DIGESTIVE CANCERS
EUROPE

Understanding the Experience and Needs of Patients with Metastatic Colorectal Cancer

Results of a European Patient Survey

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Background

[Digestive Cancers Europe](#) (DiCE) is the European umbrella organisation of a large group of [national Members](#) that offer support to patients with digestive cancers (colon, rectal, gastric, oesophageal, liver, pancreas and rare digestive cancers). We have links with over 30 patient organisations from the European World Health Organisation (WHO) region. Our mission is to contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life (QoL).

From June 2017 to December 2018, DiCE (at the time EuropaColon) conducted a survey in 15 European countries. The purpose of the survey was to identify gaps in the patient journey (before, during and after diagnosis) of patients with metastatic colorectal cancer (mCRC) across Europe and to understand areas with similarities and differences among different countries.

Here, we present the key results of our survey that offer insights on the mCRC patient journey. Part of these results have been published in the open access scientific journal *ESMO Open* (Maravic et al., 2020).

About this survey

The survey consisted of two parts. The purpose of the first part 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 across Europe.

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 reported separately.

The first part of the survey was developed by DiCE (formerly EuropaColon) and their Expert Patient Advisory Group (EPAG). It was reviewed by Evidera, who are experts in outcomes research. The first part of the survey included questions related to the **patient profile**; the second part of the survey 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**; 2. **diagnosis**; 3. **treatment**; and 4. **patient support**.

Patient participation and recruitment

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 either downloaded or 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 and was translated into 10 languages (Table 1). We 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.

Survey limitations

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) 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,[1] reflecting that recruiting large number of cancer patients is challenging. In addition, although all patients were at the metastatic stage, we did not distinguish between newly diagnosed patients or patients that had been under treatment for a few or several years.

Other limitations include that the number of participants who participated in screening 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.

Results

A. Patients' characteristics

A total of 883 patients across 15 countries in Europe, who had received a diagnosis of mCRC, completed the survey (Table 1).

Table 2 shows the overall characteristics of the respondents.

Table 1. Survey languages and country participants

Country	Language	Number of participants	% of total responses
Serbia	Serbian	170	19.25
Poland	Polish	163	18.46
Spain	Spanish	112	12.68
Hungary	Hungarian	103	11.66
Belgium	Dutch	65	7.36
Cyprus	Greek	57	6.46
United Kingdom	English	53	6.00
The Netherlands	Dutch	40	4.53
Italy	Italian	36	4.08
Turkey	Turkish	26	2.94
Portugal	Portuguese	24	2.72
Other countries*	German/English	34	3.85

* Other countries included participants from Germany, Austria, Ireland and Norway; because of the low percentage of total responses from each of these countries (< 2.5%), the data break-down from each of these countries is not included in this report.

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Table 2. Respondents' characteristics

Characteristics	Variables	Number	Percentage
Sex	Male	405	45.87
	Female	373	42.24
	No response	105	11.89
Age (years)*	≥ 71	186	21.06
	61–70	367	41.56
	51–60	204	23.10
	≤ 50	85	9.63
	No response	41	4.64
Marital Status	Single	41	4.87
	Married/Partner	687	81.59
	Divorced	60	7.13
	Widowed	91	10.81
	No response	4	0.45
Areas of living	Rural	168	19.95
	Semi-urban	271	32.19
	Urban	232	27.55
	Capital City	206	24.47
	No response	6	0.68
Education	None	6	0.71
	Primary	170	20.19
	Secondary	364	43.23
	College	149	17.70
	University	152	18.05
	Postgraduate	57	6.77
	I don't know	6	0.71
	No response	14	1.59
Employment	Employed	185	21.97
	Unemployed	34	4.04
	Retired	502	59.62
	Unemployed due to a medical condition	79	9.38
	Student/Intern	2	0.24
	Other	55	6.53
	No response	16	1.81

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

B.   The patient journey
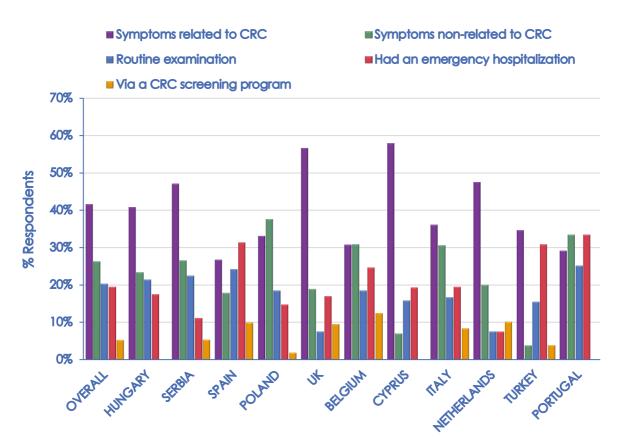
1. The patient journey – pre-diagnosis

What is it we wanted to understand?

