






# A European survey on the insights of patients living with metastatic colorectal cancer: the patient journey before, during and after diagnosis - an Eastern European perspective

Zorana Maravic <sup>1</sup>, Iga Rawicka,<sup>2</sup> Agnes Benedict,<sup>3</sup> Lucjan Wyrwicz,<sup>4</sup> Anna Horvath,<sup>5</sup> Vassiliki Fotaki <sup>1</sup>, Alfredo Carrato <sup>6</sup>, Josep M Borrás,<sup>7</sup> Ana Ruiz-Casado,<sup>8</sup> Agota Petrányi,<sup>9</sup> Liesbeth Lemmens,<sup>10</sup> Eloy Espín-Basany,<sup>11</sup> Jadranka Stanisic Trenevski<sup>12</sup>

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For numbered affiliations see end of article.

## Correspondence to

Zorana Maravic;  
zorana@digestivecancers.eu

## ABSTRACT

**Background** Despite being highly preventable and treatable if diagnosed early, colorectal cancer (CRC) remains the second leading cause of cancer-related death in Europe. Limited information is available from the patient perspective on the persisting unmet needs of the journey of the patient with CRC.

**Objective** To capture European metastatic CRC (mCRC) patients' insights during the patient journey (prediagnosis; diagnosis; postdiagnosis) through a patient survey.

**Methods** In total, 883 patients from 15 European countries participated. Participants were divided into four groups from Hungary, Poland, Serbia and 'other European countries' (n=103, 163, 170 and 447 patients, respectively).

**Results** General awareness of CRC and its symptoms prediagnosis varied among groups, with patients from Poland recording the lowest levels. Screening practices and attitudes also varied; while more patients from Serbia had been invited to CRC screening (~15%) compared with the other groups, the ones not invited claimed mostly (~20%) that would not have attended if they had been invited. Whereas most patients were diagnosed within a month after the first consultation/positive screening, the percentages varied substantially being lowest among patients in Poland (~30%) and Serbia (~25%). Although CRC-related information provision varied, with most informed patients from Hungary (~90%) and least from Serbia (~50%), all groups requested an easier-to-understand language by the healthcare team. Approximately 50% of patients from Eastern Europe had to wait longer than a month to receive treatment, in contrast to ~30% from other European countries. All groups emphasised the unmet need for support from psychologists and other patients.

**Conclusions** Our survey reveals the key aspects of the journey of the patient with mCRC and highlights the areas of similarities and differences between patients with mCRC from Eastern Europe versus those from other European countries as well as among patients from different Eastern European countries, calling for improvement particularly around awareness, screening, treatment availability, communication and support networks.

## Key questions

### What is already known about this subject?

- ▶ Previous surveys capturing the views of patients with metastatic colorectal cancer (mCRC) are limited, revealing some aspects on the emotional, financial, health-related quality of life and treatment-specific burdens, such as fears about recurrence, postsurgical symptoms or managing a stoma.

### What does this study add?

- ▶ This is the first study that captures comprehensively the journey of European patients with mCRC from prediagnosis to postdiagnosis, providing a perspective from three Eastern European countries with high CRC mortality rates and healthcare systems with several limitations as well as that from other European countries.
- ▶ The results can help to prioritise the overlooked needs of patients with mCRC.

### How might this impact on clinical practice?

- ▶ The national healthcare systems should address the findings that point to specific delays in treatment initiation, especially in Eastern Europe, and the need for more exhaustive screening for CRC.
- ▶ Healthcare teams looking after patients with CRC should look into emotional support and communication gaps.
- ▶ Healthcare professionals (HCPs), patients and carers and patient organisations should work together to fill these gaps.
- ▶ Digestive Cancers Europe and national patient organisations working on CRC with support from the national governments must help strengthen the relationships between HCPs and patients and help overcome communication barriers by providing additional emotional support and information material in a patient-friendly language.
- ▶ HCPs should flag to patients the supportive role that patient organisation can have in the patient journey.

## INTRODUCTION

Colorectal cancer (CRC) is a collective term for cancer that starts in the colon or the rectum. Colon and rectal cancers are often grouped together because they have many features in common.<sup>1</sup>

Approximately 500 000 people are newly diagnosed with CRC every year in Europe,<sup>2</sup> where CRC is the second leading cause of cancer-related death after lung cancer in both men and women; approximately 243 000 people die from CRC in Europe each year. It is second to only breast cancer as the most common cancer type in women and the third most common cancer type in men, after lung and prostate cancers.<sup>3</sup>

However, CRC is one of the most preventable cancers. Most CRCs develop from non-cancerous polyps—growths on the lining of the colon and rectum—and screening methods can detect and remove polyps before they become cancerous.<sup>4</sup> If it is detected early, the chance of cure is very high. The 5-year survival rate of people with localised-stage CRC is 90%. However, if the cancer has spread (metastasised) to distant parts of the body, the 5-year survival rate is only 14%.<sup>5</sup>

Despite this knowledge and the fact that many EU Member States are running or establishing population-based CRC screening programmes,<sup>6</sup> there is still significant variability across Europe in terms of screening and outcome rates.<sup>7</sup> Among CRC survivors, emotional, financial, health-related quality of life (QoL) and treatment-specific burdens, such as fears about recurrence, postsurgical symptoms or managing a stoma, have all been documented.<sup>8–11</sup> However, there is limited information on the patient experience among patients with metastatic CRC (mCRC).

