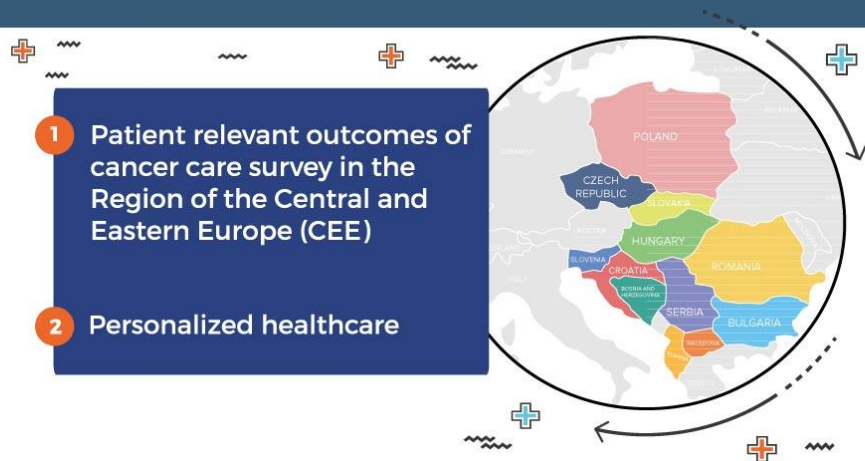


Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries



3. Meeting of cancer patient advocates, June 17. - 19. 2019, in Zagreb, Croatia



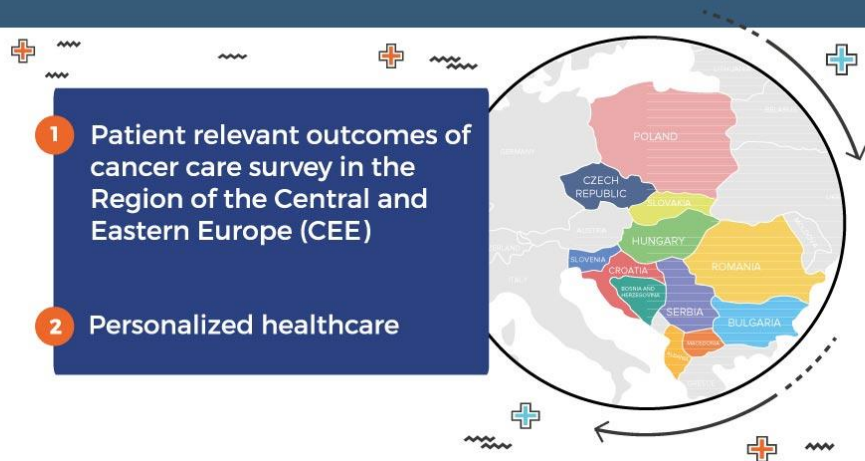
PRESENTATION OF THE RESULTS

Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries



3. Meeting of cancer patient advocates, June 17. - 19. 2019, in Zagreb, Croatia



Ivica Belina, president of Coalition of Associations in Healthcare

How the JACPO meeting came to be?

No country can fight cancer by it self!

High cancer incidence and cancer mortality throughout the countries of the CEE region

Disparities in health literacy, engagement of cancer patient organizations, advocacy

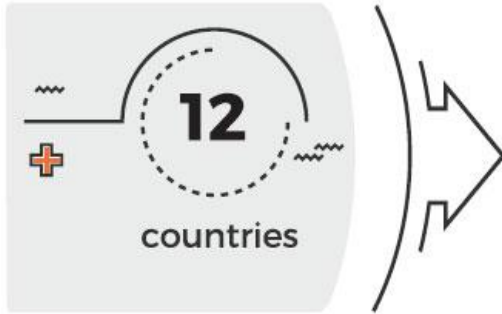
Disparities in cancer care

We wanted to share best practices, knowledge, and start common activities



How the survey came to be?

PARTNERSHIP

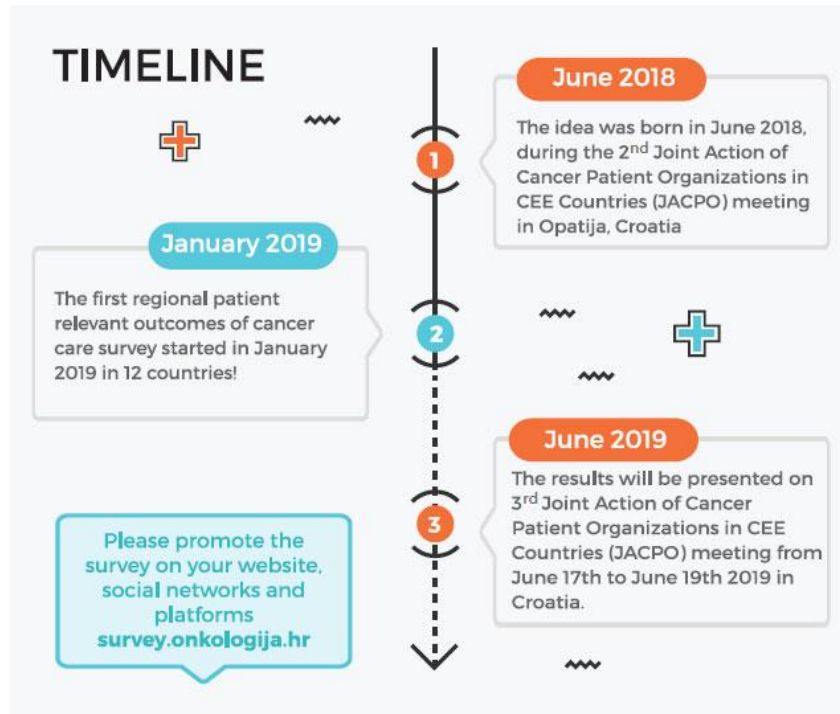


- Albania
- Bulgaria
- Bosnia & Herzegovina
- Croatia
- Czech Republic
- Hungary
- Macedonia
- Poland
- Romania
- Serbia
- Slovakia
- Slovenia

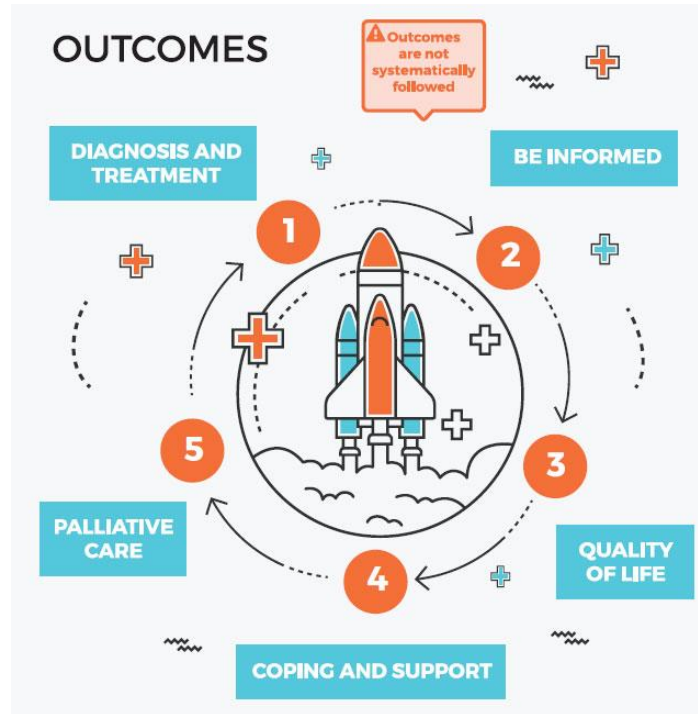


Countries of CEE region are showing **significant increase of cancer incidence and cancer mortality.**

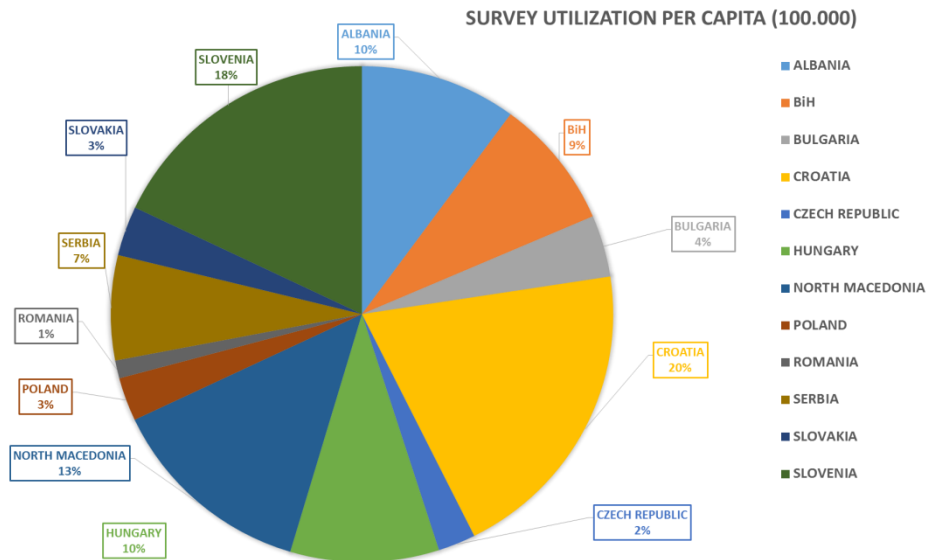
How the survey came to be?



What we wanted to achieve with the survey?



Number of participants per capita

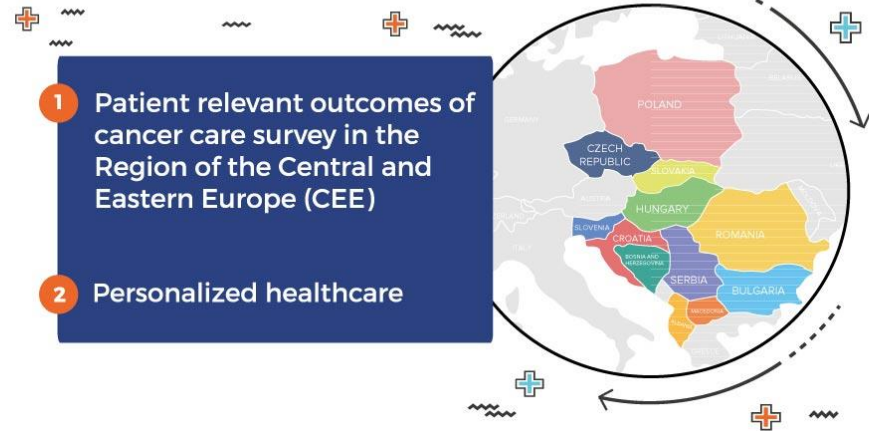


Making the Cancer Partnership work

3rd Joint Action of Cancer Patient Organizations in CEE countries

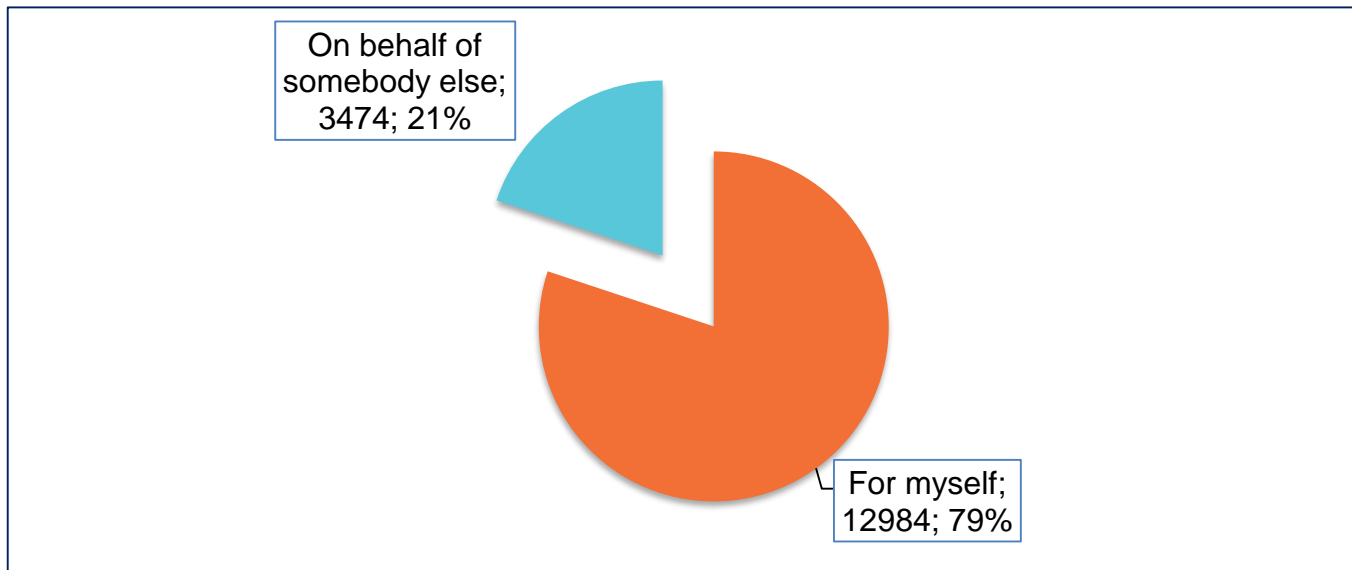


3. Meeting of cancer patient advocates, June 17. - 19. 2019, in Zagreb, Croatia



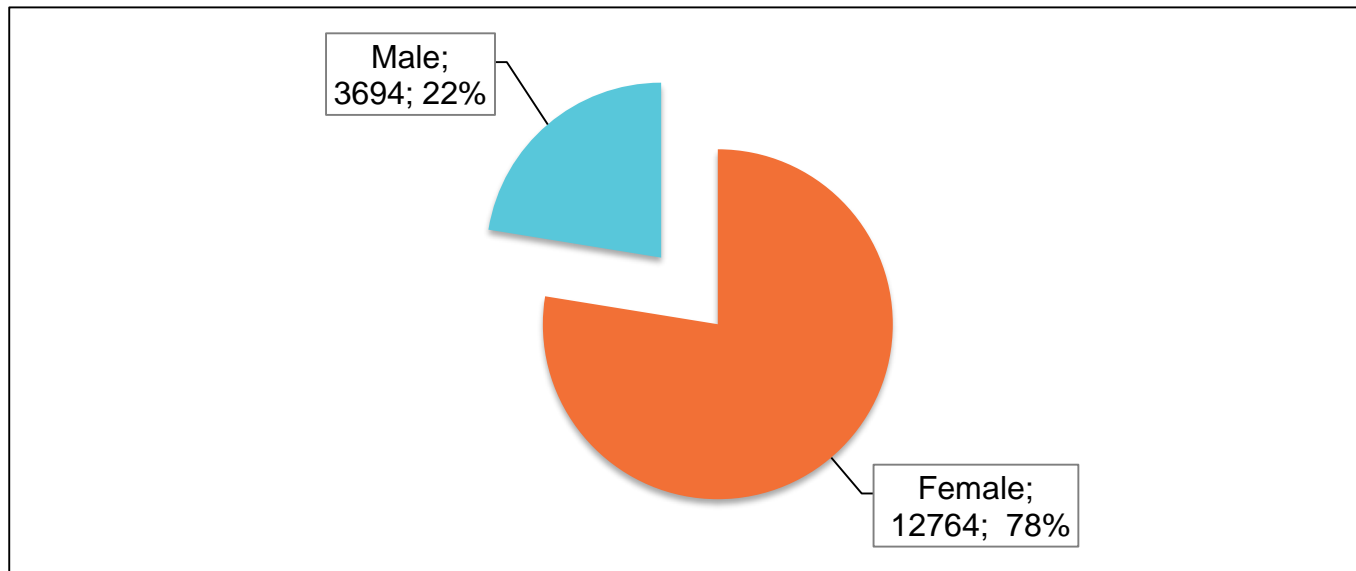
assist. prof. **Slavica Sović MD, PhD**, School of Medicine,
University of Zagreb

Personal Information



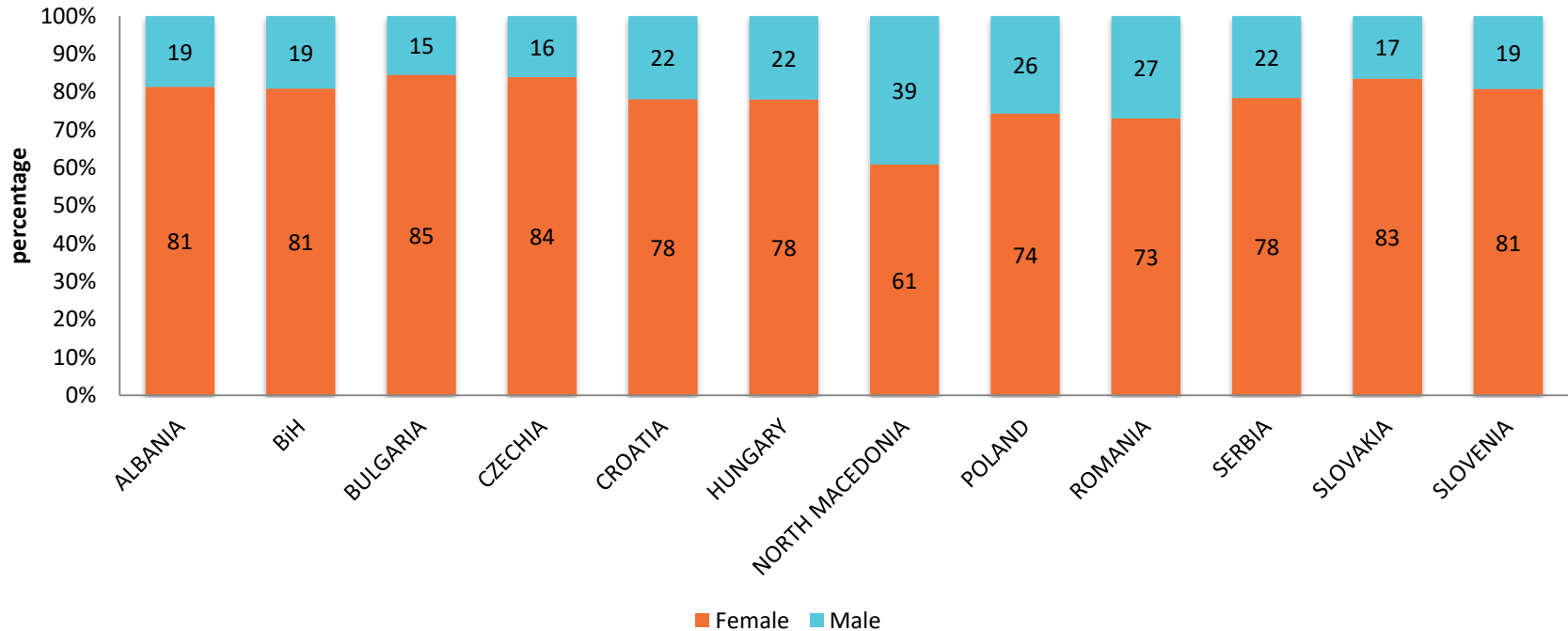
Are you filling in this questionnaire for yourself, or on behalf of somebody else? (N = 16458)