- **How much do citizens of Europe know about the symptoms of CRC?**
- **How do citizens in Europe feel about CRC screening? CRC awareness**
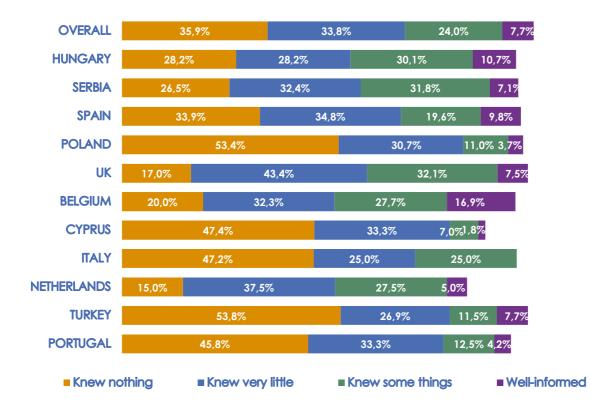
Most patients (~42%) consulted their physician/family doctor because of CRC-related symptoms (Figure 1-1). However, prior to diagnosis they had limited awareness regarding CRC (Figure 1-2) and not a clear understanding that their symptoms were CRC-related (Figure 1-3). Most patients visited their physician for the first time within a month from the moment they observed their symptoms (~39%) or within a period of 1−3 months (~30%) (Figure 1-4).

Figure 1-1. Why did you consult your physician?

Figure 1-2. What was your understanding of colorectal cancer prior to your diagnosis?

	Knew nothing	Knew very little	Knew some things	Well-informed
OVERALL	35,9%	33,8%	24,0%	7,7%
HUNGARY	28,2%	28,2%	30,1%	10,7%
SERBIA	26,5%	32,4%	31,8%	7,1%
SPAIN	33,9%	34,8%	19,6%	9,8%
POLAND	53,4%	30,7%	11,0%	3,7%
UK	17,0%	43,4%	32,1%	7,5%
BELGIUM	20,0%	32,3%	27,7%	16,9%
CYPRUS	47,4%	33,3%	7,0%	1,8%
ITALY	47,2%	25,0%	25,0%	
NETHERLANDS	15,0%	37,5%	27,5%	5,0%
TURKEY	53,8%	26,9%	11,5%	7,7%
PORTUGAL	45,8%	33,3%	12,5%	4,2%

Figure 1-3. Were you aware of CRC symptoms prior to diagnosis?

	No, I was not aware	Yes, I was aware of some or all of the symptoms	I am not sure
OVERALL	58,9%	28,4%	13,3%
HUNGARY	60,2%	29,1%	8,7%
SERBIA	31,8%	37,6%	25,9%
SPAIN	67,9%	21,4%	5,4%
POLAND	70,6%	10,4%	14,7%
UK	39,6%	52,8%	5,7%
BELGIUM	58,5%	35,4%	3,1%
CYPRUS	57,9%	21,1%	14,0%
ITALY	77,8%	16,7%	5,6%
NETHERLANDS	55,0%	30,0%	2,5%
TURKEY	57,7%	15,4%	26,9%
PORTUGAL	62,5%	37,5%	

■ No, I was not aware   ■ Yes, I was aware of some or all of the symptoms   ■ I am not sure

Figure 1-4. Time to first consultation after observing symptoms for first time

	Less than a month	1–3 months	3–6 months	6–12 months	1 year or more
OVERALL	38,6%	30,0%	12,0%	5,1%	7,5%
HUNGARY	42,7%	30,1%	8,7%	6,8%	5,8%
SERBIA	27,6%	32,9%	19,4%	7,6%	4,7%
SPAIN	42,0%	26,8%	6,3%	0,9%	4,5%
POLAND	28,2%	31,9%	13,5%	4,9%	9,8%
UK	34,0%	41,5%	7,5%	3,8%	7,5%
BELGIUM	46,2%	24,6%	4,6%	4,6%	7,7%
CYPRUS	36,8%	22,8%	8,8%	1,8%	15,8%
ITALY	36,1%	22,2%	8,3%	2,8%	19,4%
NETHERLANDS	45,0%	20,0%	10,0%	5,0%	5,0%
TURKEY	61,5%	26,9%	7,7%	3,8%	
PORTUGAL	41,7%	12,5%	29,2%	4,2%	4,2%