In 2016, Digestive Cancers Europe (DiCE) - Europa-Colon at the time - a European patient organisation that aims to give a voice to people living with all types of digestive cancers, initiated a multinational survey to understand the mCRC patient journey before, during and after diagnosis. The survey consisted of two parts. The purpose of the first part of the survey was to facilitate a better understanding on screening practices, disease awareness, sources and quality of available information on mCRC and treatments, communication with healthcare professionals (HCPs) and the level of participation in treatment decisions and the sources and quality of support provided in patients with mCRC from Eastern Europe and other European countries.

The second part of the survey focused on the QoL of patients with mCRC after diagnosis. The results from the second part of the survey will be published separately.

## METHODS

The first part of the survey was developed by DiCE (formerly EuropaColon) and their Expert Patient Advisory Group. It was reviewed by Evidera, who are experts in outcome research. The questionnaire comprised of four sections, each of which contained a comprehensive

question set. When analysing the data, we limited our analysis to questions we considered most relevant and important (final) and did not include all (initial). The number of initial and final questions and the different parts of the survey were as follows: part 1 consisted of questions related to the patient profile (initial, 12; final, 7); part 2 contained questions about the patient journey and was divided into the following four topics related to the pre-diagnostic, diagnostic and post-diagnostic stages of the disease: (1) discovery of illness (initial, 16; final, 9), (2) diagnosis (initial, 4; final, 4), (3) treatment (initial, 21; final, 18) and (4) patient support (initial, 12; final, 11). Online supplemental appendix 1 includes all analysed survey questions (final); parts 3 and 4 - QLQ-C30 and QLQ-CR29, respectively - captured the patients' QoL; these results will be presented separately (in preparation). Patients with mCRC, independently of whether they were newly diagnosed or not, were eligible to participate in the survey. The method for patient recruitment varied by country, depending on the local legal framework as well as the national patient organisation supporting the survey. All participants were informed why the study was being done as well as how the results of the survey would be used prior to completing it. Patients were invited to participate via direct outreach with a leaflet by national patient organisations or clinicians or via an invitation on the EuropaColon website or social media announcements (mainly via Twitter). Because of these two different recruitment approaches, we were not able to capture the response rate of the survey. Patients had the option to either complete the survey online via a secure link or a paper version given to them by members of their healthcare team. Taking part in the survey implied that participants consented to it. Institutional Review Board approvals were obtained where needed. The survey responses were anonymised, and no patient organisations or clinicians received monetary compensation to promote and/or conduct the survey. The survey was accessible for 18 months (June 2017–December 2018) and translated into 10 languages. We aimed to capture the views of at least 100 patients in each of the three participant Eastern European countries, independently of the country's population size or the incidence of CRC, and we also targeted patients from all over Europe, especially in regions where we had strong relationships with national patient organisations and/or clinicians. The national participating sites were recruited by the national patient organisations and included mainly tertiary referral centres.

## RESULTS

### Patient demographics

A total of 883 people across 15 countries in Europe, who had received a diagnosis of mCRC, completed the survey. Patients were divided into four groups as follows: group 1, 103 patients (35.92%, men; 51.46%, women) from Hungary (mean age, 62.06 years); group 2, 163 patients (57.67%, men; 39.26%, women) from Poland (mean age,

**Table 1** Patient demographics

Characteristics	Variables	Hungary (n=103*)	Poland (n=163*)	Serbia (n=170*)	Other European countries (n=447*)
Sex	Male	37 (35.92)	94 (57.67)	99 (58.24)	175 (39.15)
N* (%)	Female	53 (51.46)	64 (39.26)	71 (41.76)	185 (41.39)
Age (years)	≥71	22 (21.36)	38 (23.31)	45 (26.47)	81 (18.12)
N* (%)	61–70	47 (45.63)	71 (43.56)	76 (44.71)	173 (38.70)
	51–60	17 (16.50)	35 (21.47)	36 (21.18)	116 (25.95)
	≤50	16 (15.53)	2 (1.23)	2 (1.18)	65 (14.54)
Marital status	Single	7 (6.8)	4 (2.45)	1 (0.59)	29 (6.49)
N* (%)	Married/partner	71 (68.93)	124 (76.07)	128 (75.29)	364 (81.43)
	Divorced	13 (12.62)	11 (6.75)	9 (5.29)	27 (6.04)
	Widowed	12 (11.65)	24 (14.72)	32 (18.82)	23 (5.15)
Areas of living	Rural	8 (7.77)	51 (31.29)	42 (24.71)	67 (14.99)
	Semiurban	28 (27.18)	50 (30.67)	45 (26.47)	148 (33.11)
	Urban	16 (15.53)	46 (28.22)	35 (20.59)	135 (30.20)
	Capital city	50 (48.54)	16 (9.82)	48 (28.24)	92 (20.58)
Education	None	1 (0.97)	0	1 (0.59)	4 (0.89)
	Primary	15 (14.56)	29 (17.79)	22 (12.94)	104 (23.27)
	Secondary	47 (45.63)	92 (56.44)	106 (62.35)	119 (26.62)
	College	19 (18.45)	6 (3.68)	24 (14.12)	100 (22.37)
	University	18 (17.48)	21 (12.88)	11 (6.47)	102 (22.82)
	Postgraduate	3 (2.91)	8 (4.91)	1 (0.59)	45 (10.07)
	I do not know	0	3 (1.84)	0	3 (0.67)
Employment	Employed	16 (15.53)	25 (15.34)	24 (14.12)	120 (26.85)
Status N* (%)	Unemployed	2 (1.94)	3 (1.84)	12 (7.06)	17 (3.80)
	Retired	65 (63.11)	100 (61.35)	124 (72.94)	213 (47.65)
	Unemployed due to a medical condition	6 (5.83)	20 (12.27)	1 (0.59)	52 (11.63)
	Student/intern	0	0	0	2 (0.45)
	Other	10 (9.71)	14 (8.59)	5 (2.94)	26 (5.82)

\*Missing values throughout the table correspond to number of non-respondents.