Personal Information- gender



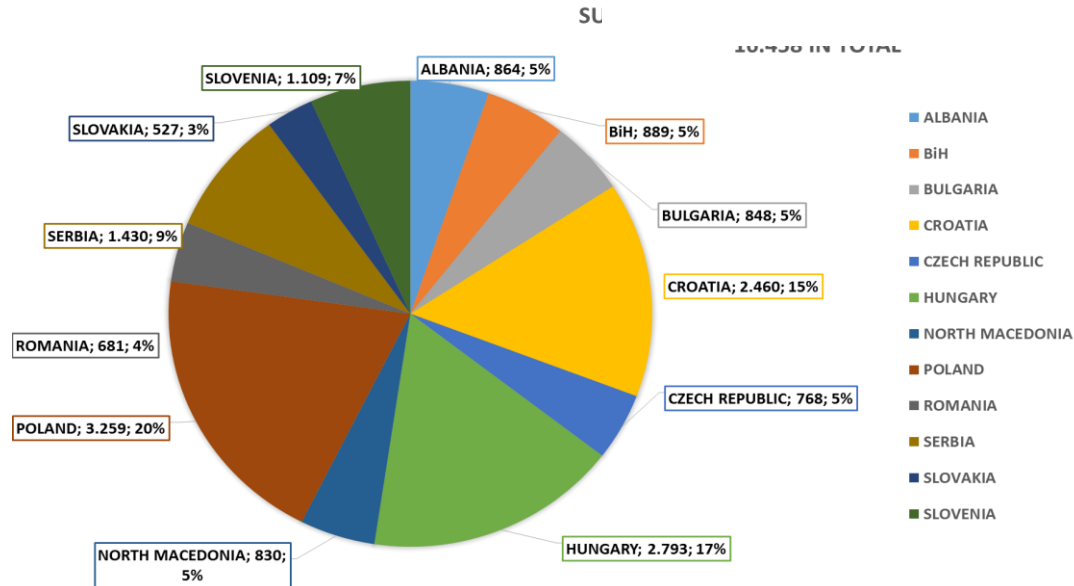
What is your/person on whose behalf you are filling the questionnaire gender? (N = 16458)

Personal Information- gender



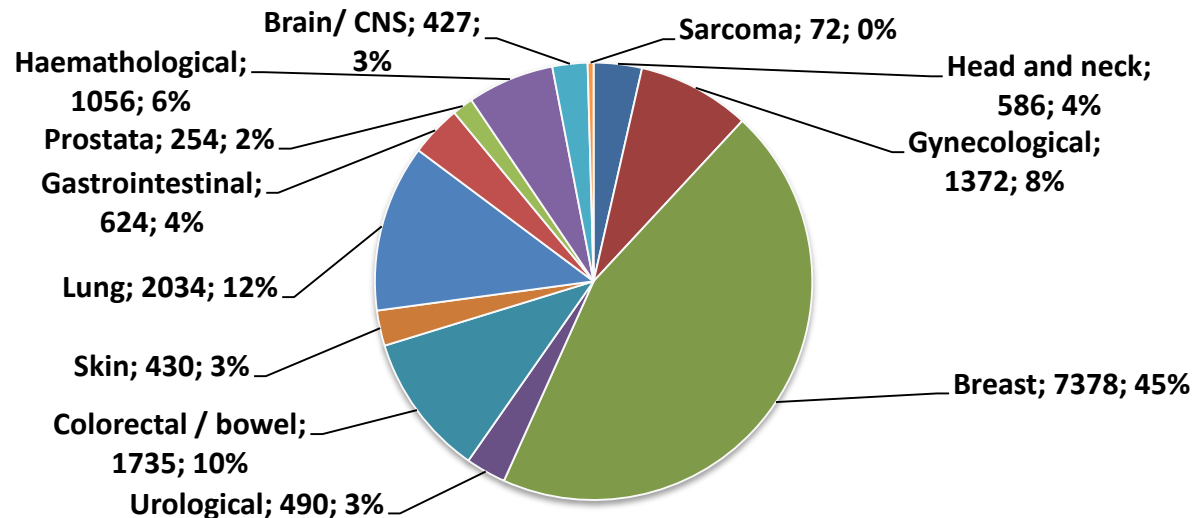
What is your/person on whose behalf you are filling the questionnaire gender? (N = 16458)

Personal Information- Participants by Country



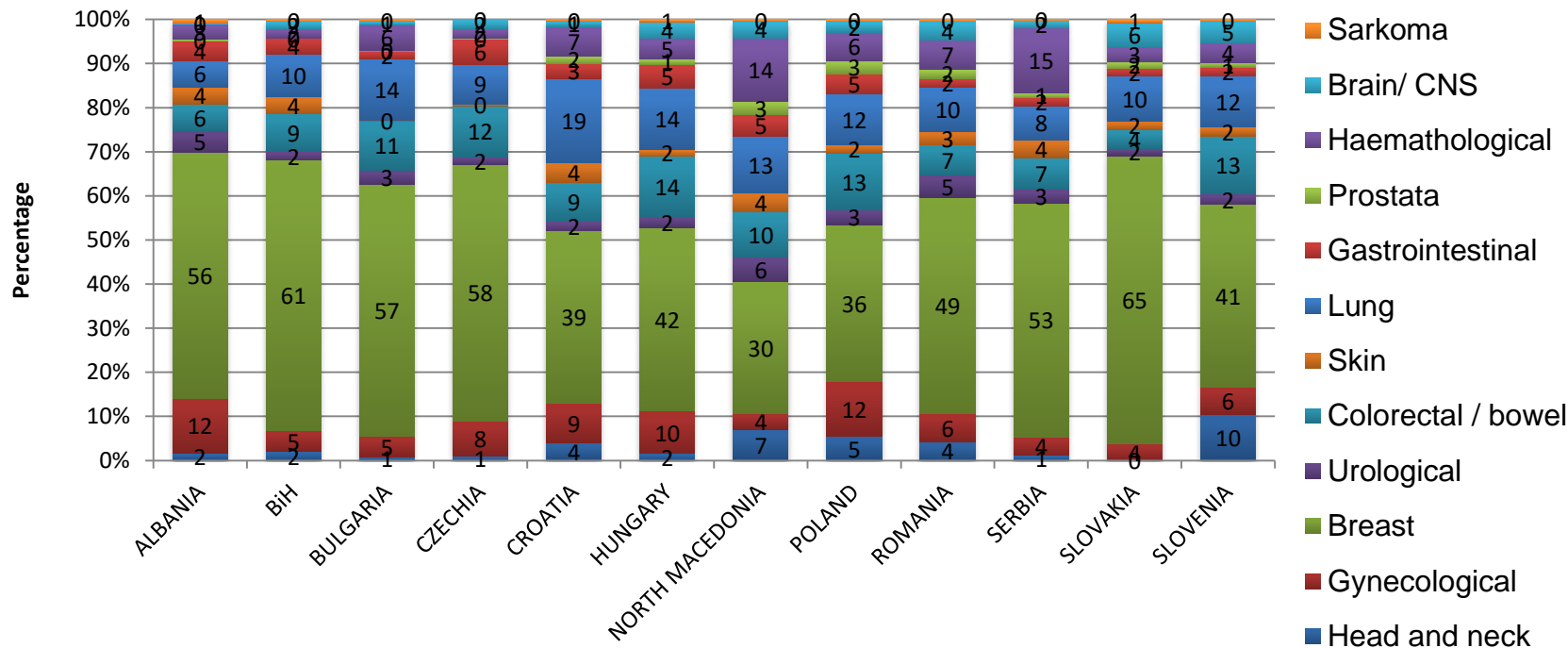
Participants by Residence Country (N = 16458)

Personal Information- type of cancer



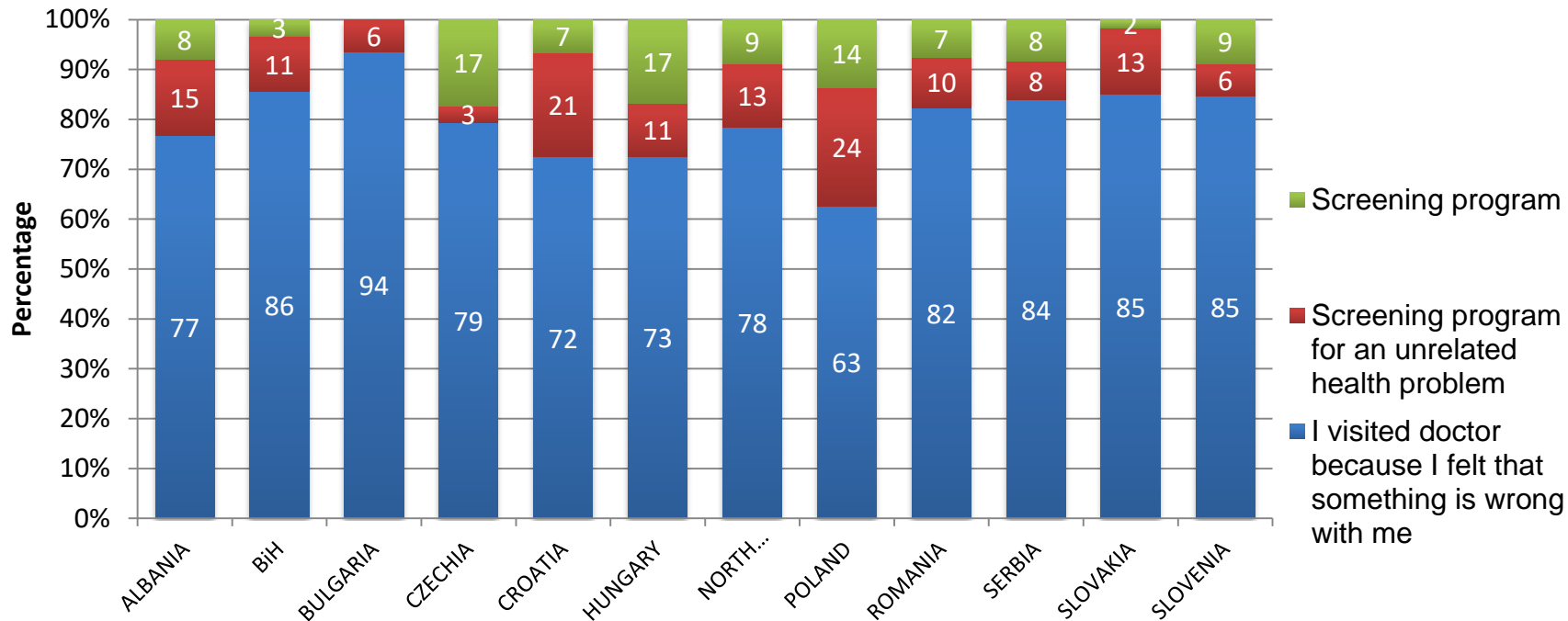
What type of cancer were you first diagnosed with? (N = 16458)

Personal Information- type of cancer



What type of cancer were you first diagnosed with? (N = 16458)

Diagnose of cancer and cancer treatment



How was your cancer diagnosed? (N = 16458)

Diagnose of cancer and cancer treatment- breast cancer

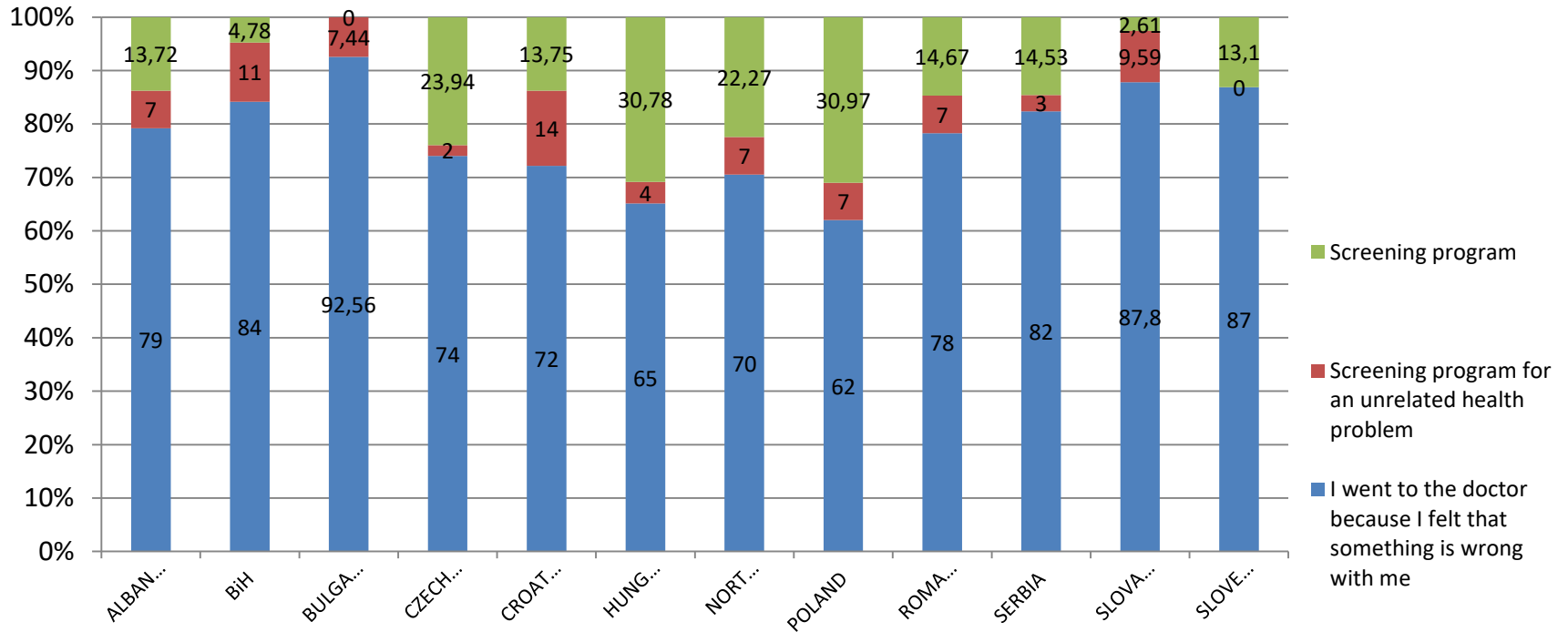
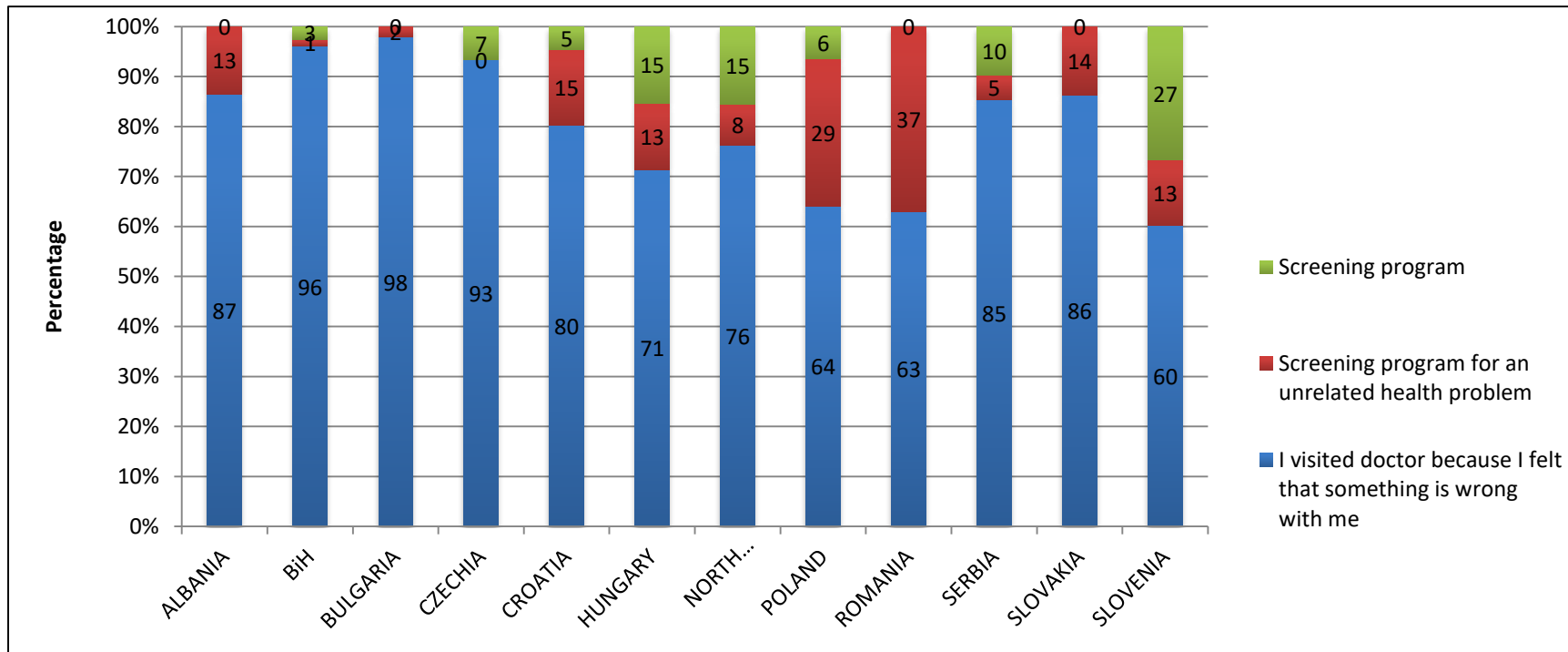


