improve cancer care.

These elements defined the four sessions of the summit. Each session featured expert speakers, a relevant case study and an interactive workshop

#### Small countries can make a big difference

Professor Mark Lawler shared his experience in improving cancer care in Northern Ireland through the development of an European Cancer Patient’s Bill of Rights in 2014. Lawler set out the vision for Cancer Control in Europe and outlined the significant disparities between different European countries. He concluded that the European Cancer Patient’s Bill of Rights was a crucial catalyst to “get things done”, and cooperation and a strong common purpose were essential to have among patients and professionals, governments, non-governmental organisations (NGO) and industry. He also reminded us all that small countries like North Ireland could do big things together with NGOs.

#### Landscape of cancer patient advocacy

Professor Richard Sullivan presented the findings from an audit conducted among patient organisations across Central and Eastern European (CEE) countries. Notably, the audit findings from 18 countries revealed that 143 national patient groups were identified and only 54 groups were found to have clear published objectives in oncology at national level and active public profile.

#### Expert media panel

A panel of international experts with experience of working with the media provided insights on engaging media and other relevant channels to engage stakeholders. The panelists explained the positive role of media to increase cancer awareness and obtain better cancer care, and improve the healthcare system in a country. The media can also aid in organizing patient advocacy groups for more effective activities. The panel featured the head of a Polish patient group, a global public health professor, a cancer research professor, a professor of cancer policy and a health journalist specialising on oncology.

#### Oncoalliance and Uchelsda

In the four workshops, the delegates engaged with a fictional patient advocacy organisation, OncoAlliance, on its journey towards better cancer care in the imaginary country of Uchelsda. Delegates learned about the role of stakeholders such as the minister for finance and the potential importance of the President’s wife! At each stage, there were new challenges to overcome as the story took on new challenges to improve cancer care and access.

#### The importance of national cancer policy

To demonstrate the essential role of National Cancer Control Plans (NCCP) in government policy and cancer care, Professor Tit Albreht illustrated that cancer was a major challenge in Europe and CEE countries, touched on the changing cancer outcomes across Europe and explained how patient organisations could play a role in implementing NCCPs. He also stated that Europe had one eighth of the World population and it had one quarter of the global total deaths from cancer. Despite 87% of all countries having a National Cancer Control Plan, this falls to just 54% in CEE with many citing implementation failures. As per the available data, CEE has 32% higher mortality from cancer than Western Europe. According to Professor Albreht, cancers in CEE countries have worse prognosis due to the lack of cancer prevention, late diagnosis, limited access to therapy, financial barriers, lack of cancer registries and national cancer control plans (NCCP).

#### Digital system and working with the media

Following a lively question and answer session on working with the media, Alivia Foundation CEO, Bartosz Polinski, showed delegates what could be achieved by utilising digital presentation of videos in an interactive, fundraising computer game designed by the Alivia Foundation. This campaign uniquely managed to engage young men who were a hard-to-reach audience for many charities.

#### Cancer Care in Turkey and The Society for Breast Health

In this specific summit, I made a presentation on cancer care and the National Cancer Control Program (NCCP) in Turkey. I also explained scientific studies and activities of The Society of Breast Health (MEMEDER) as a founder of this society. Turkey has a population of 80.000.000 and 163.500 new cancer patients in a year. Breast cancer in women (50/100.000), and lung cancer in men (60.4/100.000) are the most frequently seen cancers. The Turkish healthcare system is made up of a combination of compulsory health insurance and private medical practice. While it is possible to access free healthcare, standards and availability change considerably from region to region. Residents that are part of the social security system can get cancer care free of charge at the public and state university hospitals. The first NCCP started in 2008 (Phase I-2008-2013), and the second will be completed in 2018 (Phase II-2013-2018). The NCCP has minimally six pillars (registry, prevention, screening, treatment, advocacy and awareness, and collaboration).

Policy challenges to effective cancer care in Turkey include the increasing population (%13.5/2016), increasing number of cancer patients, aging, geographical, socioeconomic, and educational disparities that make it difficult to deliver homogenous healthcare across regions, westernization of the life style, end extensive tobacco use. Other important barriers include the lack of quality control and standardization among cancer centers, frequent bureaucratic and political changes, heterogeneity in the educational level of population, less awareness of, interest and participation in screening programs, and difficulty in the implementation of screening and treatment guidelines prepared according to national resources.