†Respondents in Cyprus were not asked their age for reasons of anonymity.

63.65 years); group 3, 170 patients (58.24%, men; 41.76%, women) from Serbia (mean age, 65.33 years) and group 4, 447 patients (39.15%, men; 41.39, women) from ‘other European countries’ (mean age, 50.67) (see online supplemental appendix 2 for participant breakdown by country). Patient demographic data are presented in detail in [table 1](#).

### The patient journey—prediagnosis

#### CRC awareness

Patients were asked a series of questions to capture their awareness on CRC-related symptoms. Most respondents from Hungary (40.78%) and Serbia (47.06%) consulted their physician because of CRC-related symptoms, and these percentages were slightly higher to those of patients from other European countries (38.93%). In Poland, the number of patients who consulted their physician because

of CRC-related symptoms (33.13%) was lower than that in other countries. In addition, the number of responses from Poland (10.43%) regarding CRC symptom awareness before diagnosis was lower to that from Hungary (29.13%) and the other European countries (28.64%), while those from Serbia were the highest (37.65%).

When asked if they were well informed or knew something about CRC before diagnosis (not limited to symptoms), the most positive responses were from Hungary (40.78%) and Serbia (38.82%), with less from other European countries (30.20%) and the least from Poland (14.72%).

#### Screening

Regarding screening, only 1.94% of participants from Hungary and 3.07% from Poland had been invited to participate in a CRC screening programme and had



attended, while 3.88% from Hungary and 1.23% from Poland had received an invitation for screening but declined to attend. In contrast, a higher number of participants from Serbia who had been invited to participate had attended (15.88%), while 9.41% had been invited but declined; these responses were slightly higher than those obtained for patients from other European countries (13.20% were invited and attended and 7.38% were invited but declined). It should be added that 15.53% of patients from Hungary, 4.91% from Poland, 7.06% from Serbia and 18.12% from other European countries were younger than 50 years old and, hence, not eligible to participate in a screening programme.

Furthermore, 54.37% of patients from Hungary, 60.74% from Poland, 40% from Serbia and 35.35% from other European countries said they were not invited for screening but were both eligible ( $\geq 50$  years) and would have attended if asked, while 17.48% from Hungary, 9.82% from Poland, 20.59% from Serbia and 8.95% from other European countries said that while they were eligible ( $\geq 50$  years), they would not have attended anyway.

#### The patient journey—diagnosis

Patients were then asked to evaluate some aspects around their diagnosis, including how long their diagnosis took from the moment of the first consultation or positive screening test and how accurate their first diagnosis was. Most patients from Hungary were diagnosed within 2 weeks, similar to patients from other European countries (Hungary, 55.34%; other European countries, 57.05%), while 80.58% and 76.74% of these patients, respectively, were diagnosed within the first month. A similar trend but at a lower rate was observed among patients in Poland, with 31.90% diagnosed within the first 2 weeks and 57.05% within the first month. Patients from Serbia reported the longest delays in diagnosis, with only 24.12% diagnosed within 2 weeks and 48.24% diagnosed within a month. Although the levels of misdiagnosis were highest among patients in Serbia (27.65%) compared with those in Hungary (16.5%) and Poland (18.4%), they were close to those reported by patients in other European countries (25.95%).

#### The patient journey—after diagnosis

##### HCP-patient communication

When asked to evaluate the levels of information they had received by their HCP, patients from Hungary showed the highest levels of satisfaction among all patient groups, with 91.26% agreeing or strongly agreeing they had been given enough information compared with 62.57% of patients from Poland, 49.42% from Serbia and 67.56% from other European countries.

Patients were asked if they had received clear information from their doctor on a range of topics related to their diagnosis including disease nature, origin, stages and progression, examinations, possible treatments, consequences and side effects (figure 1, top graph). Although the percentages differed in different

countries, the trend was similar among groups with information on examinations, the nature of disease, possible treatments and consequence of treatments and side effects receiving the most positive responses (figure 1, top graph). In agreement with the levels of satisfaction regarding the information they received, patients from Hungary were the best informed among all groups (figure 1, top graph).

Respondents indicated that the information most important to them was that about the disease, treatments, side effects and clinical trials and this was consistent among all four patient groups (figure 1, bottom graph).

##### Treatment

Although most patients from all four groups were undergoing treatment at the time of the survey, the percentages varied (Hungary, 91.26%; Poland, 90.18%; Serbia, 55.29%; other European countries, 61.74%). The percentage of patients who had to wait for more than a month after diagnosis to receive treatment was similar among patients in Hungary (47.57%), Poland (49.08%) and Serbia (49.41) but higher than that of patients from other European countries (29.30%). The percentage of patients who had to wait for more than a year after diagnosis to receive treatment was 3.88% in Hungary, 5.52% in Poland and 4.71% in Serbia, while in other European countries, it was only 0.45%.