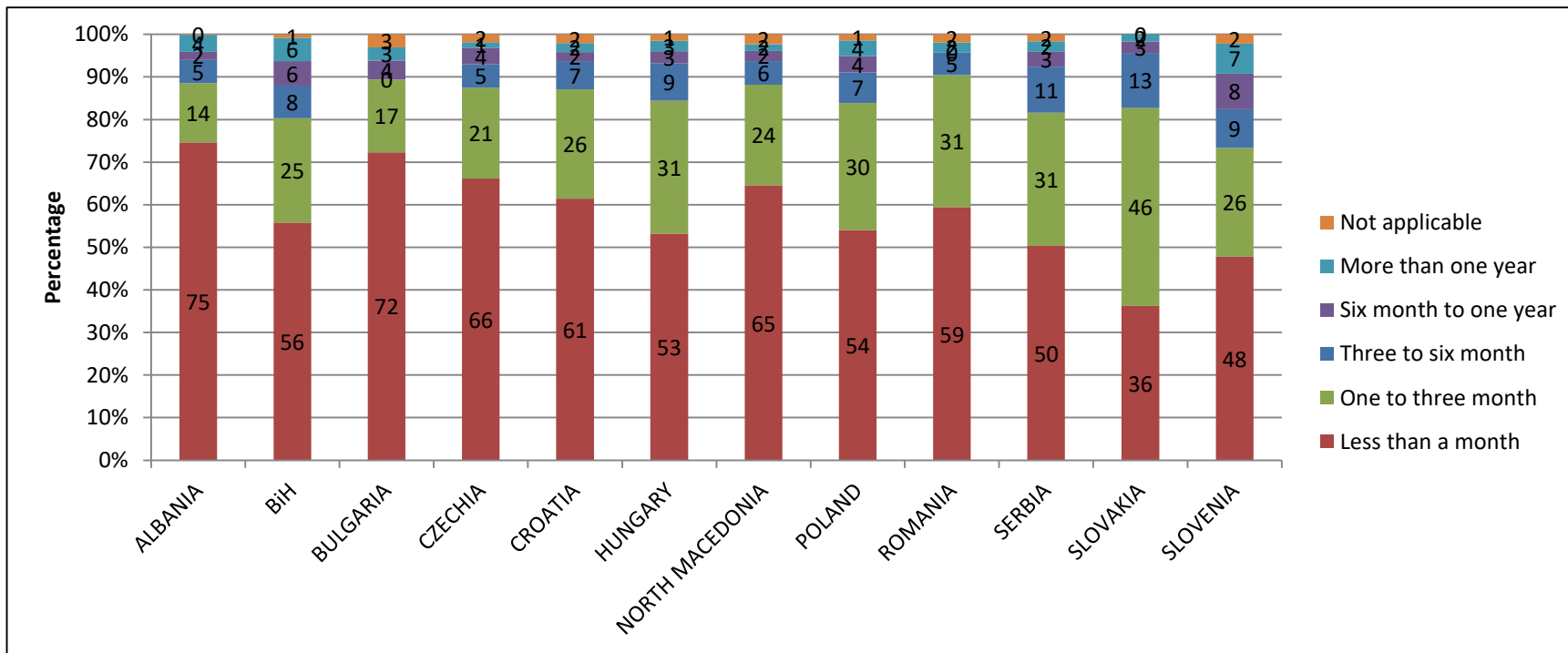
Figure 7. How was your breast cancer diagnosed? (N = 7378)

Diagnose of cancer and cancer treatment-colon cancer



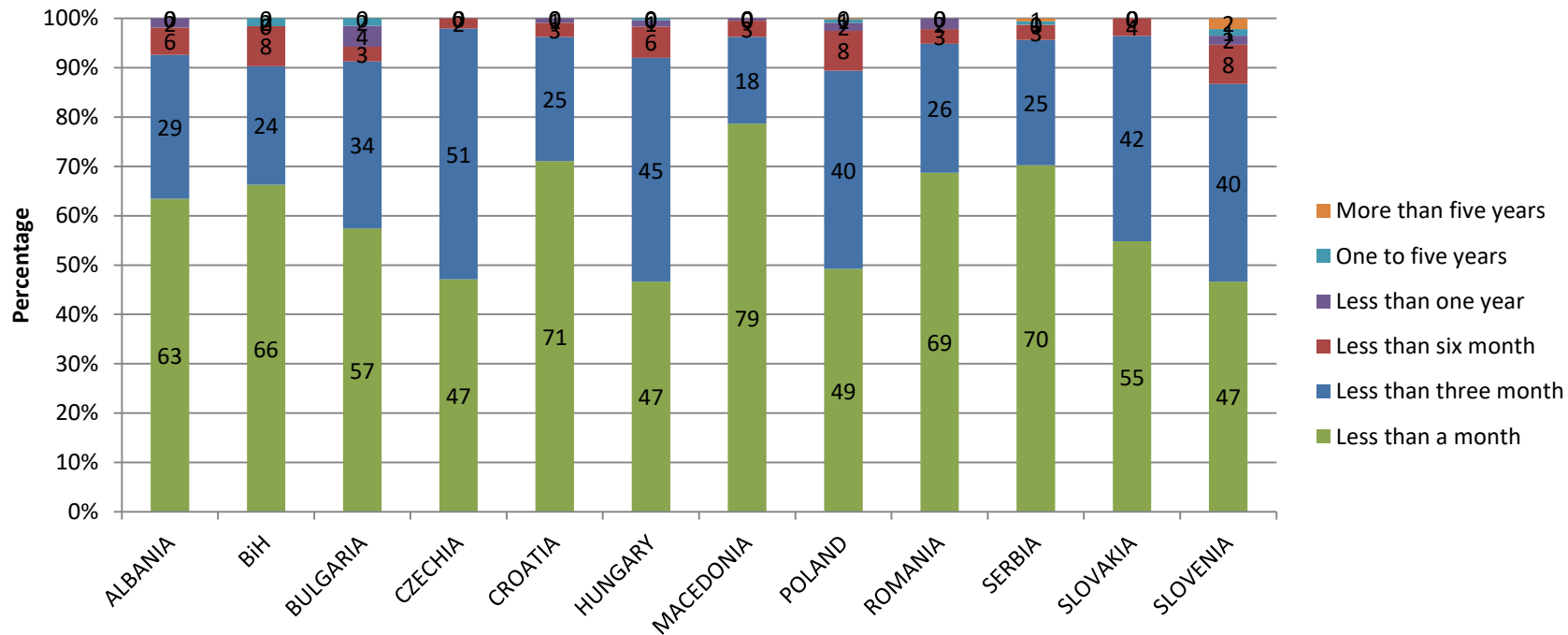
How was your colon cancer diagnosed? (N = 1735)

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)

Diagnose of cancer and cancer treatment- first treatment

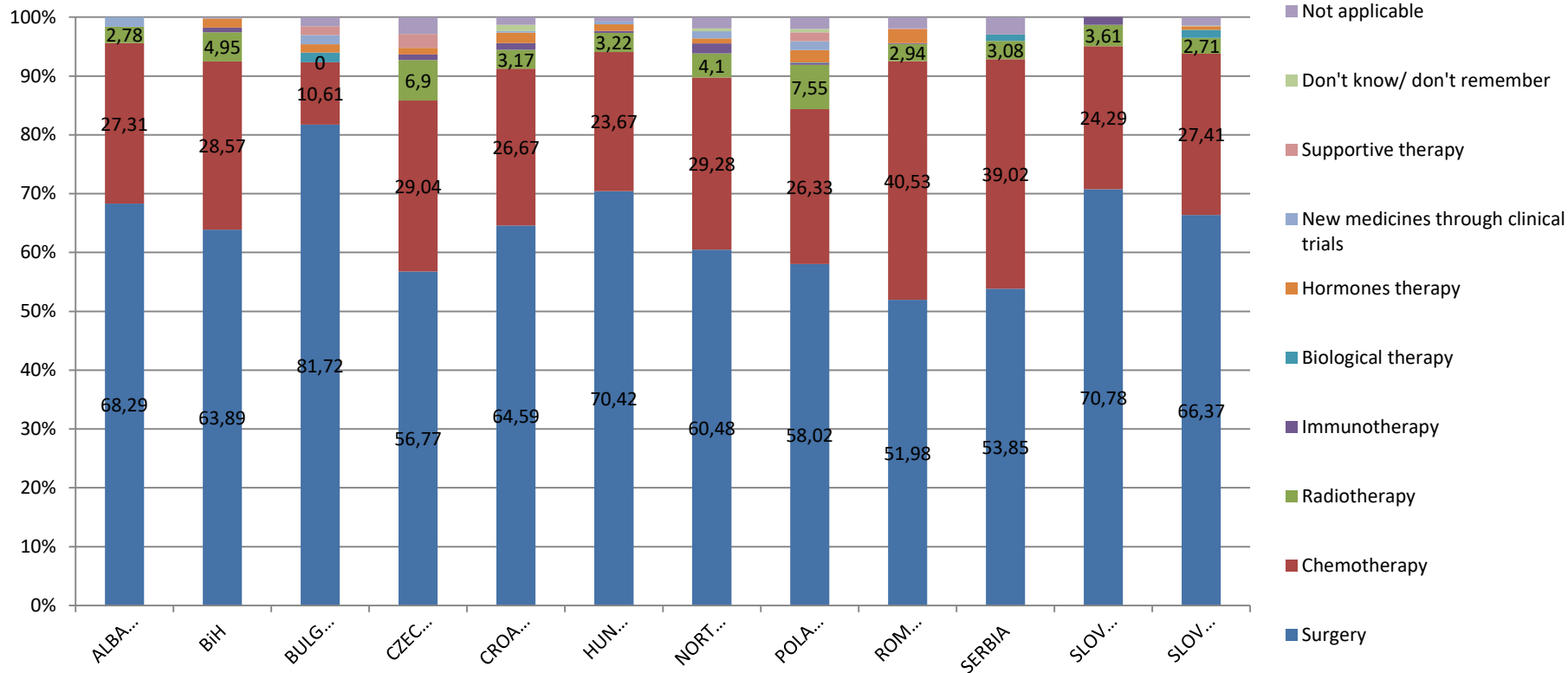


After you were diagnosed with cancer, how long did you wait for the first treatment?

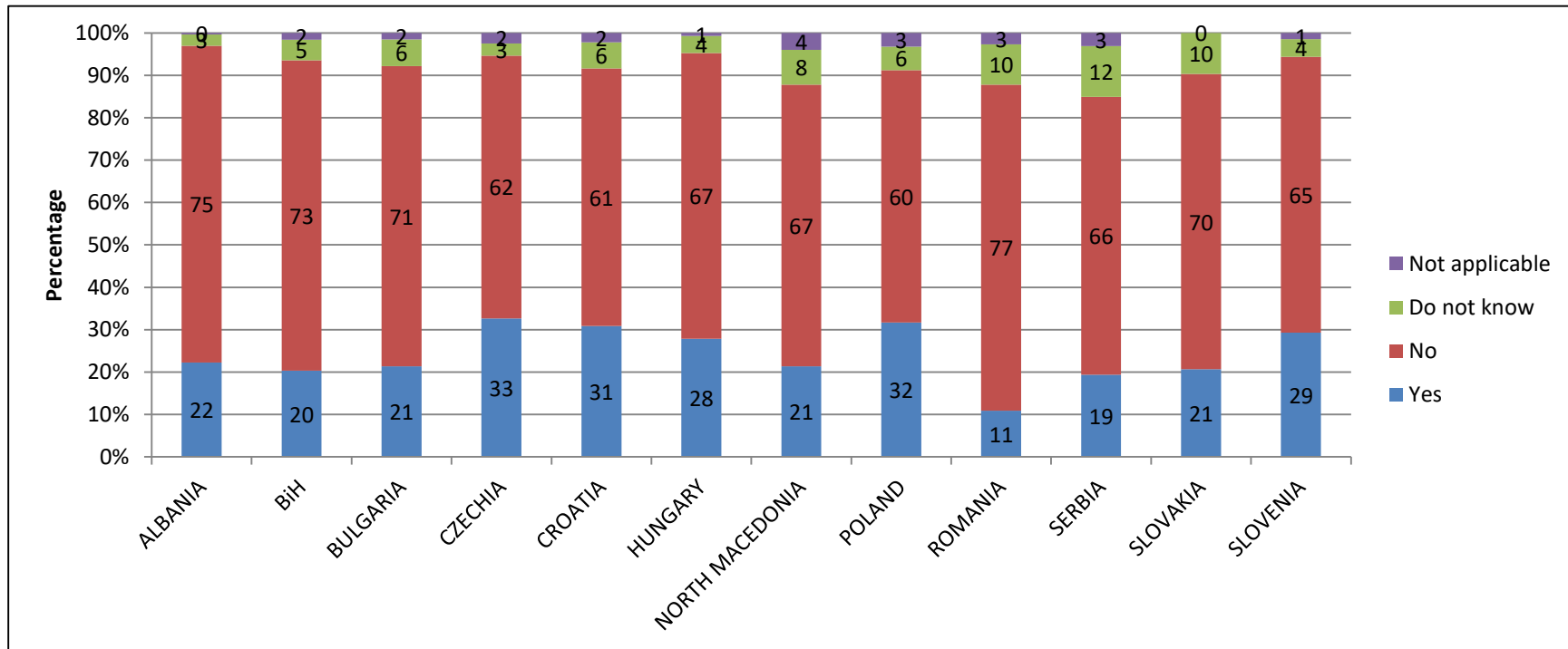
(N = 16458)

3rd JACPO June 18th – June 19th 2019

What was your first treatment?

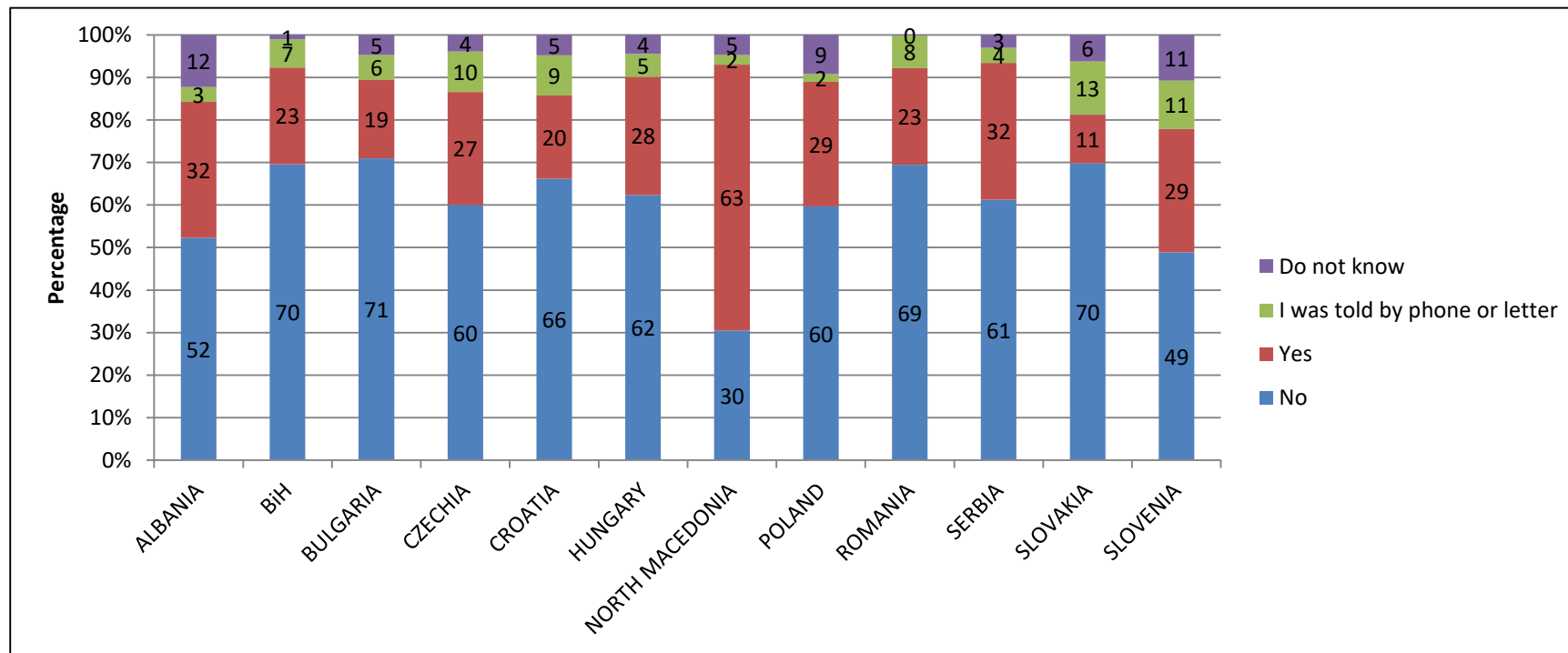


Diagnose of cancer and cancer treatment- advanced disease



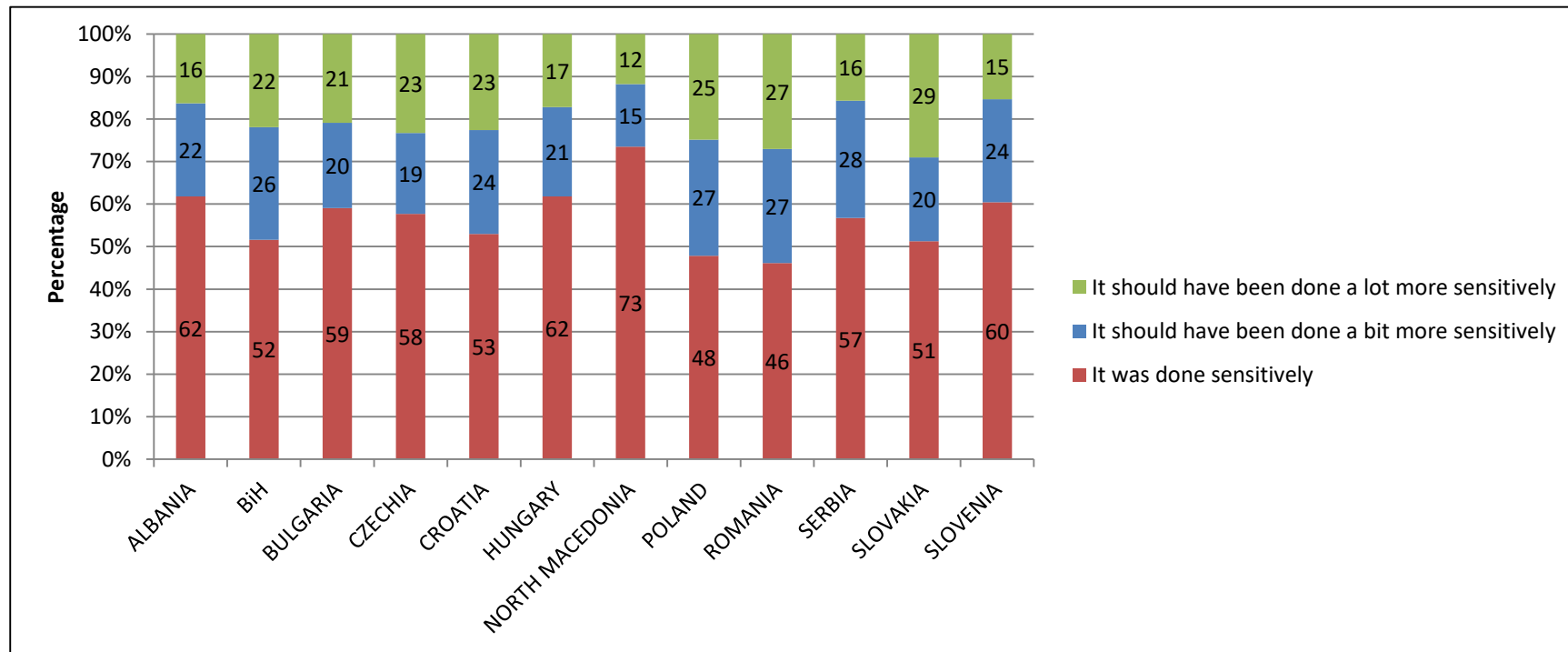
Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?
(N = 16458)