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In a few words…

Despite the fact that CRC is the cancer type with the third highest frequency among men and women in Europe, people's awareness around CRC symptoms (prior to diagnosis) is not very high. National and EU campaigns are needed to raise public awareness around CRC symptomology, so people seek medical support more actively and visit their doctor promptly when CRC-related symptoms appear.

Screening

CRC can be highly preventable if detected early. Although our survey included ~14% of patients (5–39%) younger than 50 years old who would not have been invited to CRC screening, the overall number of eligible patients who had participated in screening reached a low 11% (Figure 1-5).

Established facts

In 2015, 24 countries in the European Union had established or were preparing to organize country-wide CRC screening programmes.[2] An analysis of different programs in several European countries showed that the lowest participation rates in Europe (e.g. in Croatia and the Czech Republic) were under 25%,[3] but not as low as suggested by our survey. However, the All.Can patient survey revealed that only 14% of patients with CRC said their diagnosis came about as part of a routine screening programme,[1] which nears the result of our survey.

Our survey also revealed a significant minority of patients who fall into the defined average-risk population for CRC screening (individuals ≥ 50 years, with no additional risk factors), but either were invited but declined the invitation to a screening programme (7%) or who would decline such an invitation if they received one (13%). These results suggest a need for better awareness around CRC and CRC screening, which is supported by the relatively low percentage of patients (~32%) who "knew something" or were "well-informed" about CRC prior to their diagnosis. However, although patients from Serbia and Hungary were better informed about CRC before diagnosis (~40% of patients) compared to the other patient groups (Figure 1-2), they would decline at a higher rate (~18% in Hungary and ~21% in Serbia compared to 13% overall) a screening invitation if they received one (Figure 1-5). 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, emphasising the need to take these additional factors into account when trying to improve screening patient uptake.

Figure 1-5. In relation to screening, which of the following describes you best?

- Diagnosed via participation in a CRC screening program
- Although >50 not invited but would go
- Invited to participate in a CRC screening program but declined
- Although >50 not invited but would NOT go
- <50 years old

	Diagnosed via participation	Although >50 not invited but would go	Invited but declined	Although >50 not invited but would NOT go	<50 years old
OVERALL	11,0%	45,2%	6,5%	12,9%	13,9%
HUNGARY	1,9%	54,4%	3,9%	17,5%	15,5%
SERBIA	15,9%	40,0%	9,4%	20,6%	7,1%
SPAIN	20,5%	31,3%	6,3%	8,0%	6,3%
POLAND	3,1%	60,7%	1,2%	9,8%	4,9%
UK	24,5%	32,1%	9,4%	5,7%	26,4%
BELGIUM	9,2%	27,7%	20,0%	3,1%	12,3%
CYPRUS	1,8%	42,1%		21,1%	17,5%
ITALY	16,7%	38,9%	8,3%	22,2%	13,9%
NETHERLANDS	17,5%	47,5%	5,0%	2,5%	15,0%
TURKEY	3,8%	46,2%		7,7%	38.5%
PORTUGAL	4,2%	25,0%	8,3%	4,2%	37,5%

In a few words…

CRC screening practices are still not customary among European citizens. The number of patients over 50 years of age who attend screening is lower than the minimum of 45% participation rate recommended in Europe (the desirable rate is 65%)[4–6]. This low attendance may be the result of limitations of national health systems but also of additional factors that may include lack of awareness, cultural barriers and personal misbeliefs. Governments should promote screening strategies – not only do they save lives and result in better QoL because of a reduced need for treatments, but they benefit societies more broadly at financial, physiological and emotional levels. National governments and patient organisations should work together towards this clear and tangible goal.