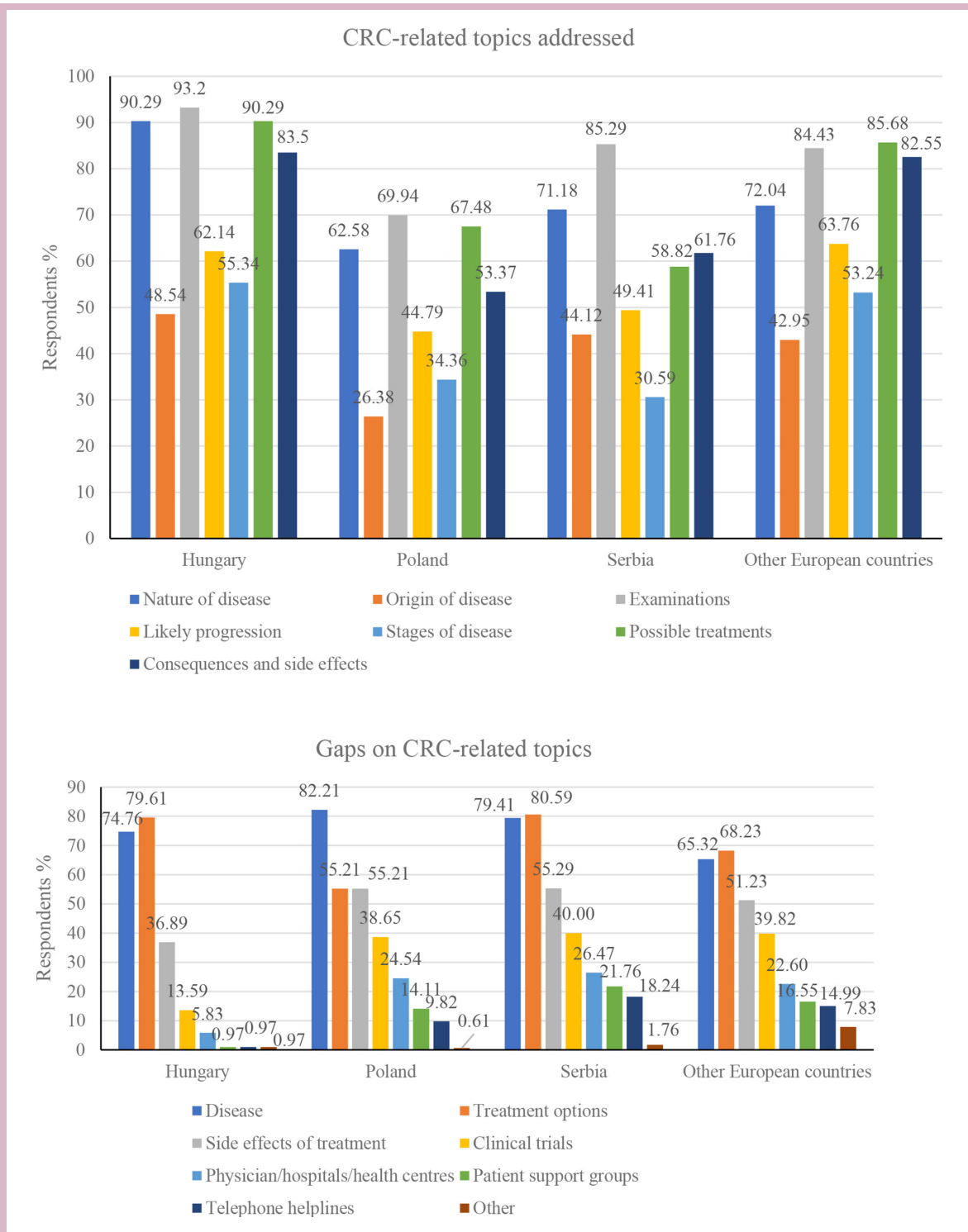
Most respondents from all four groups received surgery and chemotherapy; very few respondents from Hungary, Poland and Serbia received other treatments, such as immunotherapy, or entered a clinical trial, in contrast to 7.16% of patients from other European countries. The breakdown for all treatments is shown in figure 2 (top graph).

A great variation was observed among countries in the number of patients who felt that their views were considered when it came to treatment decisions, with the most positive answers from patients in Hungary (82.52%) and the least in Serbia (29.41%), while the number of positive responses from patients in Poland (51.53%) was similar to that of patients from other European countries (56.15%). The number of patients who did not know what type of chemotherapy drugs they had received varied from approximately 25% to 35% (Hungary, 23.3%; Poland, 28.83%; Serbia, 36.47%; other European countries, 26.85%).

When asked whether they underwent molecular testing for RAS, patients from Poland showed the highest percentage of affirmative responses (31.9%) compared with those of the other groups, while a high percentage of patients from Serbia (38.24%) did not know what molecular testing was (figure 2, bottom graph).