Diagnose of cancer and cancer treatment-support



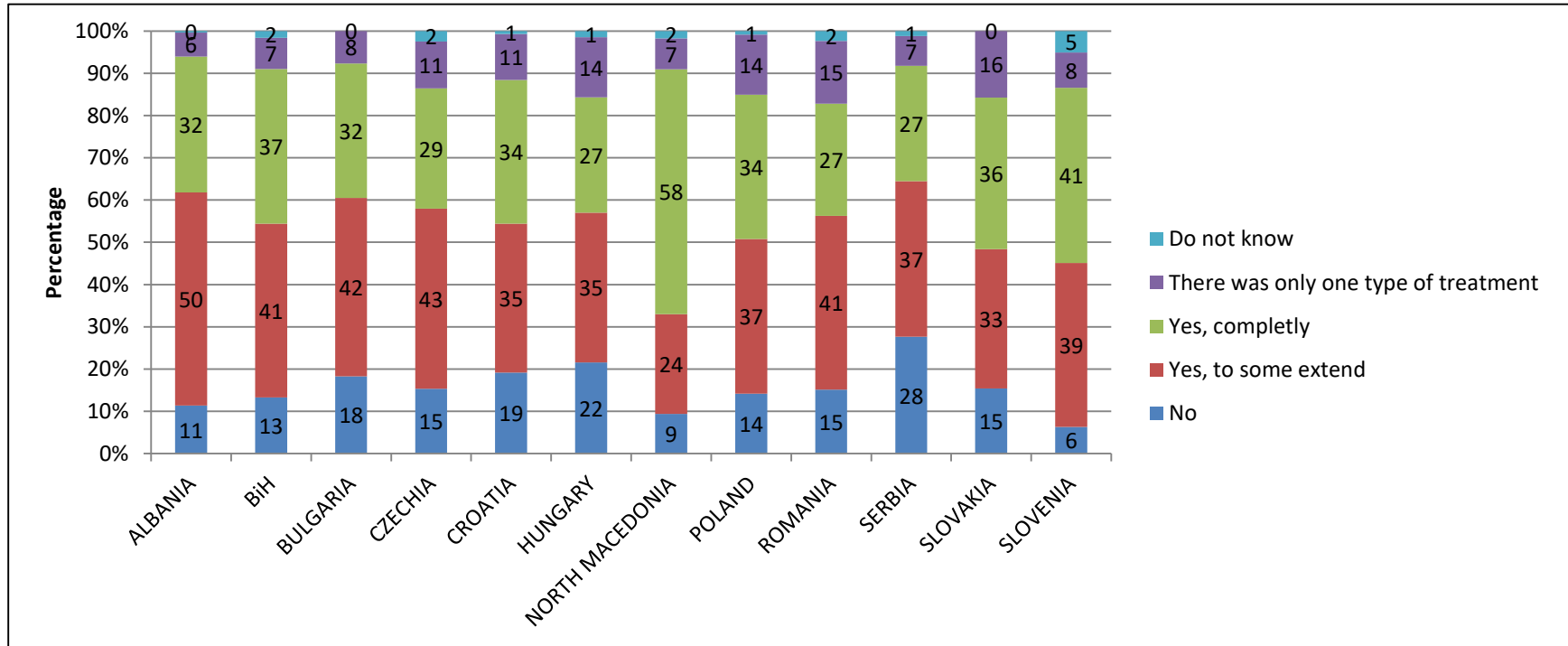
When you were first told that you had cancer, had you been told you could bring a family member or friend with you? (N = 16458)

Diagnose of cancer and cancer treatment-diagnosis communication



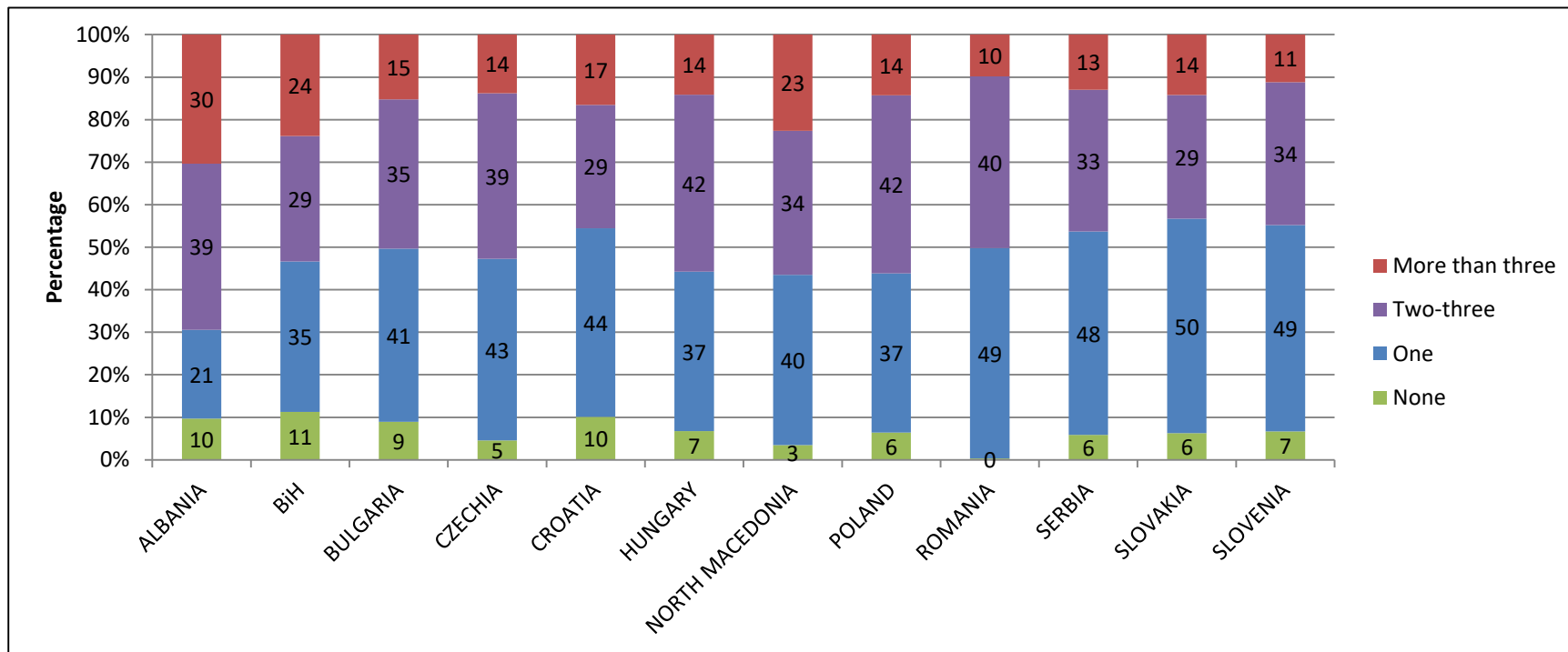
How do you feel about the way you were told you had cancer? (N = 16458)

Diagnose of cancer and cancer treatment- treatment options



Before your cancer treatment started, were your treatment options explained to you? (N = 16458)

Diagnose of cancer and cancer treatment-doctor communication



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

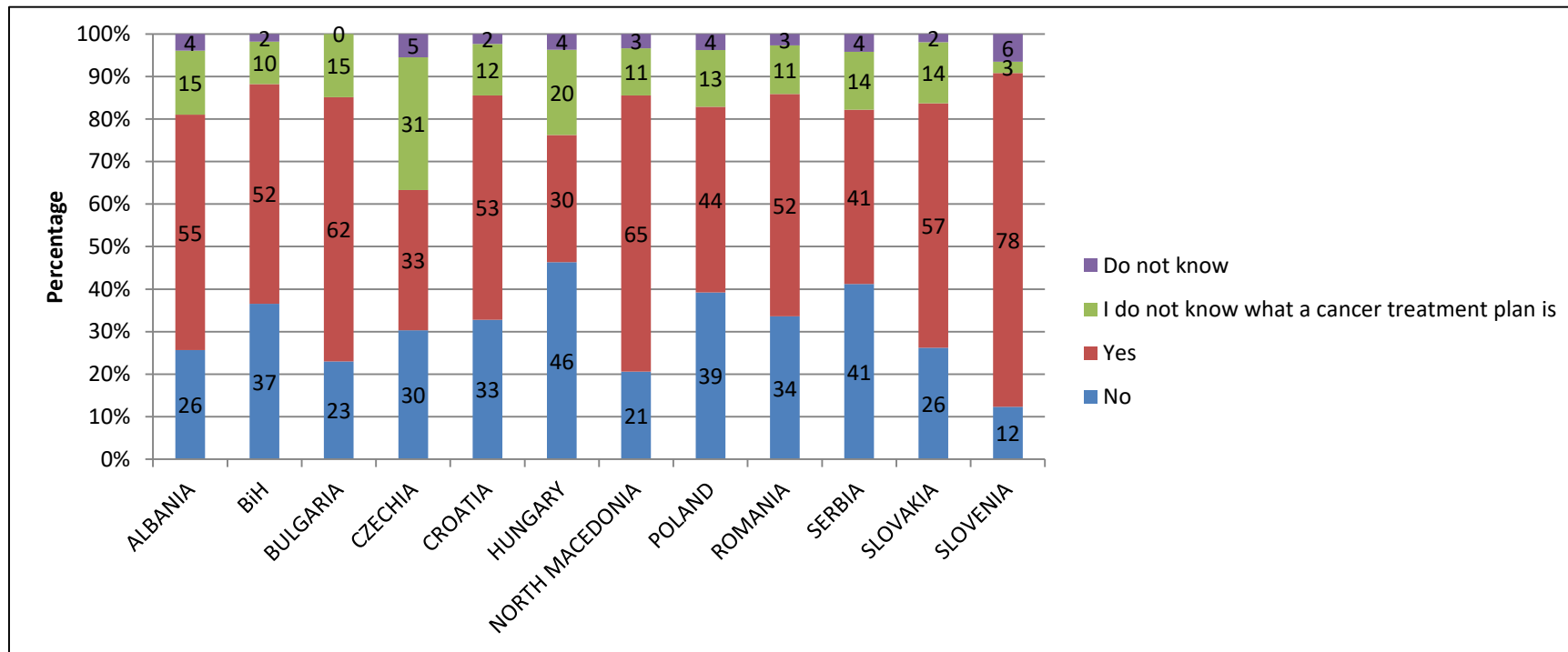
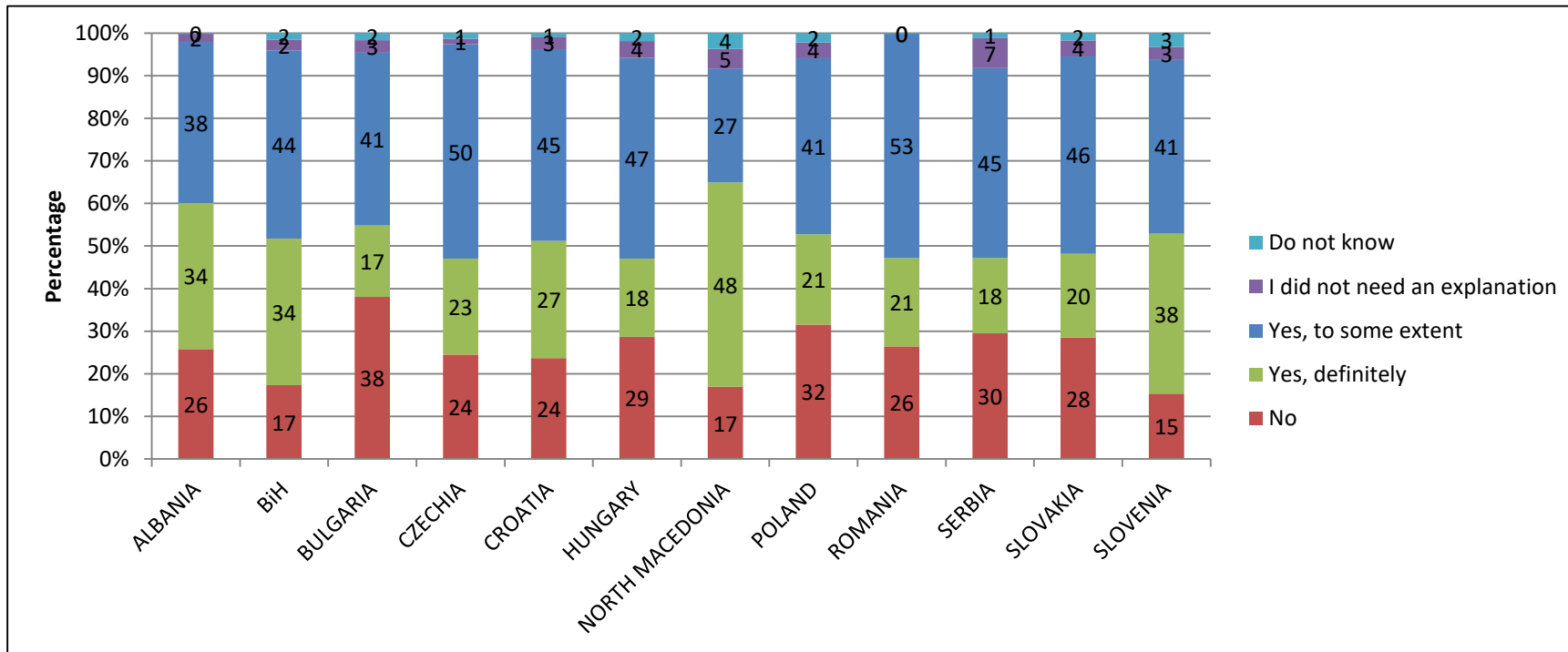


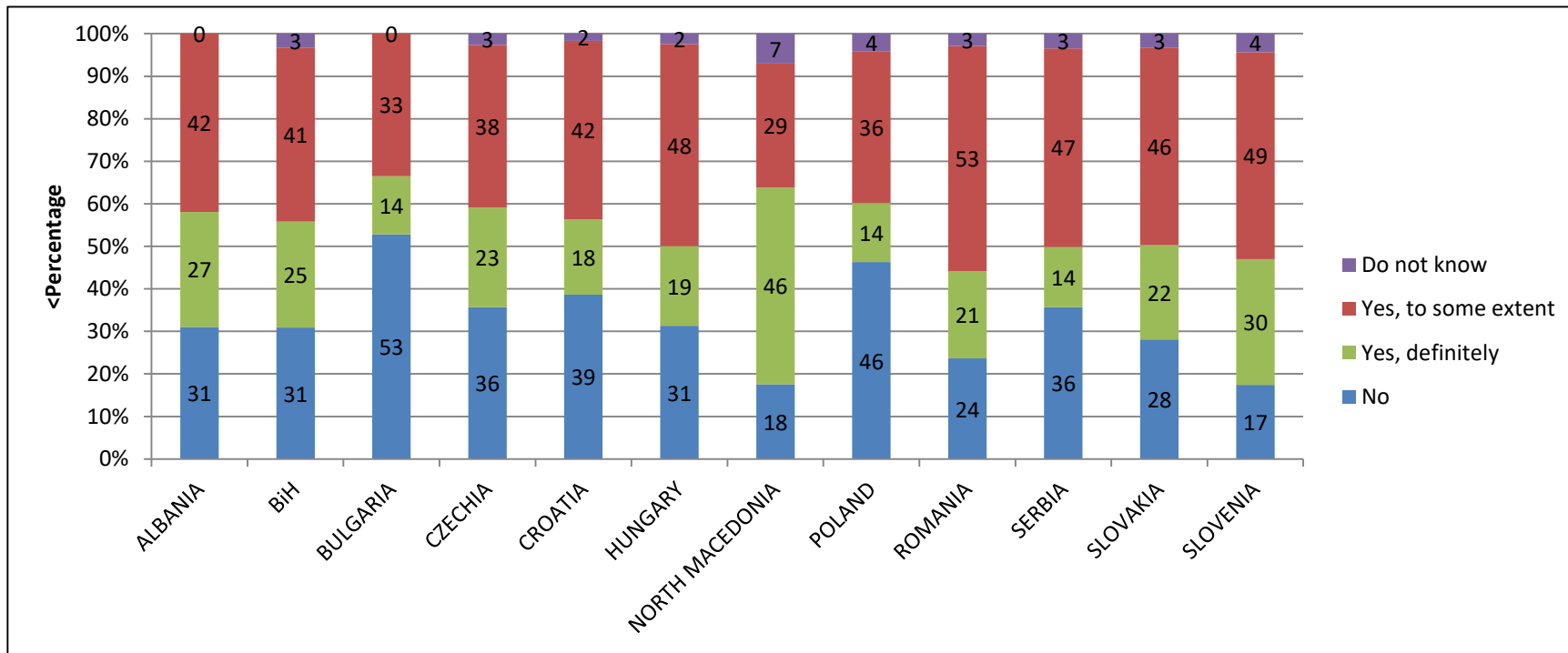
Figure 18. Have you been given a cancer treatment plan? (N = 16458)

