Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries

PRESENTATION OF THE RESULTS

1. Patient relevant outcomes of cancer care survey in the Region of the Central and Eastern Europe (CEE)
2. Personalized healthcare
Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries

Ivica Belina, president of Coalition of Associations in Healthcare
How the JACPO meeting came to be?

<table>
<thead>
<tr>
<th>No country can fight cancer by it self!</th>
</tr>
</thead>
<tbody>
<tr>
<td>High cancer incidence and cancer mortality throughout the countries of the CEE region</td>
</tr>
<tr>
<td>Disparities in health literacy, engagement of cancer patient organizations, advocacy</td>
</tr>
<tr>
<td>Disparities in cancer care</td>
</tr>
<tr>
<td>We wanted to share best practices, knowledge, and start common activities</td>
</tr>
</tbody>
</table>

Let's make Cancer Partnership work!
How the survey came to be?

Countries of CEE region are showing significant increase of cancer incidence and cancer mortality.
How the survey came to be?

TIMELINE

**January 2019**

The first regional patient relevant outcomes of cancer care survey started in January 2019 in 12 countries!

**June 2018**

The idea was born in June 2018, during the 2nd Joint Action of Cancer Patient Organizations in CEE Countries (JACPO) meeting in Opatija, Croatia.

**June 2019**

The results will be presented on 3rd Joint Action of Cancer Patient Organizations in CEE Countries (JACPO) meeting from June 17th to June 19th 2019 in Croatia.

Please promote the survey on your website, social networks and platforms survey.onkologija.hr
What we wanted to achieve with the survey?
Number of participants per capita

SURVEY UTILIZATION PER CAPITA (100,000)

- Albania: 10%
- Bih: 9%
- Bulgaria: 3%
- Croatia: 3%
- Czech Republic: 13%
- Hungary: 10%
- North Macedonia: 10%
- Poland: 3%
- Romania: 1%
- Serbia: 7%
- Slovenia: 18%

3rd JACPO June 18th – June 19th 2019
Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries

1. Patient relevant outcomes of cancer care survey in the Region of the Central and Eastern Europe (CEE)
2. Personalized healthcare

assist. prof. Slavica Sović MD, PhD, School of Medicine, University of Zagreb

3rd JACPO June 18th – June 19th 2019
Are you filling in this questionnaire for yourself, or on behalf of somebody else? (N = 16458)
What is your/person on whose behalf you are filling the questionnaire gender? (N = 16458)
What is your/person on whose behalf you are filling the questionnaire gender? (N = 16458)
Participants by Residence Country (N = 16458)
What type of cancer were you first diagnosed with? (N = 16458)
What type of cancer were you first diagnosed with? (N = 16458)
How was your cancer diagnosed? (N = 16458)
Diagnose of cancer and cancer treatment - breast cancer

Figure 7. How was your breast cancer diagnosed? (N = 7378)
How was your colon cancer diagnosed? (N = 1735)

<table>
<thead>
<tr>
<th>Country</th>
<th>Screening program</th>
<th>Screening program for an unrelated health problem</th>
<th>I visited doctor because I felt that something is wrong with me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>87</td>
<td>13</td>
<td>96</td>
</tr>
<tr>
<td>BiH</td>
<td>96</td>
<td>3</td>
<td>98</td>
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<tr>
<td>Bulgaria</td>
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<td>8</td>
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<tr>
<td>Czechia</td>
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<td>71</td>
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<td>13</td>
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<td>North...</td>
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<td>29</td>
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</tr>
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<td>Slovakia</td>
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<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Slovenia</td>
<td>27</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3rd JACPO June 18th – June 19th 2019
Diagnose of cancer and cancer treatment-time for diagnosis

After first seeing a doctor about the health problem caused by your cancer, how long did it take to be diagnosed with cancer? (N = 16458)

3rd JACPO June 18th – June 19th 2019
After you were diagnosed with cancer, how long did you wait for the first treatment?

(N = 16458)

3rd JACPO June 18th – June 19th 2019
What was your first treatment?