##### Levels of support

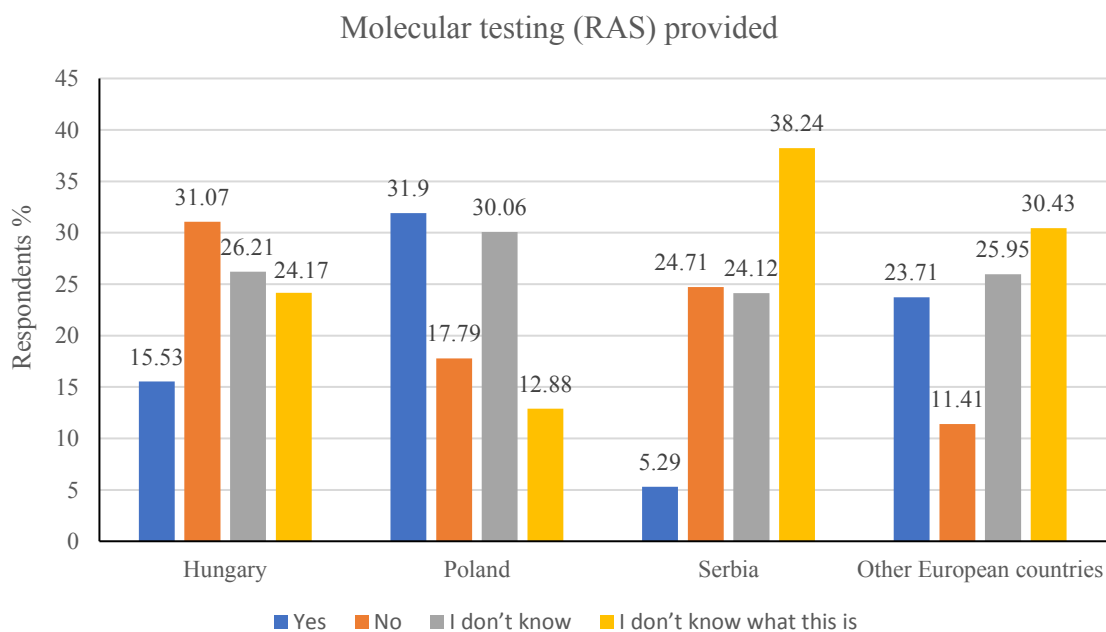
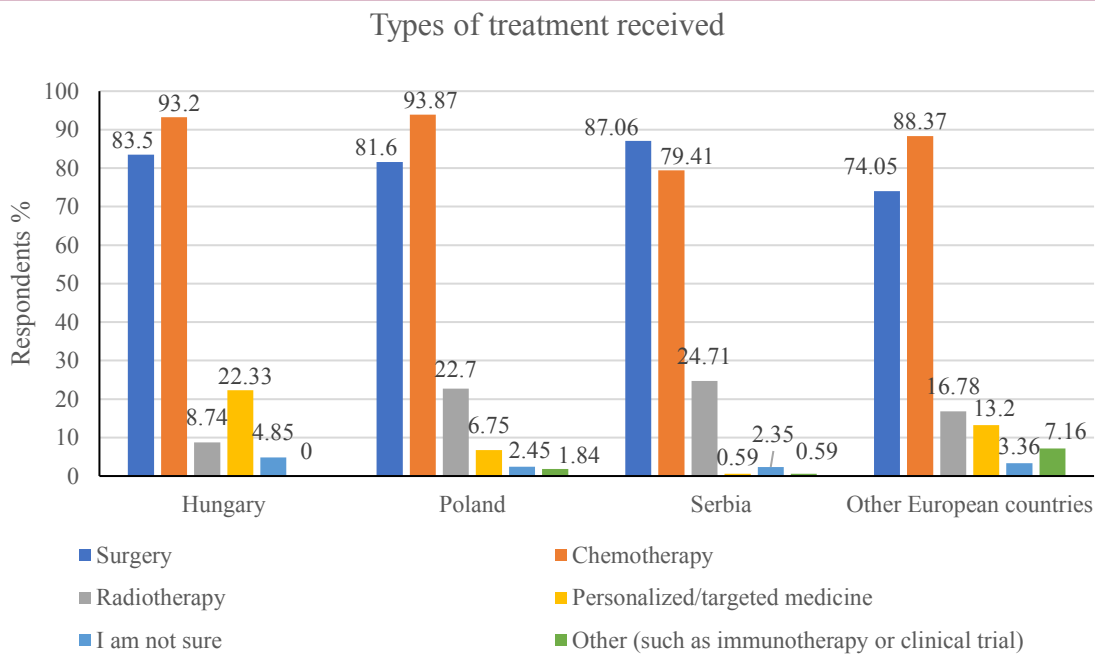
Patients stated that their partners and their children were their main source of support followed by their friends, and this was consistent across groups (figure 3, top left graph).



**Figure 1** Colorectal cancer (CRC) information provision at and after diagnosis for patients with metastatic CRC from Hungary, Poland, Serbia and other European countries. The top graph depicts the percentage of respondents who received clear information on different disease topics at diagnosis, while the bottom graph shows the topics that are most important for patients from each of the four groups.

Most patients were largely satisfied with the level of emotional support they received from clinicians and nurses, except for patients in Serbia who showed considerably lower levels of satisfaction (figure 3, top right graph). When asked what would improve the relationship with the

healthcare team the most overall popular response was ‘to be spoken to in a language I can understand’, which was opted by 56% of patients from Serbia. Although the percentages of the different responses varied among groups, other popular responses included inclusion in



**Figure 2** Types of treatment and molecular testing for patients with metastatic colorectal cancer from Hungary, Poland, Serbia and other European countries. The top graph depicts the different treatments that patients received, while the bottom graph shows the percentage of respondents who received molecular testing and their awareness around it.

shared decision-making and being treated as an individual and not as a number (figure 3, middle graph).