Diagnose of cancer and cancer treatment- side effects



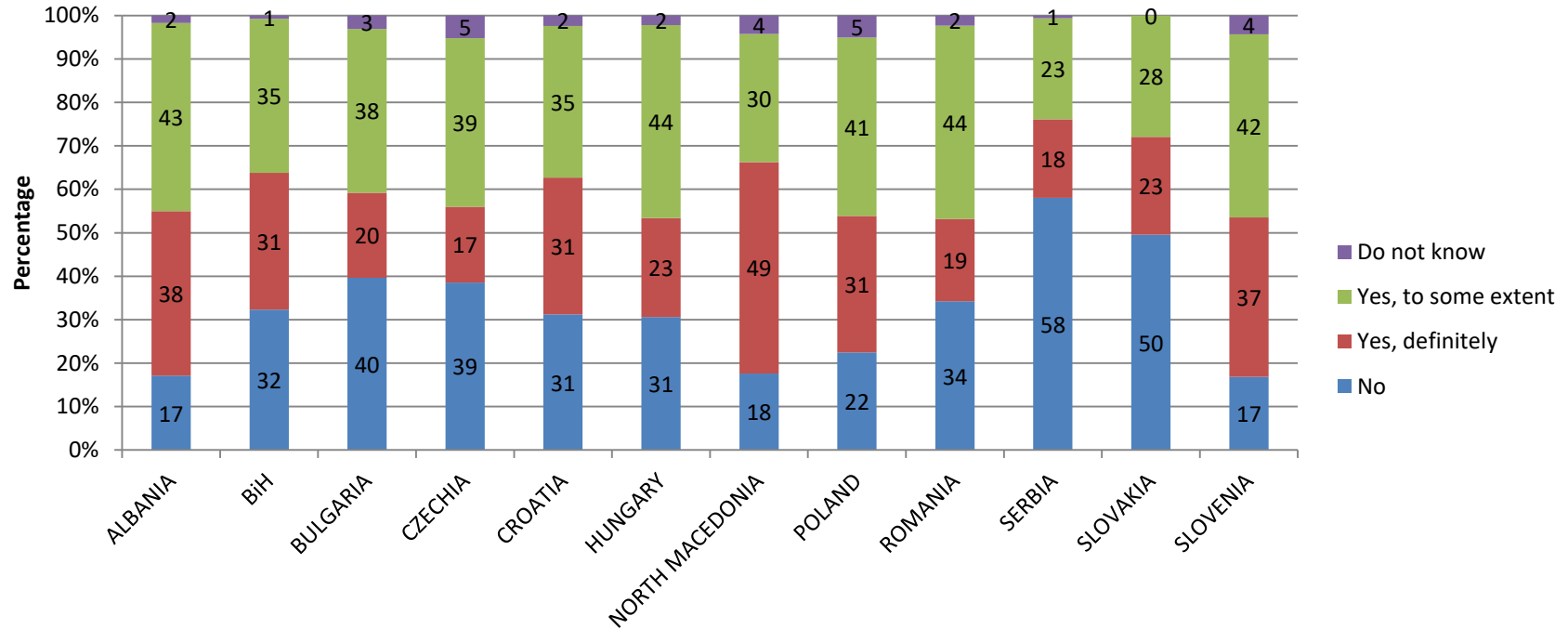
Were the possible side effects of treatment(s) (short term and long term) explained in a way you could understand? (N = 16458)

Diagnose of cancer and cancer treatment-side effects management



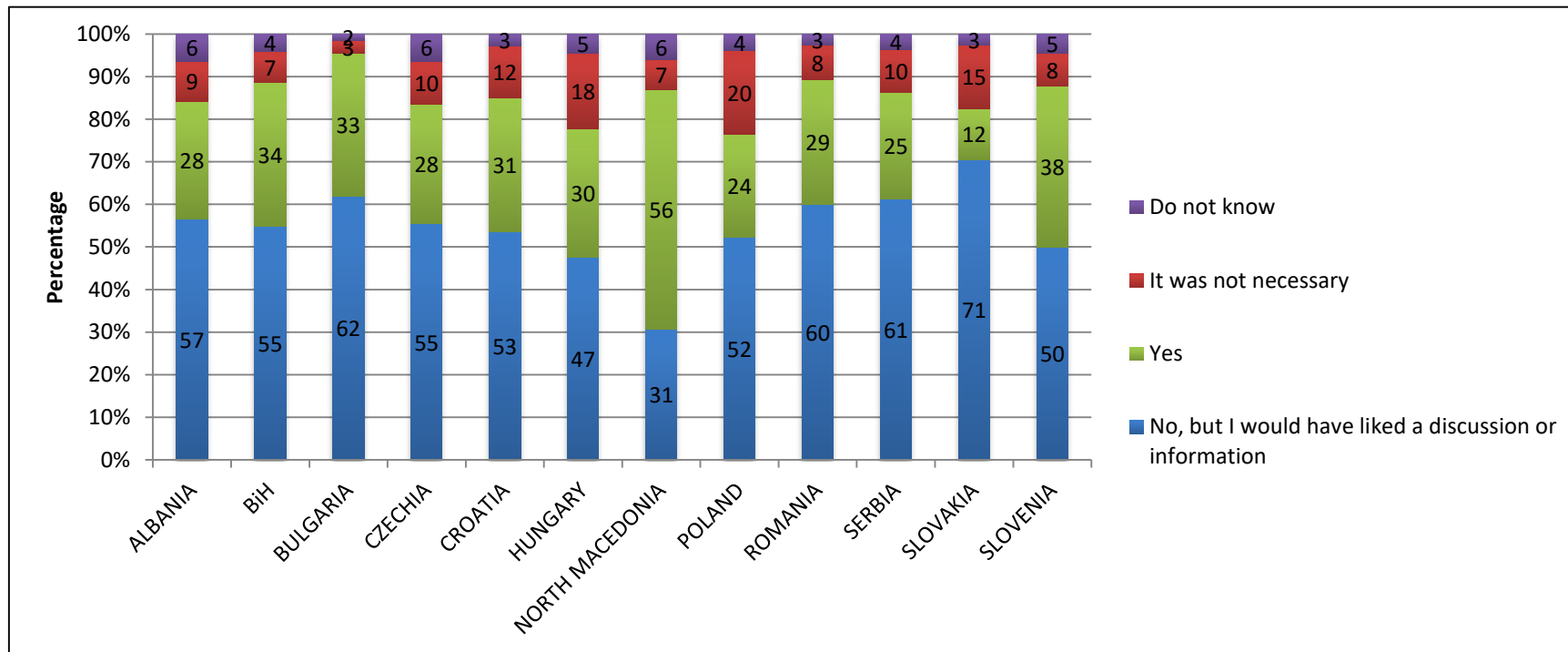
Were you offered practical advice and support in dealing with the side effects of your treatment(s)?

Diagnose of cancer and cancer treatment-decisionmaking



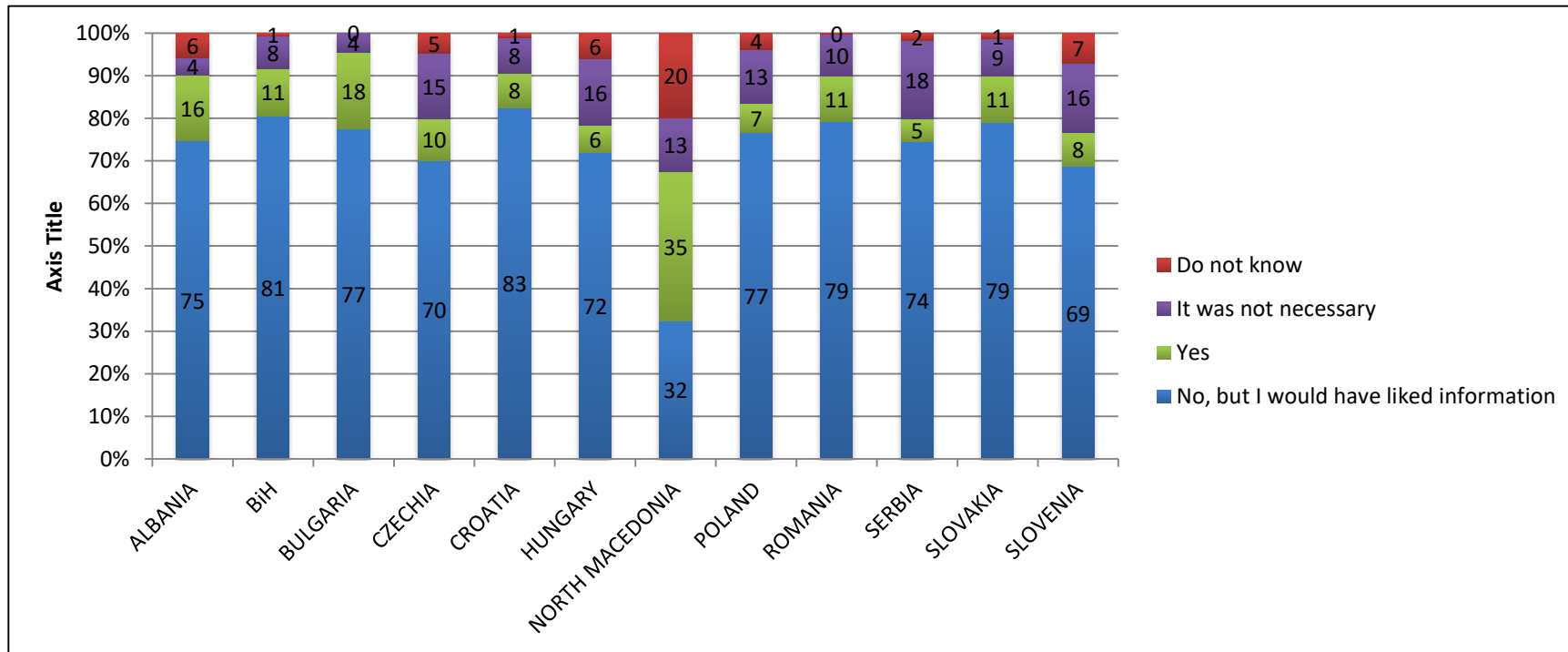
Were you involved as much as you wanted to be in decisions about your care and treatment?

Support to patients and caregivers- day to day activities



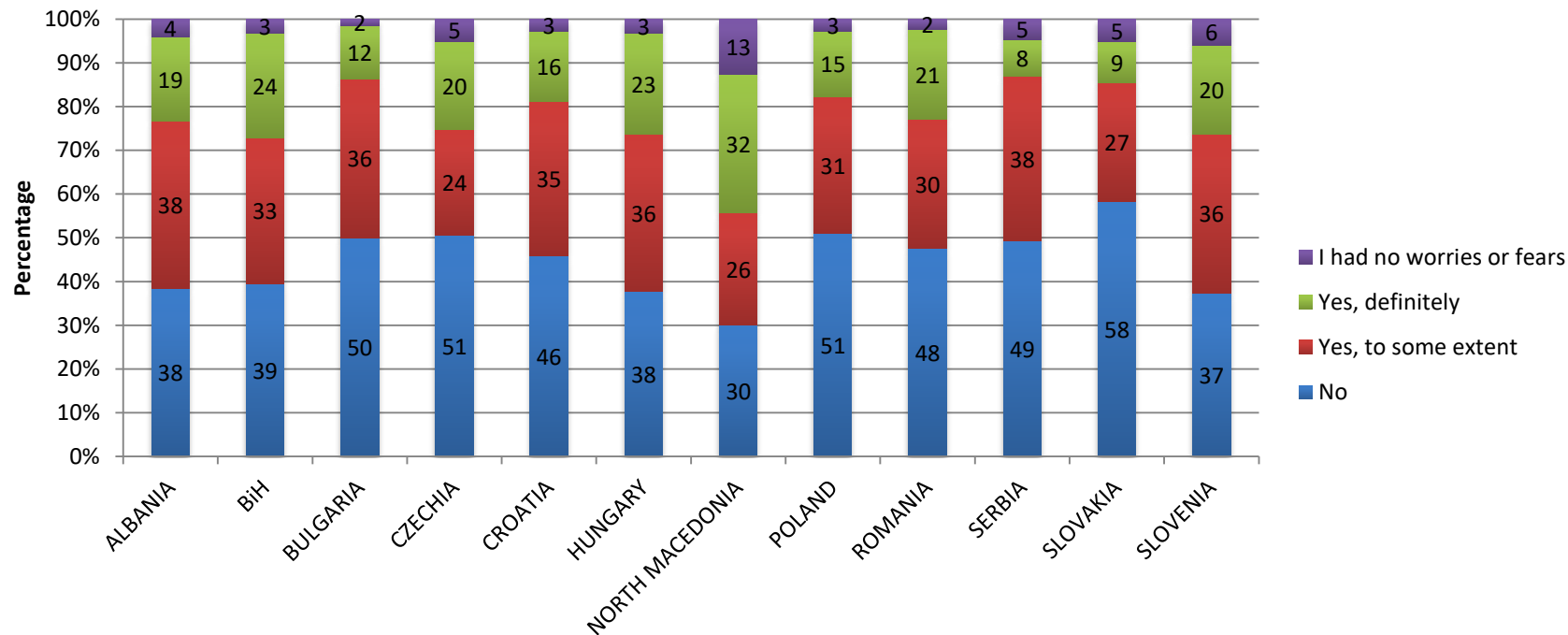
Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?

Support to patients and caregivers- financial benefits



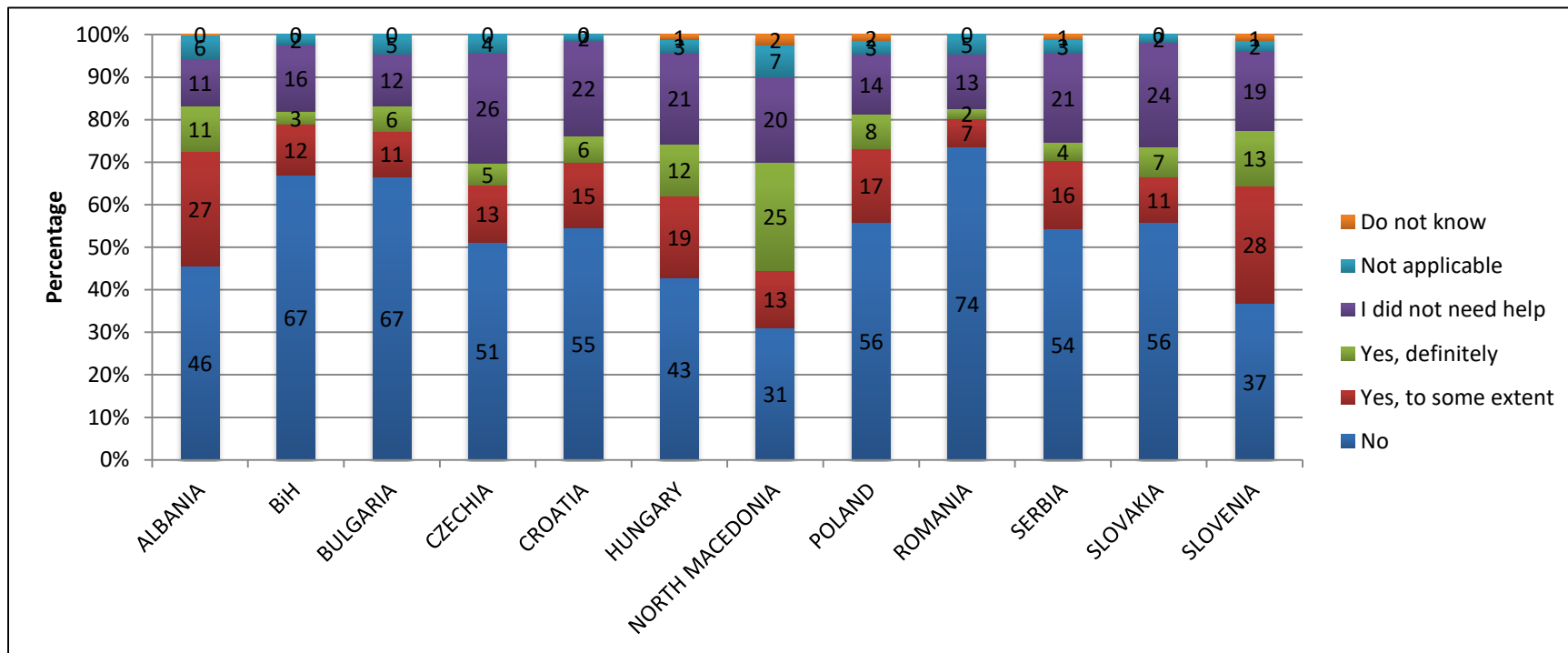
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?
(N = 16458)

Support to patients and caregivers- worries



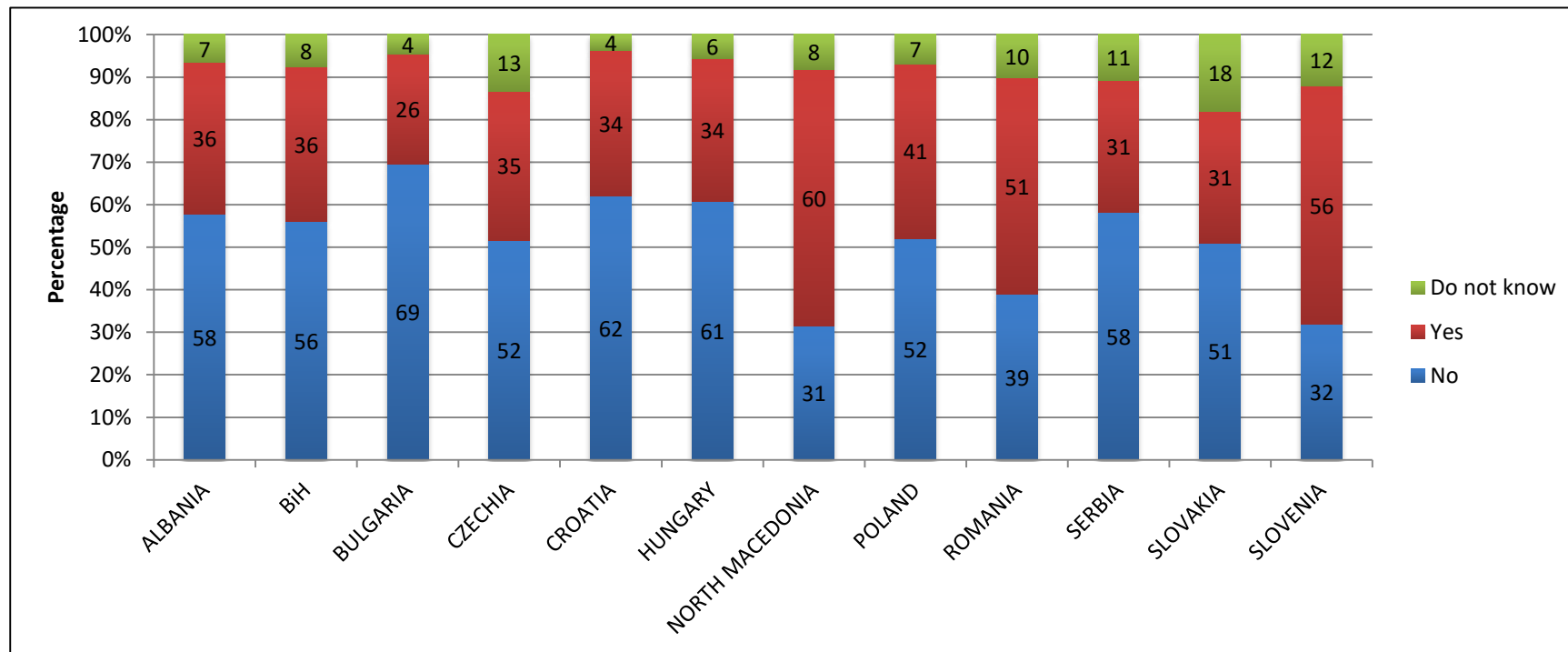
. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?
(N = 16458)