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2. The patient journey – diagnosis

What is it that we wanted to understand?
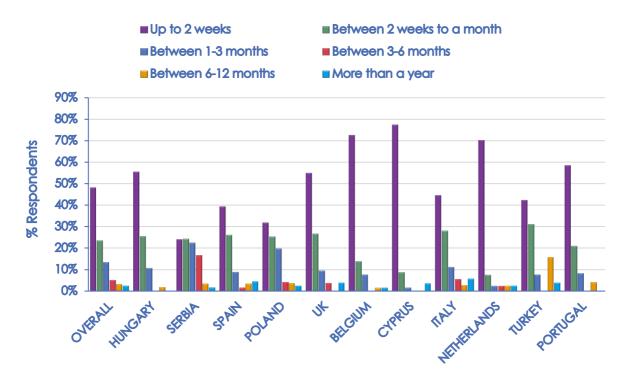
- **Is CRC diagnosed promptly among European patients?**
- **What is the percentage of initial errors in the diagnosis?**
- **Are patients satisfied with the process that leads to diagnosis?**
- **What are the gaps in the information patients receive when first diagnosed?**
- **What are the information sources patients choose?**

The process of diagnosis

A prompt and accurate diagnosis is key in providing appropriate CRC management. Most patients (~71%) were diagnosed within two to four weeks after the first consultation (Figure 2-1). However, ~25% of respondents were initially given a wrong diagnosis (Figure 2-2). This approximates the findings from the All.Can survey, where 21% of respondents with CRC said their cancer was initially diagnosed as something different.[1]

Overall, ~40% of patients were very satisfied with the process that led to their diagnosis, while ~20% were very dissatisfied (Figure 2-3).

Figure 2-1. How soon were you diagnosed with CRC after the first consultation or positive screening test?

Figure 2-2. Percentages of respondents whose colorectal cancer was initially misdiagnosed

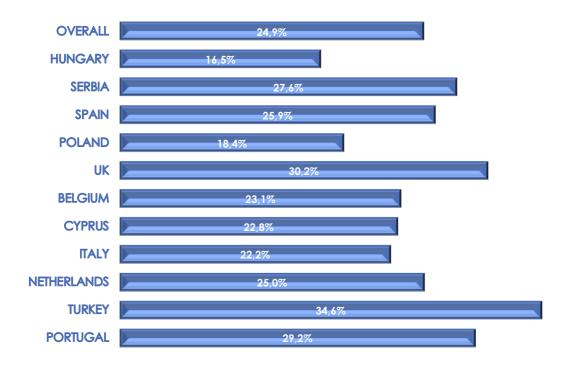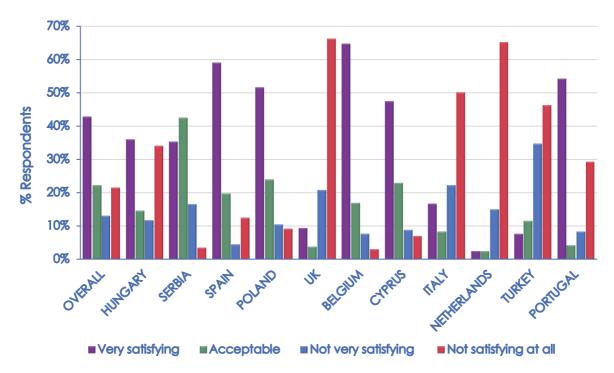| Country	Percentage
OVERALL	24,9%
HUNGARY	16,5%
SERBIA	27,6%
SPAIN	25,9%
POLAND	18,4%
UK	30,2%
BELGIUM	23,1%
CYPRUS	22,8%
ITALY	22,2%
NETHERLANDS	25,0%
TURKEY	34,6%
PORTUGAL	29,2%

Figure 2-3. How would you rate the process of establishing your diagnosis?

In a few words…

In most cases, CRC diagnosis in Europe is achieved within a month, a very reasonable timeframe. However, the fact that CRC may be mistaken initially for another condition (i.e. inflammatory bowel syndrome, haemorrhoids, etc.) in one out of four patients (in close agreement with the percentage of dissatisfied patients), is a worrying figure, which highlights that awareness around CRC symptomology needs to be increased among primary care physicians.