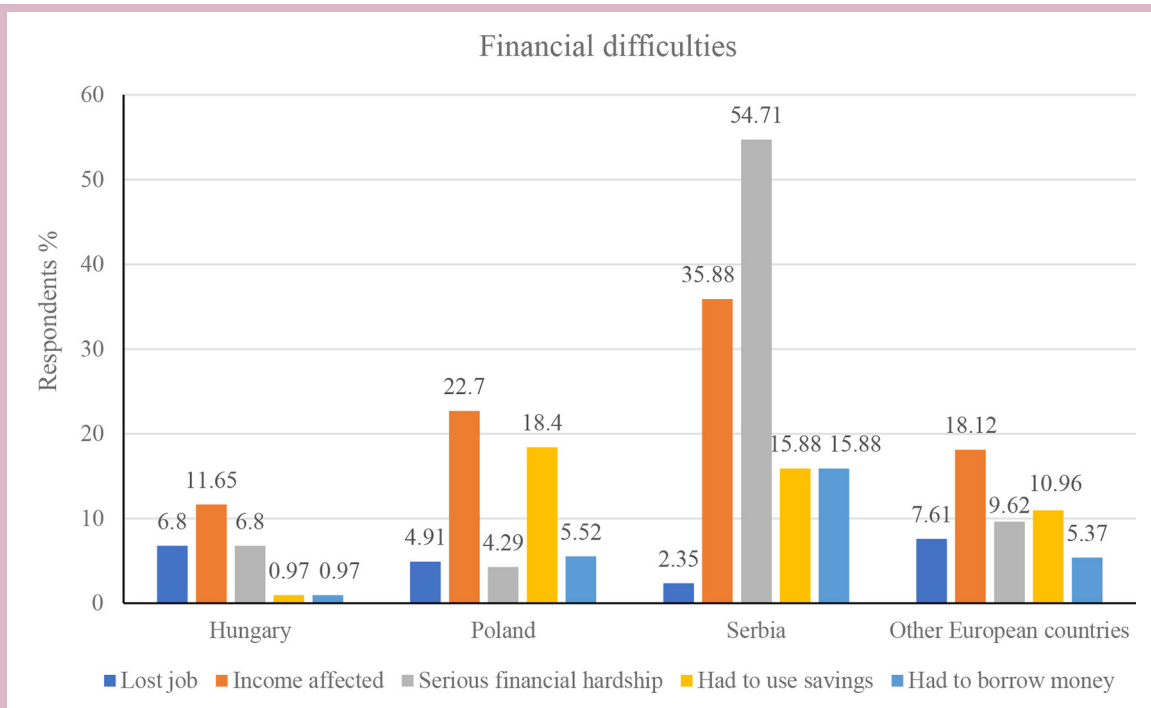
Patients were asked what would help that is not currently available to them; the top two answers selected among patients from Eastern Europe were a psychologist and talking to other patients, while those from other

European countries mostly preferred apps for mobiles and/or tablets and a psychologist. For patients from Eastern Europe, the next preferred option included patient support programmes or apps, while from other European countries, a helpline was among the first three preferences (figure 3, bottom graph).

**Figure 3.**



**Figure 3** Understanding the support provision and areas of improvement in the patient-healthcare professional (HCP) relationship in patients with metastatic colorectal cancer (mCRC) from Hungary, Poland, Serbia and other European countries.



**Figure 4** Financial hardship of patients with metastatic colorectal cancer from Hungary, Poland, Serbia and other European countries. Graph showing the percentage of the different problems patients from each of the four groups face.

### Impact on life

A very high number of respondents from Serbia (78.24%) said they had encountered difficulties (physical, financial or other) as a result of their CRC diagnosis, while 24.27% from Hungary, 48.47% from Poland and 37.36% from other European countries gave an affirmative response to this question. More patients from other European countries (7.61%) and Hungary (6.8%) lost their jobs compared with those from Poland (4.91%) and Serbia (2.35%). However, patients from Hungary seemed to be less affected financially because of their diagnosis compared with patients from the other groups (figure 4).

### DISCUSSION

CRC is differentiated from many other types of cancer in that it is 'preventable, treatable and beatable'.<sup>12</sup> However, it is still the second leading cause of cancer-related death in both men and women in Europe.<sup>3</sup> Therefore, it is instructive to look at the patient journey before, during and after diagnosis, to understand patients' challenges and barriers, which could be overcome to help improve outcomes.

The survey has highlighted some areas with considerable similarities and differences between patients with CRC from Eastern Europe versus those from other European countries as well as among patients from three Eastern European countries (Hungary, Poland and Serbia). These three countries not only share geographical similarities but also show high CRC mortality levels<sup>13</sup> and limitations in their healthcare systems compared with other countries in Europe.<sup>14</sup>

Our survey revealed lowest CRC symptom awareness among patients from Poland and highest among patients from Serbia compared with the other groups. Moreover, patients from Poland were also the least knowledgeable about CRC among the four groups of patients.

Although our survey included a variable number of patients (~5–18%) younger than 50 years old who would not have been invited to CRC screening, the number of eligible patients who had overall participated was very low in Hungary (1.94%) and Poland (3.07%) and relatively higher in Serbia (15.88%) and other European countries (13.20%). In 2015, 24 countries in the European Union had established or were preparing to organise country-wide CRC screening programmes for people 50 years or older.<sup>15</sup> An analysis of different programmes in several European countries showed that the lowest participation rates in Europe (eg, in Croatia and the Czech Republic) were under 25%,<sup>6</sup> but not as low as suggested by our survey. However, the All.Can survey<sup>16</sup> revealed that only 14% of patients with CRC said their diagnosis came about as part of a routine screening programme, which is similar to the result of our survey (13.2% of patients from other European countries).

Our survey also revealed a significant minority of patients who fall into the defined average-risk population for CRC screening (individuals  $\geq 50$  years, with no additional risk factors), but either were invited but declined the invitation to a screening programme (7% of patients from other European countries) or who would decline such an invitation if they received one (9% of patients from other European countries). These results



suggest a need for better awareness around CRC and CRC screening, which is supported by the relatively low percentage of patients (30% of patients from other European countries) who knew something about CRC prior to their diagnosis. However, although patients from Serbia were better informed about CRC before diagnosis (40% of patients) compared with the other patient groups, they would decline at a higher rate (~20%) a screening invitation if they received one. This indicates that other factors, such as cultural beliefs, misconceptions and different attitudes around CRC screening, may also contribute to low participation in screening programmes and emphasises the need to consider this when trying to improve screening patient uptake.