Support to patients and caregivers- social services



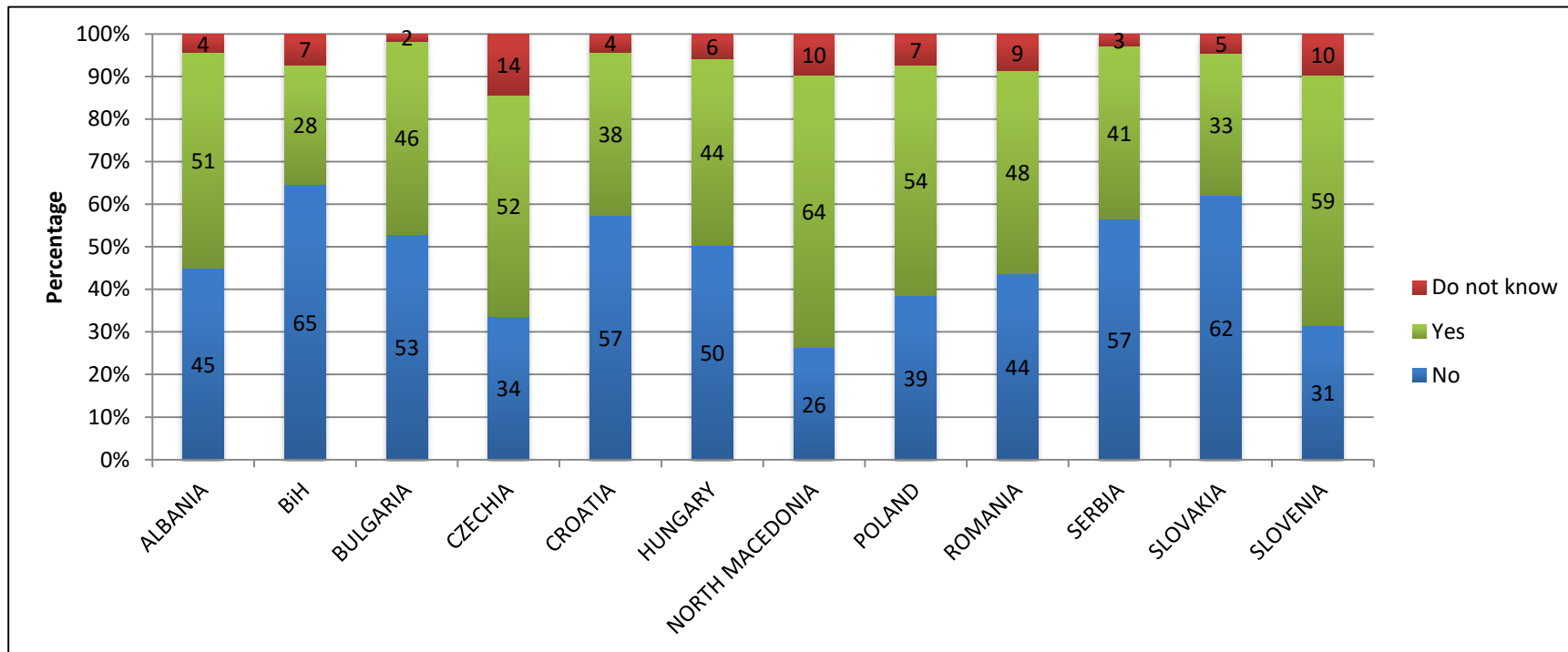
During your cancer treatment, and once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps, psychological support)? (N = 16458)

Support to patients and caregivers- written information



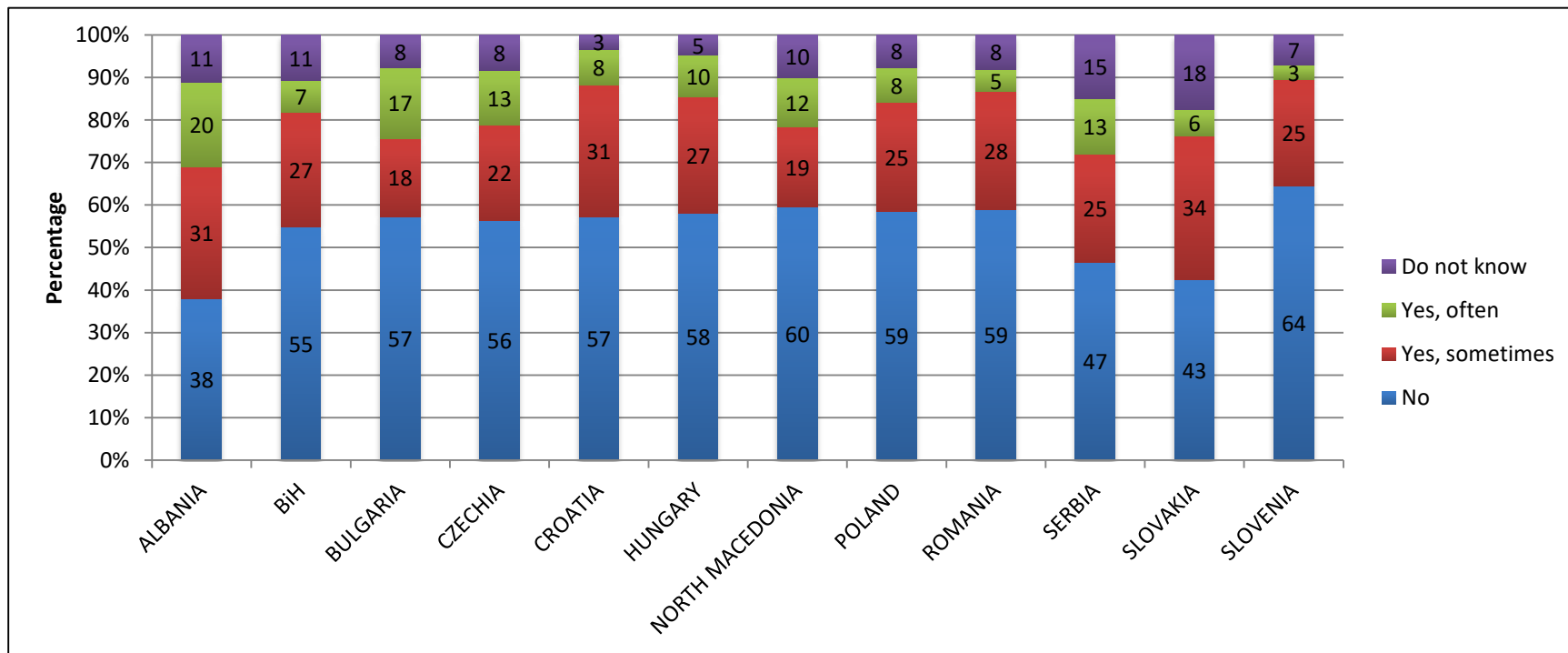
Were you given clear written information about what you should or should not do after leaving hospital?
(N = 16458)

Support to patients and caregivers-who to call?



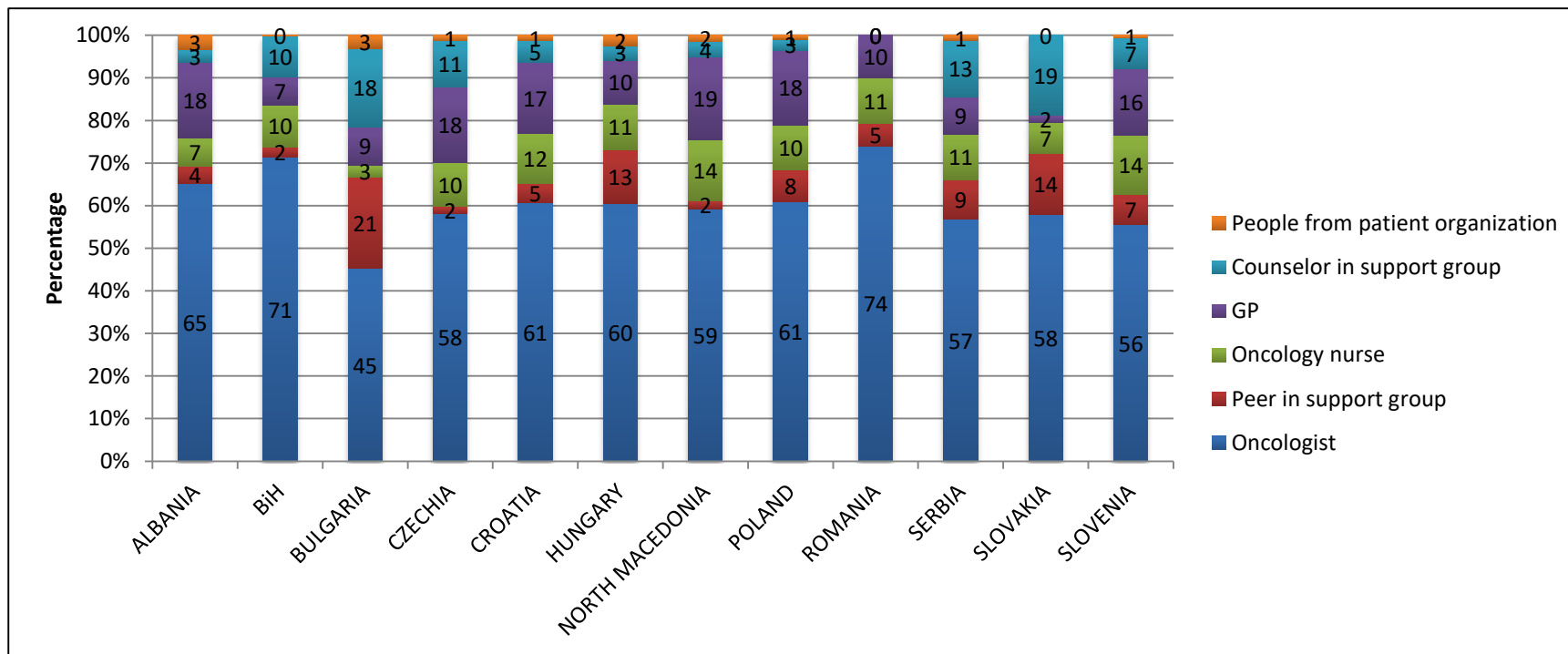
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? (N = 16458)

Support to patients and caregivers-HCP communication



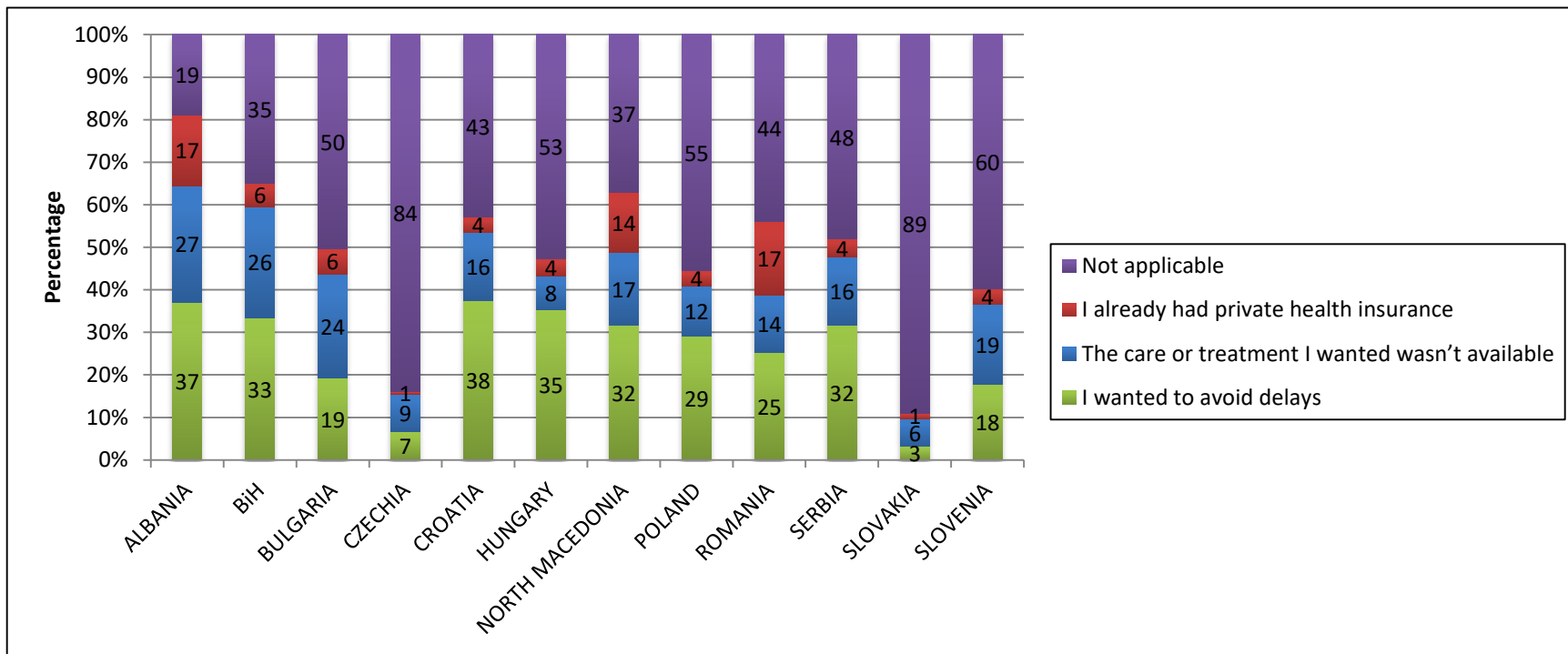
Did groups of doctors and nurses talk in front of you as if you weren't there? (N = 16458)

Support to patients and caregivers-trust



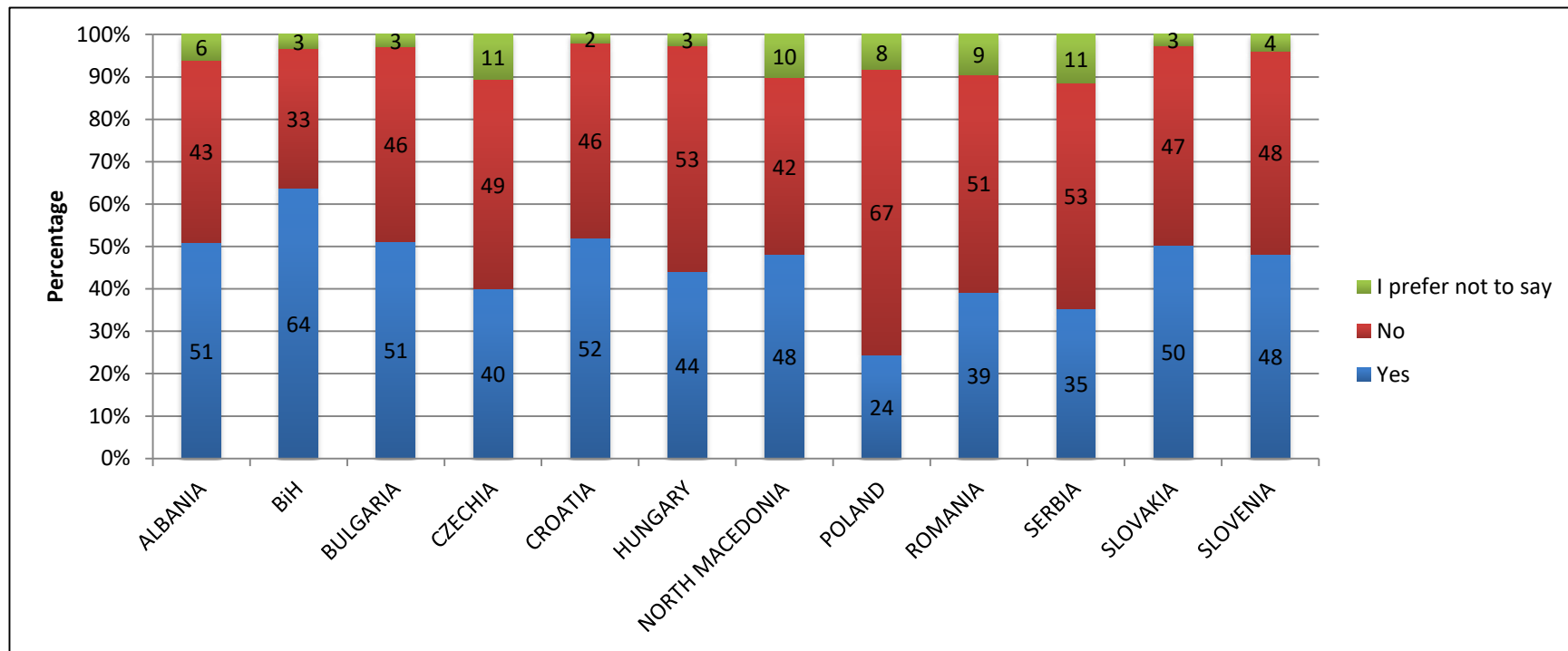
Who gave you most confidence and most trust?
(N = 16458)