Information provision at diagnosis

Established facts
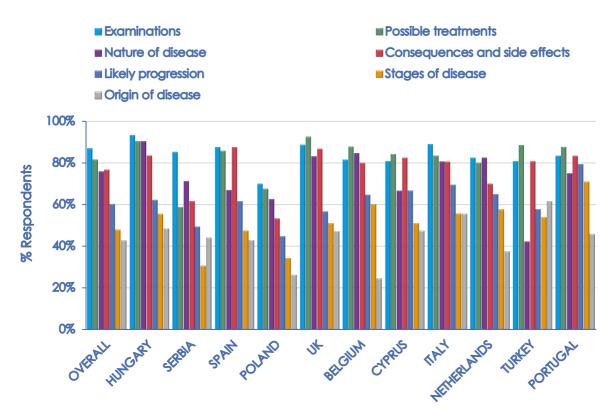
Patients with fulfilled information needs and patients who experience less information barriers in general have a better QoL and less anxiety and depression[7]; hence, adequate information provision is a very important need to address in the CRC patient journey.

Patients 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 only half or less than half of patients having received information on these topics (Figure 2-4).

Approximately 68% of patients sought additional information (Figure 2-5) from a variety of sources, with the three top options being the internet (46%), the general practitioner or family doctor (26%) and other patients with CRC (21%) (Figure 2-6).

Figure 2-4. Percentage of respondents who received information on the following topics

Figure 2-5. Percentage of respondents who sought additional information around their disease

Country	Percentage
OVERALL	68,4%
HUNGARY	61,2%
SERBIA	72,4%
SPAIN	43,8%
POLAND	78,5%
UK	69,8%
BELGIUM	50,8%
CYPRUS	52,6%
ITALY	69,4%
NETHERLANDS	77,5%
TURKEY	80,8%
PORTUGAL	58,3%
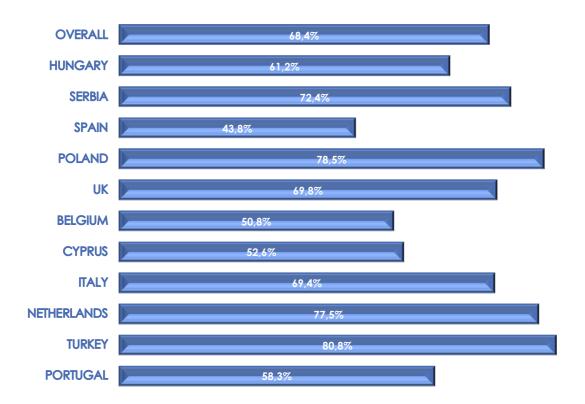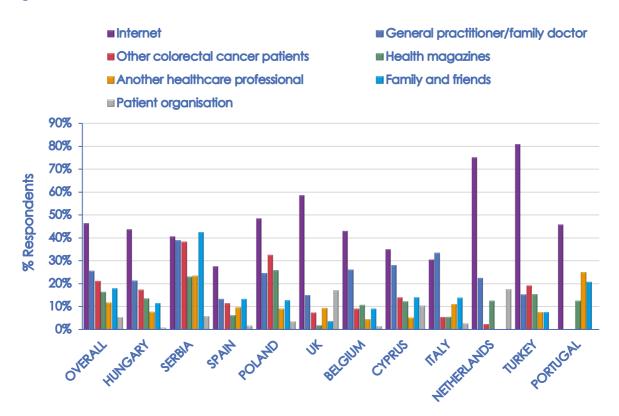
Figure 2-6. Sources of additional information

Legend:
- Internet
- General practitioner/family doctor
- Other colorectal cancer patients
- Health magazines
- Another healthcare professional
- Family and friends
- Patient organisation

Y-axis: % Respondents (0% to 90%)

X-axis categories: OVERALL, HUNGARY, SERBIA, SPAIN, POLAND, UK, BELGIUM, CYPRUS, ITALY, NETHERLANDS, TURKEY, PORTUGAL

In a few words…

Information around a great range of topics is provided to patients with CRC. However, gaps still exist and even the best-informed patients will keep searching for information, especially on the internet. This highlights the importance of providing clear and patient-friendly information. Patient organisations are placed in an ideal position for providing patient information that is reliable, relevant and in the right tone, helping patients to resolve any additional doubts using trustworthy and easy to understand sources.

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3. The patient journey – after diagnosis: treatment

What is it we wanted to understand?