Our survey revealed differences in the time of diagnosis between patient groups; approximately 80% of respondents from Hungary and other European countries were diagnosed within the first month after the first consultation or positive screening test, while ~60% of patients from Poland and ~50% from Serbia were diagnosed within this time frame. An additional concern to the delays in diagnosis in patients from Serbia is the fact that approximately one-third of these patients were initially misdiagnosed, while in other European countries, the misdiagnosis rate was one in four. This corresponds to the findings from the All.Can survey, where 21% of respondents with CRC said their cancer was initially diagnosed as something different.<sup>16</sup>

It is reassuring that the majority of patients agreed or strongly agreed that they were given enough information by their HCPs. However, the percentages of informed patients varied among patient groups, with patients from Hungary (~90%) being the most informed and those from Serbia (~50%) the least. Well-informed patients from other European countries were ~68%, similar to the result produced by the All.Can survey, with 62% of patients saying they were given enough information about their cancer care and treatment.<sup>16</sup>

Patients from the four groups were generally satisfied with the level of information they received around the nature of the disease, examinations and treatments and consequences and side effects; however, substantial knowledge gaps remained around the origin, stages and progression of the disease, with approximately half or less than half of patients having received information on these topics. Previous studies have shown that patients with fulfilled information needs, and patients who experience less information barriers, in general have a better QoL and less anxiety and depression<sup>17</sup>; hence, adequate information provision is a very important need to address in the CRC patient journey. However, this information needs to be delivered in a clear, non-technical format, as highlighted by patients from all four groups.

Approximately 30% of patients from other European countries had to wait for more than a month to receive treatment, while in each of the three Eastern European countries, this reached ~50% of patients. Moreover, the number of patients from Eastern Europe who had to wait for more

than a year to receive treatment was considerably higher (3.9–5.5%) to that in other European countries (0.45%), raising concerns about the availability of hospitals, consultants and treatments in Eastern Europe, in accordance with the previous reports.<sup>14</sup> Prompt CRC treatment is crucial as studies have shown that survival is improved in patients treated within 30 days of their diagnosis.<sup>18</sup>

The latest treatment guidelines from the *European Society for Medical Oncology* state that biological (personalised) medicines are indicated for the treatment of patients with mCRC<sup>19</sup>; however, substantial variations in the number of patients who received personalised medicines was observed among the country groups, with the highest rates observed in Hungary (22%) and the lowest in Serbia (0.59%). This may be, at least in part, a consequence of the fact that at the time of the survey, personalised treatment for mCRC was not reimbursed in Poland and was reimbursed with restrictions in Serbia. The number of patients from Eastern Europe who received immunotherapy or participated in a clinical trial neared zero, while that of patients from other European countries was ~7%. Molecular testing practices also varied among patient groups, with ~50% or more of patients not knowing whether they had been tested or what RAS testing was.

The survey also revealed that when it comes to treatment decisions, most of patients' views are not considered, although the high percentage of positive answers by patients from Hungary was a promising exception. Patients in Serbia felt the least included in treatment decisions, in line with the fact they were the least aware of the type of chemotherapy drugs they received.

The survey confirms the vital role that family members have in supporting CRC patients, particularly partners and children, which was consistent throughout the four groups. It is estimated that family caregivers provide over half of the care needed by cancer patients<sup>20</sup> and that cancer patients want medical decisions to be made in conjunction with family members.<sup>21 22</sup> More than half of all patients were very satisfied with the emotional support they received from their clinicians and nurses, except for patients from Serbia who showed lower rates of satisfaction (~35%). In fact, patients from Serbia opted overall for more issues than need to be tackled to improve the relationship with the healthcare team compared with patients from the other three groups.

Approximately a quarter of patients from Eastern Europe said they would benefit from seeing a psychologist, with a slightly lower percentage among patients from other European countries. A previous report suggests that a significant minority of CRC survivors experience clinically meaningful distress across the trajectory of the illness,<sup>23</sup> validating the need for professional support for some patients. The number of patients who agreed that talking to other patients and having patient support programmes in place would help (but are not currently available) shows the importance of building communities of patients. In addition, the request for specific apps

highlights the importance that technology can play in supporting patients.

It is not surprising that at least one in five of the respondents from the four groups had encountered difficulties during their patient journey. However, it is concerning that this was the case among ~50% and ~80% of patients in Poland and Serbia, respectively, in agreement with the highest number of patients from these countries having their income negatively affected as a result of their diagnosis.

Although we cannot be absolutely certain about the generalisability of the data presented, several facts are in favour of it. As mentioned above, some of the results captured were in accordance with those obtained in the All.Can survey.<sup>16</sup>

In addition, the answers of patients from Eastern Europe, and especially those from Serbia and Poland, revealed the biggest gaps in information provision, treatment availability and support, which coincides with the fact that these countries have more limited healthcare resources compared with those of other European countries.<sup>14</sup>

Even though this survey represents the first attempt to capture different stages of the mCRC patient journey, it has some limitations. One can argue that the patient sample (883 patients overall; 447 patients from other European countries) is not large enough to draw strong conclusions. However, the All.Can International Cancer Patient Survey aiming at obtaining the patient perspective in insufficiencies in cancer care is considered the biggest survey of its kind with 3981 respondents from more than 10 countries worldwide,<sup>16</sup> reflecting that recruiting large number of cancer patients is challenging. Other limitations include that the number of screening participants might be underestimated due to a selection bias since the survey was addressed to patients at the metastatic stage rather than to all patients with CRC.

## CONCLUSION

Faced with CRC being the second leading cause of cancer-related death in Europe, it is essential to look at the patient journey from all perspectives. The survey revealed several key areas in CRC that require attention and improvement, including awareness of CRC and its symptoms, low rates of CRC screening and a reluctance to participate even if available, lack of provision of information and the need for greater patient support including psychologists, patient networks and patient support programmes.