Support to patients and caregivers-out of pocket costs



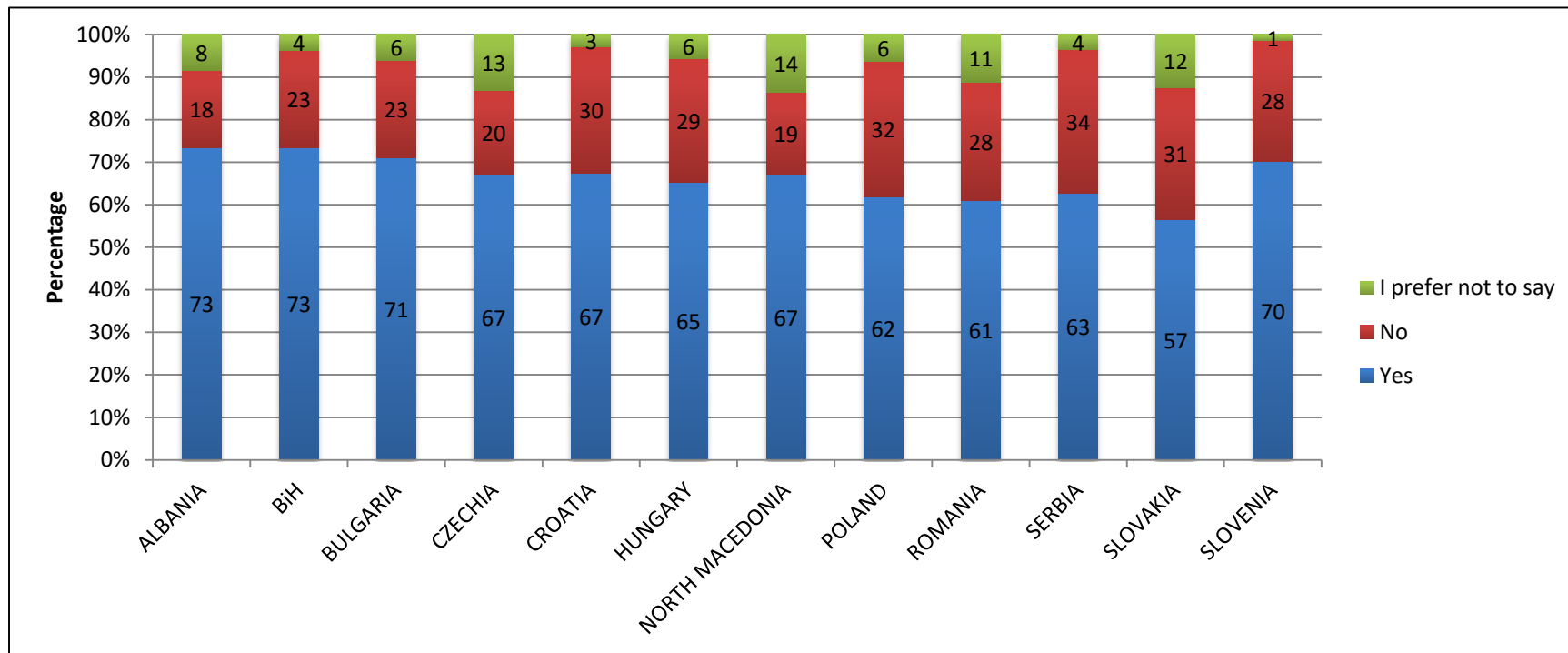
If you paid for any of your cancer care and treatment yourself, why was this? (N = 16458)

Support to patients and caregivers alternative treatments



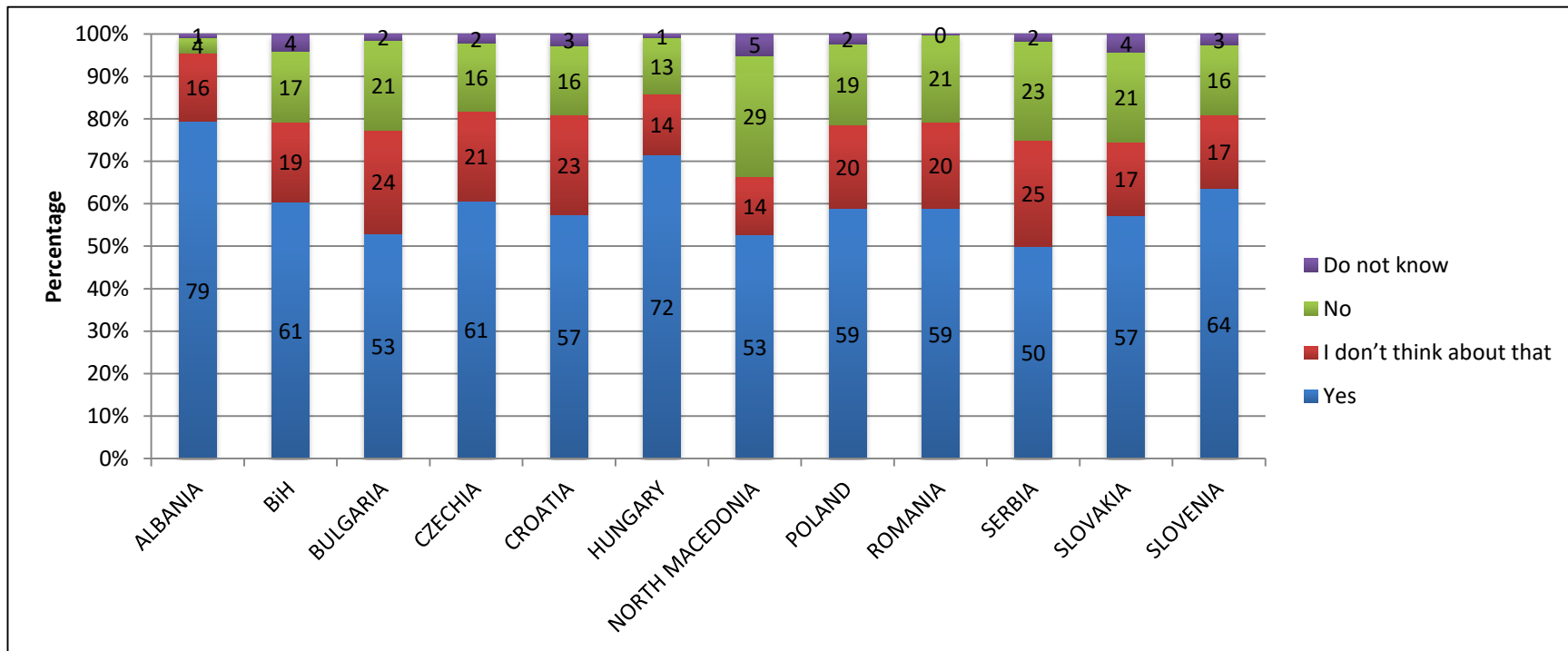
Did you buy any alternative preparations or pay for any alternative treatments? (N = 16458)

Support to patients and caregivers- alternative treatments



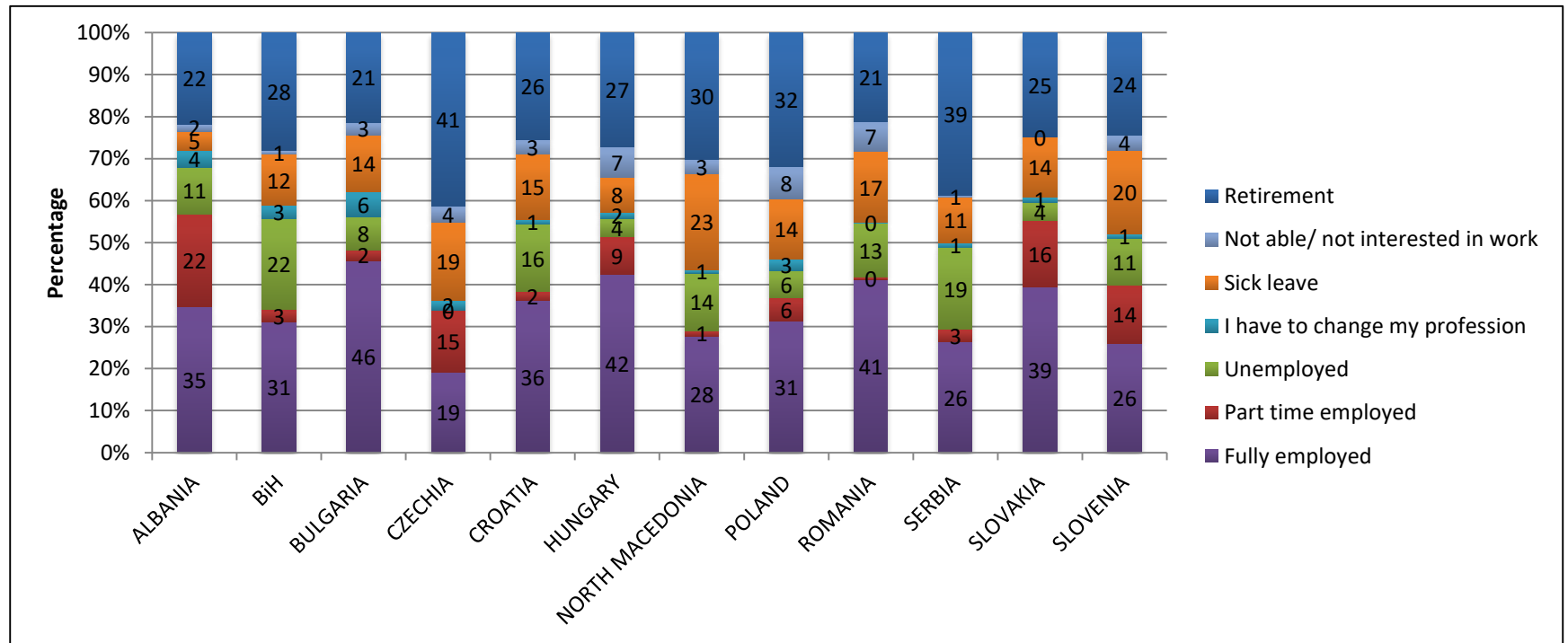
If you bought some alternative treatments, or pay for some alternative treatments, did you inform your doctor about it?
(N = 16458)

Support to patients and caregivers- financial burden



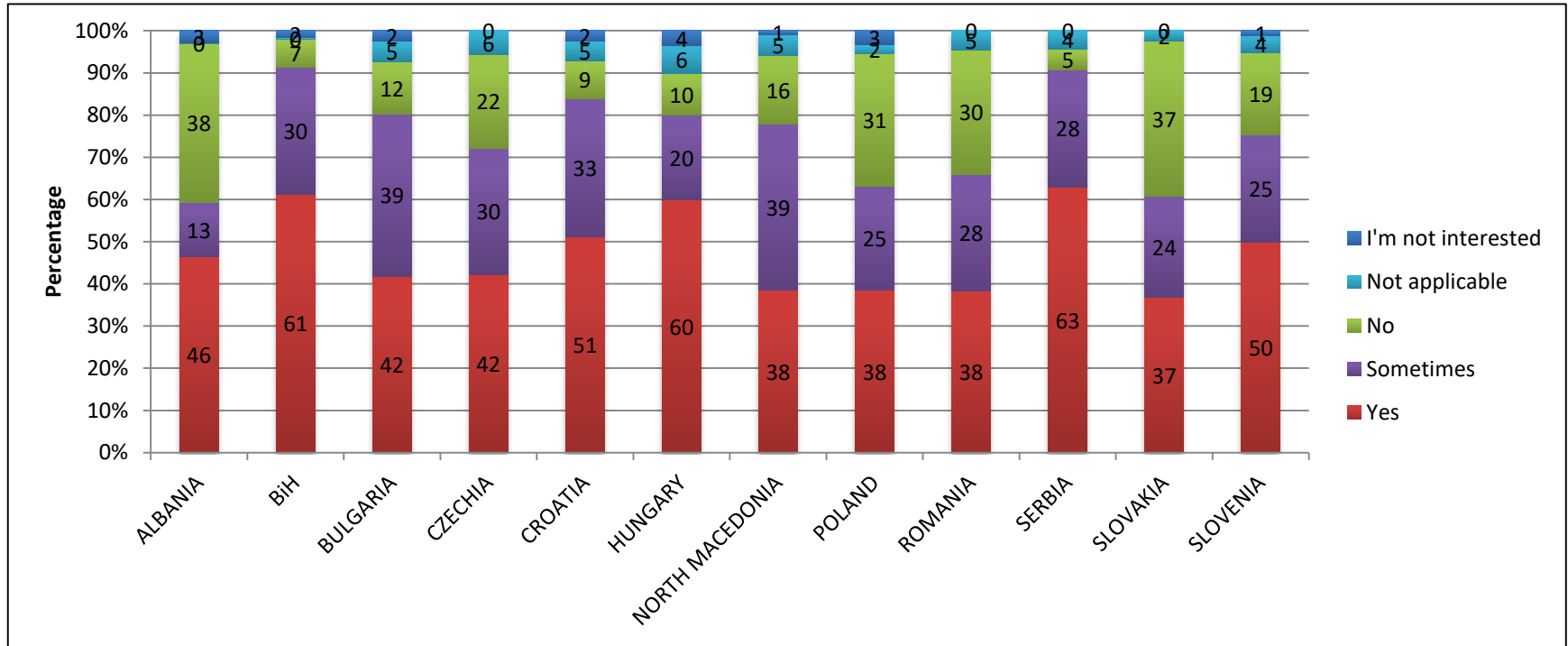
Do you feel that your cancer care is a financial burden for your family? (N = 16458)

Quality of life-working status



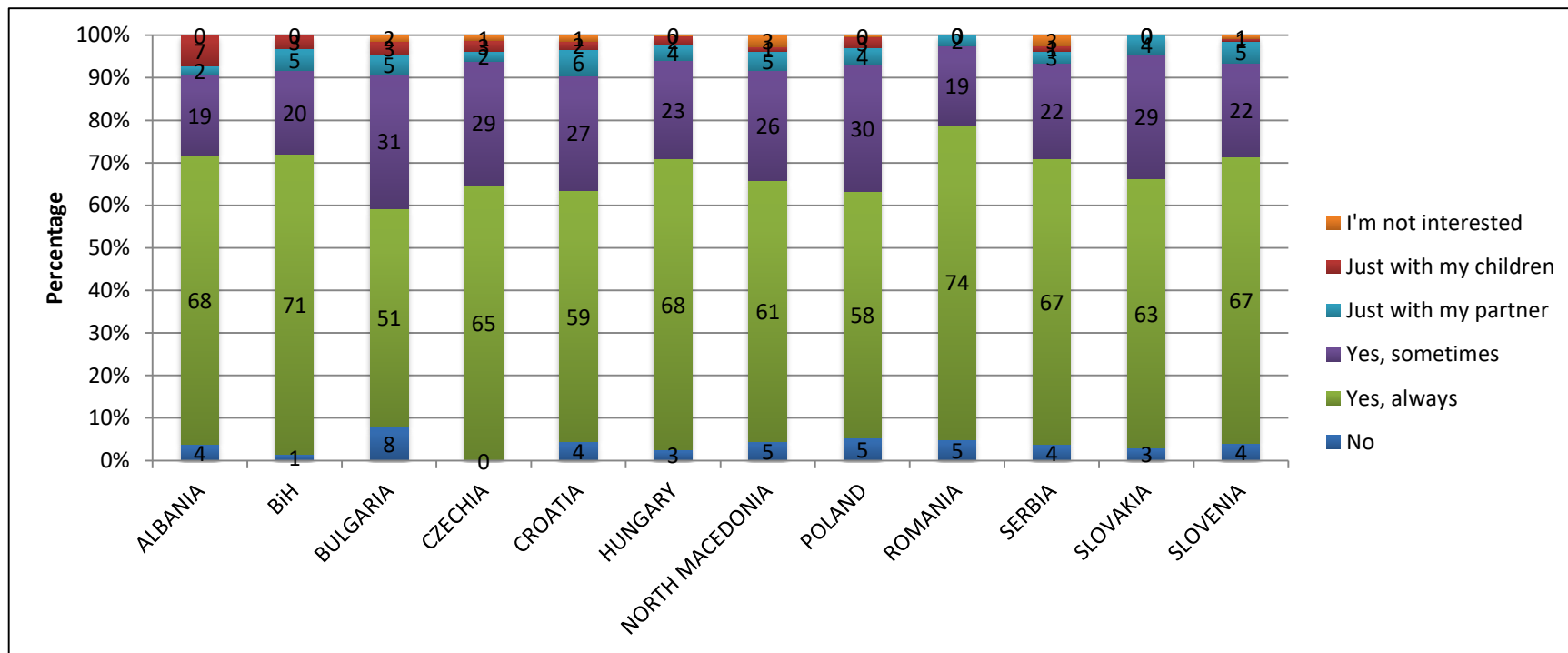
What is your working status since you were diagnosed or treated? (N = 16458)

Quality of life-support of your working environment



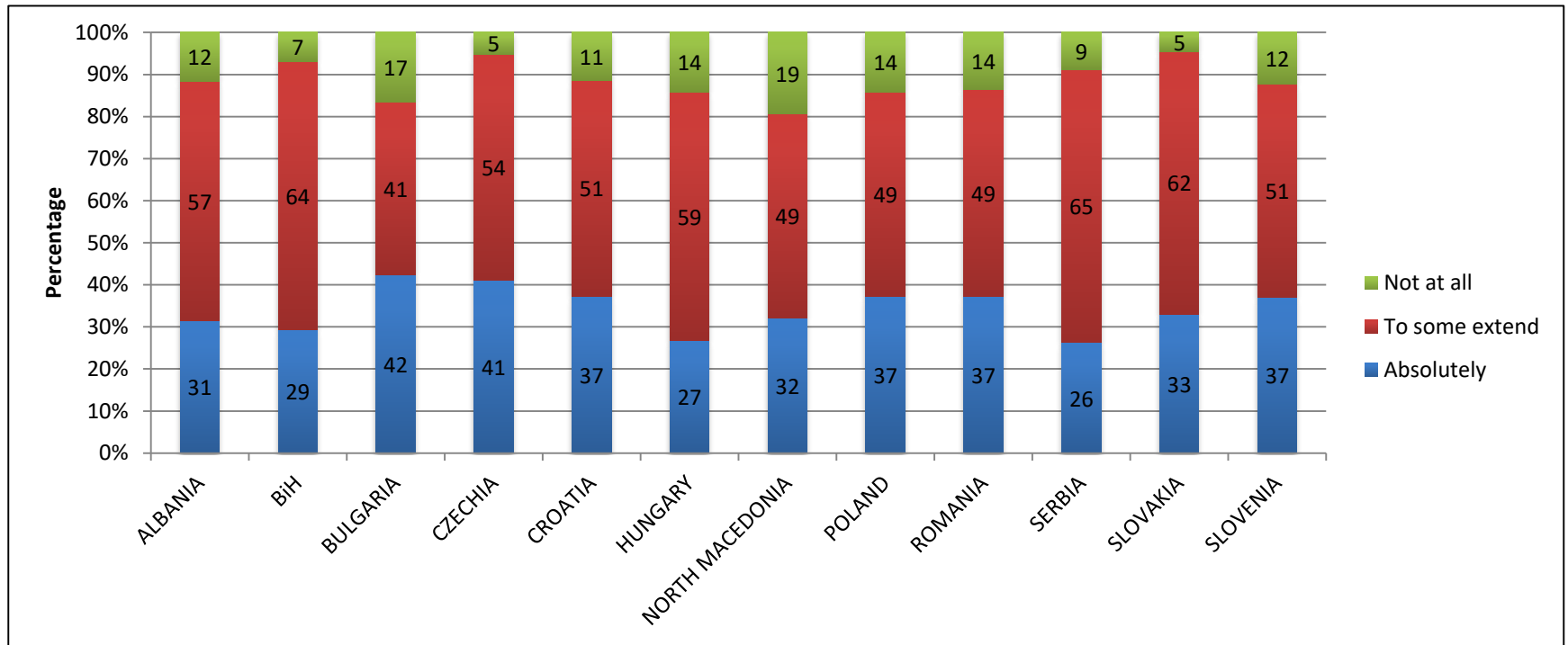
Do you have the support of your working environment since you were diagnosed or treated?