- Surgery
- Chemotherapy
- Radiotherapy
- Immunotherapy
- Biological therapy
- New medicines through clinical trials
- Hormones therapy
- Supportive therapy
- Don't know/ don't remember
- Not applicable

3rd JACPO June 18th – June 19th 2019
Diagnose of cancer and cancer treatment - advanced disease

Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?
(N = 16458)

3rd JACPO June 18th – June 19th 2019
When you were first told that you had cancer, had you been told you could bring a family member or friend with you? (N = 16458)

3rd JACPO June 18th – June 19th 2019
How do you feel about the way you were told you had cancer? (N = 16458)
Before your cancer treatment started, were your treatment options explained to you? (N = 16458)

<table>
<thead>
<tr>
<th>Country</th>
<th>Do not know</th>
<th>There was only one type of treatment</th>
<th>Yes, completely</th>
<th>Yes, to some extend</th>
<th>No</th>
</tr>
</thead>
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<td>8%</td>
<td>2%</td>
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<tr>
<td>BiH</td>
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<td>32%</td>
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<tr>
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<tr>
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<tr>
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<tr>
<td>ROMANIA</td>
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<td>SLOVAKIA</td>
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<td>8%</td>
<td>2%</td>
<td>1%</td>
<td>6%</td>
</tr>
</tbody>
</table>

3rd JACPO June 18th – June 19th 2019
Before your cancer treatment started, how many conversations did you have with the doctor who runs your treatment? (N = 16458)
Diagnose of cancer and cancer treatment-treatment plan

Figure 18. Have you been given a cancer treatment plan? (N = 16458)
Diagnose of cancer and cancer treatment- side effects

Were the possible side effects of treatment(s) (short term and long term) explained in a way you could understand? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Diagnose of cancer and cancer treatment-side effects management

Were you offered practical advice and support in dealing with the side effects of your treatment(s)?

3rd JACPO June 18th – June 19th 2019
Diagnose of cancer and cancer treatment decisionmaking

3rd JACPO June 18th – June 19th 2019

Were you involved as much as you wanted to be in decisions about your care and treatment?
Support to patients and caregivers- day to day activities

Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers - financial benefits

Did hospital staff give you information about how to get financial help or any benefits you might be entitled to? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers- worries

During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears? (N = 16458)
Support to patients and caregivers - social services

During your cancer treatment, and once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps, psychological support)? (N = 16458)
Were you given clear written information about what you should or should not do after leaving hospital? (N = 16458)

<table>
<thead>
<tr>
<th>Country</th>
<th>Do not know</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
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<td>7%</td>
</tr>
<tr>
<td>BiH</td>
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<td>12%</td>
</tr>
</tbody>
</table>

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers-who to call?

Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers - HCP communication

Did groups of doctors and nurses talk in front of you as if you weren’t there? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers - trust

Who gave you most confidence and most trust?
(N = 16458)

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers-out of pocket costs

If you paid for any of your cancer care and treatment yourself, why was this? (N = 16458)
Did you buy any alternative preparations or pay for any alternative treatments? (N = 16458)
Support to patients and caregivers - alternative treatments

If you bought some alternative treatments, or pay for some alternative treatments, did you inform your doctor about it? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Support to patients and caregivers- financial burden

Do you feel that your cancer care is a financial burden for your family? (N = 16458)
Quality of life-working status

What is your working status since you were diagnosed or treated? (N = 16458)
Quality of life-support of your working environment

Do you have the support of your working environment since you were diagnosed or treated?
Can you talk openly about your disease with your friends and family members? (N = 16458)
Has your daily routine changed a lot since you were diagnosed with cancer? (N = 16458)
How would you describe your management of treatment side-effects (nausea, fatigue, skin changes, loss of hair, pain, loss of appetite …)? (N = 16458)
Quality of life- influence of treatment side-effects

Have you experienced the influence of treatment side-effects on your every-day life? (N = 16458)
Palliative care in advanced disease

To what extent would you agree or disagree with the following statement about death? (N=11 628)

*We don’t talk about death and dying enough in this country.*
Overall experience with cancer care

During the whole of your care and treatment for cancer, how often were appointments cancelled by the hospital or clinic you were due to attend? (N = 16458)

3rd JACPO June 18th – June 19th 2019
Overall experience with cancer care (3)

Kruskal-Wallis ANOVA test:
\[ H(11, N=16458) = 662.62; P < 0.001 \]

Figure 83. Distribution of overall score (How would you rate your cancer care?) by Country! (N = 16458)

Table 1. Results of the multiple comparisons of the distribution of overall score (How would you rate your cancer care?), Kruskal-Wallis ANOVA TEST

*Countries in each row do not differ one from each other in distribution of overall score (How would you rate your cancer care?)
Health care professionals give confidence and trust to participants and caregivers

Processes of health care to be improved:
• Delivering bad news
• Waiting time
• Providing information about treatment
• Providing information about health care and social care support
• Health service and social service support (for example, district nurses, home helps, psychological support)
## Conclusions (2)

<table>
<thead>
<tr>
<th>Diagnose influence daily routine</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is financial burden for participant and family</td>
</tr>
<tr>
<td>Social networks support is welcome</td>
</tr>
</tbody>
</table>

![Social networks support](image-url)