### Author affiliations

<sup>1</sup>Digestive Cancers Europe, Brussels, Belgium

<sup>2</sup>EuropaColon Polska, Otwock, Poland

<sup>3</sup>Evidera Budapest, Budapest, Central Hungary, Hungary

<sup>4</sup>Department of Oncology and Radiotherapy, Maria Skłodowska-Curie Memorial Cancer Center, Warsaw, Poland

<sup>5</sup>Department of Internal Medicine, Semmelweis University, Budapest, Hungary

<sup>6</sup>Medical Oncology Research Laboratory, Ramón y Cajal Health Research Institute (IRYCIS), Madrid, Spain

<sup>7</sup>Department of Clinical Sciences, University of Barcelona, Barcelona, Catalunya, Spain

<sup>8</sup>Department of Medical Oncology, Hospital Universitario Puerta de Hierro Majadahonda, Majadahonda, Comunidad de Madrid, Spain

<sup>9</sup>Department of Oncology, Semmelweis University of Medicine, Budapest, Hungary

<sup>10</sup>Health Education, COPE-Unlimited, Kermt, Belgium

<sup>11</sup>Department of Surgery, Vall d'Hebron University Hospital, Barcelona, Catalunya, Spain

<sup>12</sup>Dom Zdravlja Vozdovac, Belgrade, Serbia

**Twitter** Iga Rawicka @IgaRawicka

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### ORCID iDs

Zorana Maravic <http://orcid.org/0000-0001-6263-0313>

Vassiliki Fotaki <http://orcid.org/0000-0001-9112-3257>

Alfredo Carrato <http://orcid.org/0000-0001-7749-8140>

## REFERENCES

- American Cancer Society. What is colorectal cancer? Available: <https://www.cancer.org/cancer/colon-rectal-cancer/about/what-is-colorectal-cancer.html>
- Ferlay J, Colombet M, Soerjomataram I, *et al*. Cancer incidence and mortality patterns in Europe: estimates for 40 countries and 25 major cancers in 2018. *Eur J Cancer* 2018;103:356–87.
- World Health Organization. Colorectal cancer. Available: <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/news/news/2012/2/early-detection-of-common-cancers/colorectal-cancer>
- American Society of Colon and Rectal Surgeons. Colon cancer myths vs reality. Available: <https://www.fascrs.org/patients/disease-condition/colon-cancer-myths-vs-reality>
- Cancer.net. Colorectal cancer – statistics. Available: <https://www.cancer.net/cancer-types/colorectal-cancer/statistics>
- International Agency for Research on Cancer. *Cancer screening in the European Union report on the implementation of the Council recommendation on cancer screening*, 2017.
- Senore C, Basu P, Anttila A, *et al*. Performance of colorectal cancer screening in the European Union member states: data from the second European screening report. *Gut* 2019;68:1232–44.
- Wong EYT, Chua C, Beh SY, *et al*. Addressing the needs of colorectal cancer survivors: current strategies and future directions. *Expert Rev Anticancer Ther* 2015;15:639–48.
- McMullen CK, Bulkley JE, Altschuler A, *et al*. Greatest challenges of rectal cancer survivors: results of a population-based survey. *Dis Colon Rectum* 2016;59:1019–27.

- 10 Frick MA, Vachani CC, Hampshire MK, *et al.* Survivorship after lower gastrointestinal cancer: patient-reported outcomes and planning for care. *Cancer* 2017;123:1860–8.
- 11 Chongpison Y, Hornbrook MC, Harris RB, *et al.* Self-reported depression and perceived financial burden among long-term rectal cancer survivors. *Psychooncology* 2016;25:1350–6.
- 12 Bean KB. Colorectal cancer: preventable, treatable, and beatable! *Gastroenterol Nurs* 2005;28:1–2.
- 13 Globocan. *Estimated cancer incidence mortality and prevalence worldwide in 2012*, 2012.
- 14 Minicozzi P, Walsh PM, Sánchez M-J, *et al.* Is low survival for cancer in eastern Europe due principally to late stage at diagnosis? *Eur J Cancer* 2018;93:127–37.
- 15 Navarro M, Nicolas A, Ferrandez A, *et al.* Colorectal cancer population screening programs worldwide in 2016: an update. *World J Gastroenterol* 2017;23:3632–42.
- 16 All.can. *Patient insights on cancer care: opportunities for improving efficiency*, 2019.
- 17 Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 2011;22:761–72.
- 18 Roder D, Karapetis CS, Olver I, *et al.* Time from diagnosis to treatment of colorectal cancer in a South Australian clinical Registry cohort: how it varies and relates to survival. *BMJ Open* 2019;9:e031421.
- 19 Van Cutsem E, Cervantes A, Adam R, *et al.* ESMO consensus guidelines for the management of patients with metastatic colorectal cancer. *Ann Oncol* 2016;27:1386–422.
- 20 Blum K, Sherman DW. Understanding the experience of caregivers: a focus on transitions. *Semin Oncol Nurs* 2010;26:243–58.
- 21 Schäfer C, Putnik K, Dietl B, *et al.* Medical decision-making of the patient in the context of the family: results of a survey. *Support Care Cancer* 2006;14:952–9.
- 22 Hobbs GS, Landrum MB, Arora NK, *et al.* The role of families in decisions regarding cancer treatments. *Cancer* 2015;121:1079–87.
- 23 Mosher CE, Winger JG, Given BA, *et al.* Mental health outcomes during colorectal cancer survivorship: a review of the literature. *Psychooncology* 2016;25:1261–70.