Quality of life-communication with friends and family



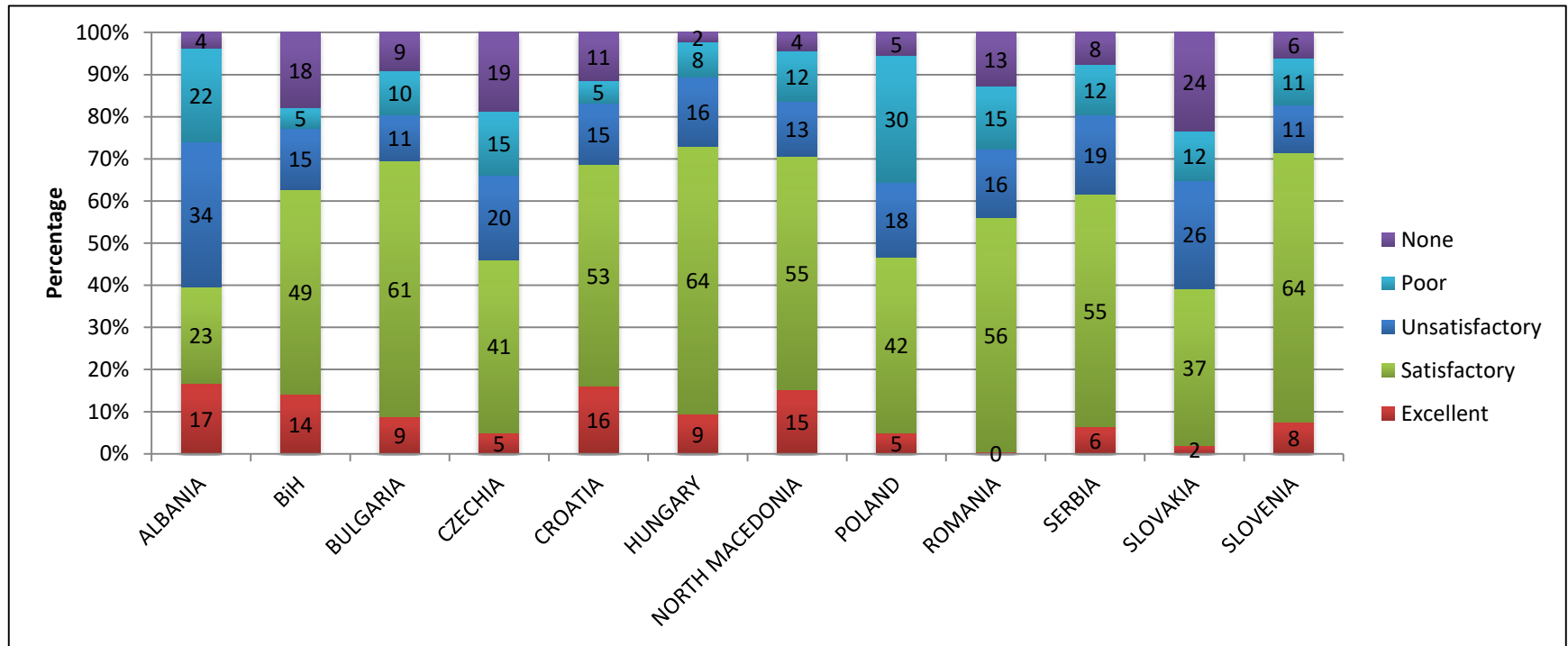
Can you talk openly about your disease with your friends and family members? (N = 16458)

Quality of life- daily routine



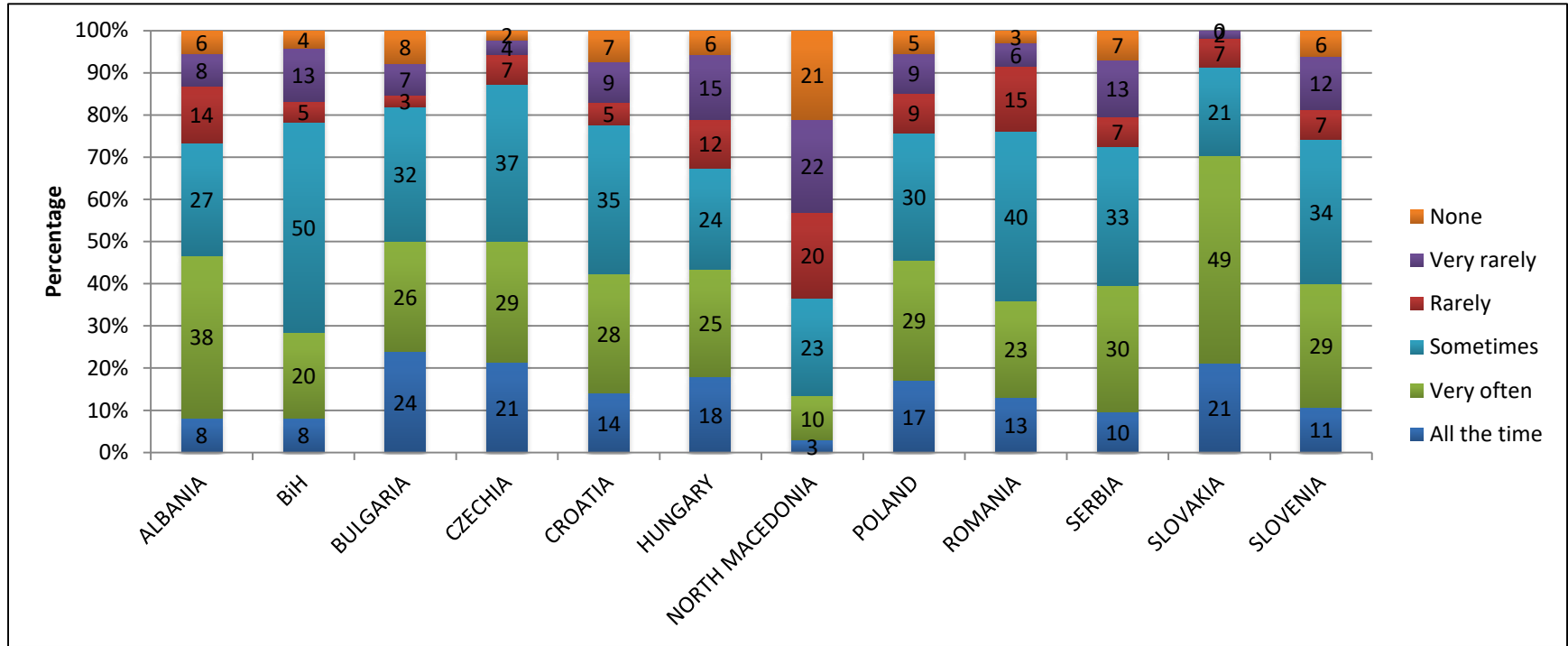
Has your daily routine changed a lot since you were diagnosed with cancer? (N = 16458)

Quality of life- management of treatment side-effects



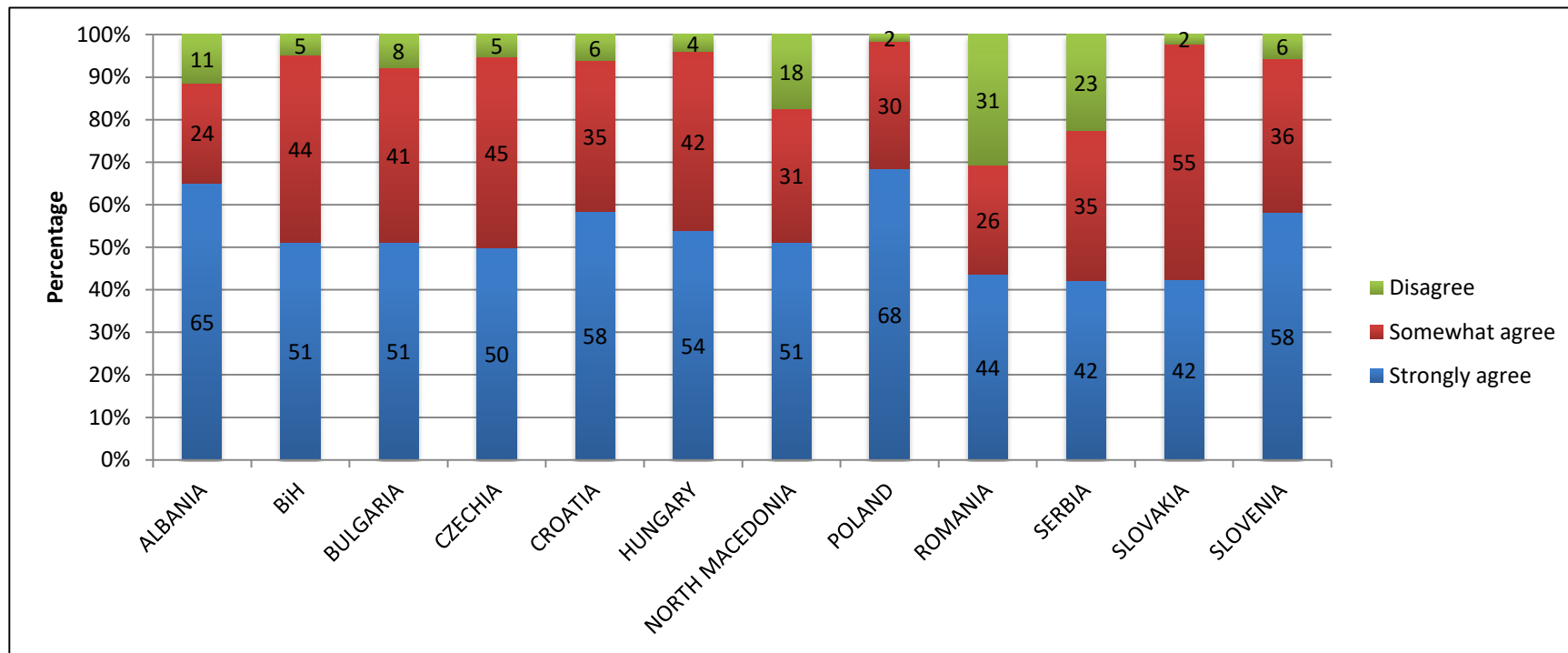
How would you describe your management of treatment side-effects (nausea, fatigue, skin changes, loss of hair, pain, loss of appetite ...)? (N = 16458)

Quality of life- influence of treatment side-effects



Have you experience the influence of treatment side-effects on your every-day life? (N = 16458)

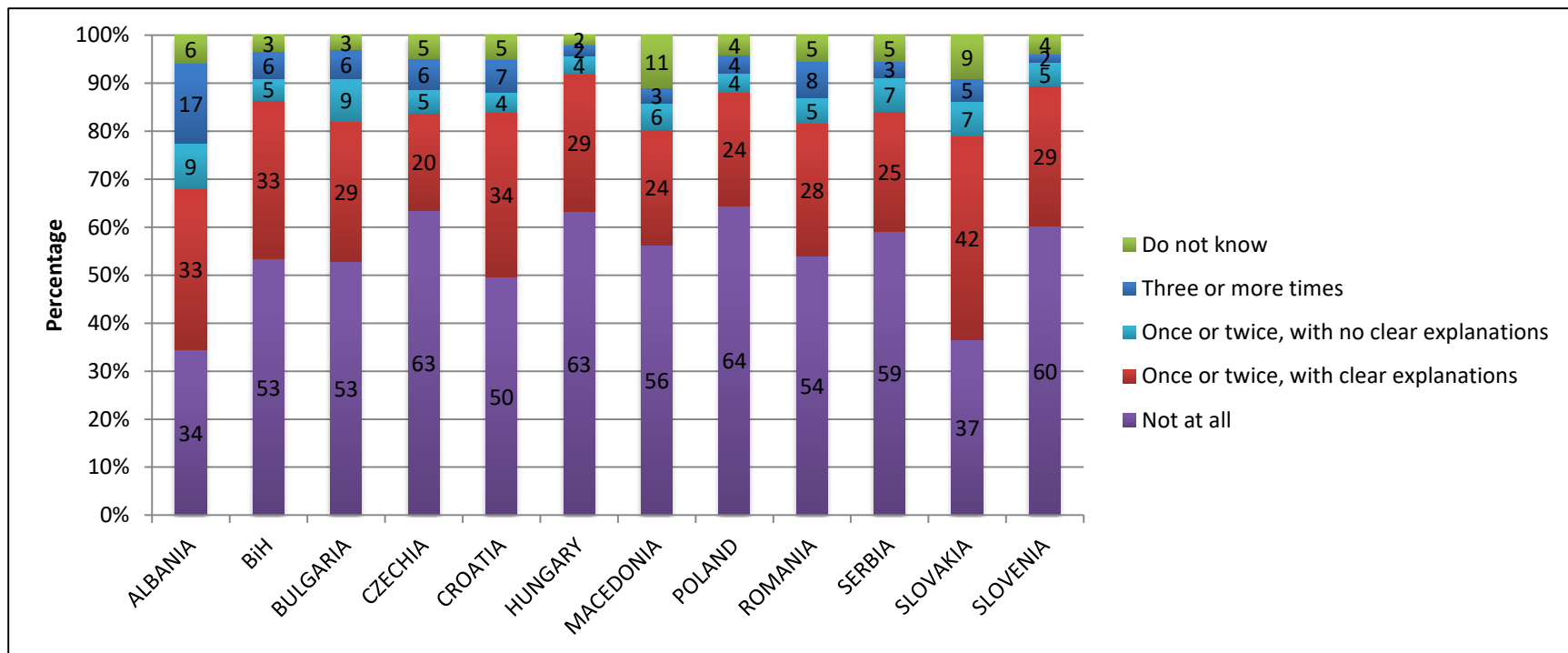
Palliative care in advanced disease



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

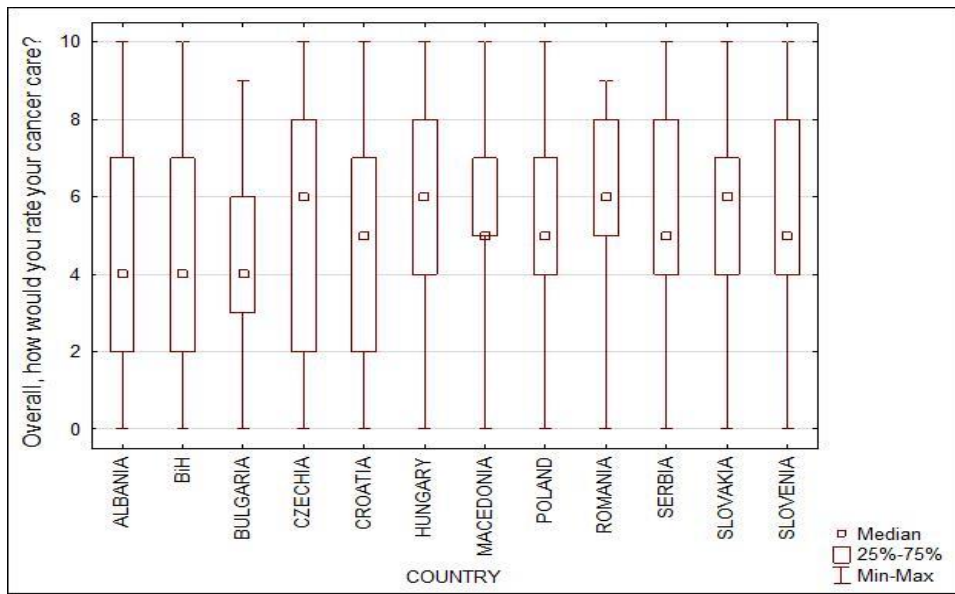
We don't talk about death and dying enough in this country.

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)

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)

COUNTRIES*		
ALBANIA	BIH	BULGARIA
BIH	ALBANIA	CROATIA
BULGARIA	ALBANIA	
CZECHIA	CROATIA POLAND	SLOVAKIA SLOVENIA
CROATIA	BIH	CZECHIA
HUNGARY	MACEDONIA	SERBIA SLOVAKIA
MACEDONIA	HUNGARY ROMANIA	SERBIA SLOVAKIA
POLAND	CZECHIA	SLOVAKIA SLOVENIA
ROMANIA	MACEDONIA	
SERBIA	HUNGARY MACEDONIA	SLOVAKIA SLOVENIA
SLOVAKIA	CZECHIA HUNGARY MACEDONIA	POLAND SERBIA SLOVENIA
SLOVENIA	CZECHIA POLAND	SERBIA SLOVAKIA

*Countries in each row do not differ one from each other in distribution of overall score (How would you rate your cancer care?)

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

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)

Diagnose influence daily routine

It is financial burden for participant and family

Social networks support is welcome