#### **Steps taken by the healthcare system to overcome those challenges**

Establishment of cancer early diagnosis, screening and treatment centers (KETEM) in Turkey (270 centers in 81 cities), participation of representatives of PAGs in National Cancer Advisory Board (NCAB), and promotion of anti-tobacco and anti-alcohol efforts (smoking is prohibited in indoors areas, and alcohol consumption and sale are also prohibited in some areas) were steps taken by the healthcare system to overcome those challenges. Mobile breast, cervix and colo-rectal cancer screening systems started screening target population, working maternity leave was extended to 10 months.

#### **What did go well in Turkey?**

According to data from the Cancer Control Department of Turkey, active cancer registry program worked well and was extended to the whole country, the number of KETEMs increased from 122 to 270. Additionally, tobacco consumption and incidence of lung cancer decreased, and early stage breast cancer increased in the last decade.

Participation of PAG delegates in NCAB, strong support and commitment from politicians, media, system managers, physicians and scientific environment were also positive steps. The government also increased resources allocated to cancer prevention, screening and treatment. Great efforts were made by the national scientific societies to educate healthcare professionals and target population with aid of postgraduates courses, certification programs, and conferences, and awareness activities.

#### **The Society of Breast Health (MEMEDER-2007–2017)**

The Society of Breast Health is a scientific and social, non-governmental, non-profit patient advocacy group (PAG). It is funded by breast experts, survivors, their relatives and volunteers. The aims of the society are to produce basic clinical trials, to promote breast cancer knowledge and awareness in population, communicate with other international and national societies, institutes, governmental organizations. The other objectives of the society are as follows: to find feasible, reliable, and cost-effective guidelines for breast cancer (BC) screening, diagnosis and treatment suitable for national infrastructure and limited resources, and to share and convince system providers to implement results of clinical trials.

#### **Completed or ongoing projects of the society**

To conduct a survey on breast cancer awareness and knowledge in Turkish women (3) and BC treatment delay in Turkey and 11 Eastern European Countries (4-5), Bahcesehir organized a population based BC Mammography Screening Project (6-8), i.e., BC Registry Project (2005-2017, 25.000 BC patients registered). Many BC awareness projects were among the most important projects conducted by the Society of Breast Health. Since half of the BC patients in the registry program and Bahcesehir Screening Project were under 50 years old, The Cancer Control Department decreased screening age from 50 to 40 years in Turkey.

#### **Five blind men and an elephant**

Kawal dip Sehmi, CEO of the International Alliance of Patient Organisations (IAPO) focused on a grassroots movement which has grown its membership globally. Sehmi reminded delegates of the tale of five blind men and an elephant and the importance of collaboration between patient organisations and stakeholders to get the full picture and improve cancer care for patients everywhere.

#### **Developing a campaign and delegates' ideas**

Throughout the workshops, delegates were tasked with developing plans for OncoAlliance given the challenges presented in the case study. The fourth and final workshop involved developing a comprehensive campaign for OncoAlliance. Whilst the exercise focused on how the fictional patient group, based in Ucheldsa, would campaign to improve cancer outcomes following the development of a National Cancer Control Programme, each of the breakout groups arrived at very different conclusions.

The structure of the summit was designed so that delegates would be introduced to several disciplines for achieving sustainable and measurable change throughout the two days. The concluding workshop worked through creative campaign development, drawing upon all three previous workshop sessions. Each breakout group presented a summary of a campaign. Notably, each took equally valid, but quite different routes.

The first one focused on the need for a registry to gather the essential evidence. The second one noted the importance of early detection with awareness and screening programs. The third one employed political pressures to drive rapid change, and then drew upon celebrity and mass media to engage the public in the priorities for a new NCCP.

#### **Conclusions**

Cancer incidence and mortality rates have been increasing in Turkey and other developing countries. Cancer patients have a relatively advanced stage at diagnosis due to the lack of national cancer control plans or difficulty in the implementation of available plans. There are many policy challenges to obtain effective cancer care in spite of steps taken to overcome them. PAGs such as The Society of Breast Health can provide both advocacy and produce clinical trials and establish guidelines according to the country's social, cultural factors and economic resources. The Board of Directors of PAGS should include active cancer experts, survivors, and volunteers and they should participate in the healthcare system to explain their problems and solutions so that they can be easily solved. Every country has a national cancer control plan (NCCP), and healthcare system partners should strictly adhere to and follow this plan without any compromise.

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