- **Is treatment provision delayed after a CRC diagnosis?**
- **What are the most common types of treatment European patients with CRC receive?**
- **Do patients with CRC have the opportunity to participate in clinical trials?**
- **How aware are patients of their treatment and of molecular testing?**
- **Are patients' views taken into consideration?**
- **To whom from the healthcare team will a patient most likely reach out to for medical information and what type of information is most relevant to patients?**
- **Do patients receive sufficient information about their treatment and related side effects?**
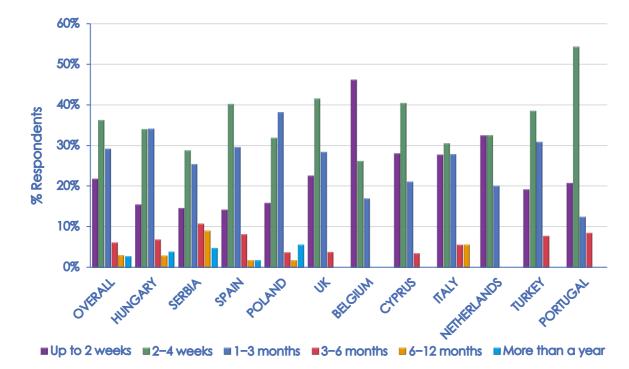
Time to treatment

Established facts

Prompt CRC treatment is crucial as studies have shown that survival is improved in patients treated within 30 days of their diagnosis.[8,9]

Most patients (~58%) started treatment within a month of diagnosis ([Figure 3-1]). However, ~3% of patients waited for more than a year to start treatment after diagnosis; this was mainly observed in Eastern European countries (Hungary, Poland and Serbia), raising concerns about the availability of hospitals, consultants and treatments in Eastern Europe, in accordance with previous reports.[10]

Figure 3-1. Time between diagnosis and initiation of treatment

Legend: ■ Up to 2 weeks ■ 2–4 weeks ■ 1–3 months ■ 3–6 months ■ 6–12 months ■ More than a year

Types of treatment

Patient treatment mainly included surgery (~83%) and chemotherapy (~93%) (Figure 3-2).

The latest treatment guidelines from ESMO (European Society for Medical Oncology) state that biological (personalised) medicines are indicated for the treatment of patients with mCRC[11]; however, substantial variations in the number of patie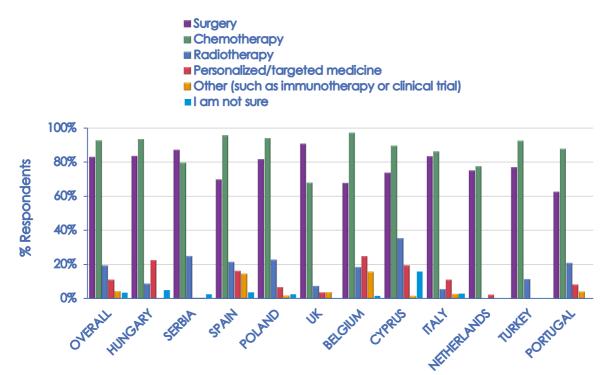nts who received personalised medicines was observed among the country groups, with the highest rates observed in Belgium (~24%) and Hungary (~22%) and the lowest in Serbia (0.59%) and Turkey (0%), which may be, at least in part, a consequence of differences in market access and reimbursement policies among different countries. It should be noted that these numbers do not capture the treatments of ~3.3% of respondents who were not aware of the type of treatment they were receiving.

The overall number of patients who were offered to participate in a clinical trial was ~28%; however, the variation among different countries was substantial (Figure 3-3). Molecular testing practices also varied among patient groups, with more than 50% of patients not knowing whether they had been tested for the biomarker RAS or what RAS testing was (Figure 3-4).

Figure 3-2. Percentage of respondents who received the following treatments

- Surgery
- Chemotherapy
- Radiotherapy
- Personalized/targeted medicine
- Other (such as immunotherapy or clinical trial)
- I am not sure

Figure 3-3. Percentage of respondents who were offered to participate in a clinical trial

OVERALL	28,1%
HUNGARY	35,9%
SERBIA	16,5%
SPAIN	42,9%
POLAND	19,6%
UK	17,0%
BELGIUM	52,3%
CYPRUS	7,0%
ITALY	16,7%
NETHERLANDS	30,0%
TURKEY	30,8%
PORTUGAL	4,2%

Figure 3-4. Did you undergo molecular testing (RAS)?

	Yes	No	I don't know	I don't know what this is
OVERALL	21,7%	18,3%	27,7%	29,3%
HUNGARY	15,5%	31,1%	26,2%	24,3%
SERBIA	5,3%	24,7%	24,1%	38,2%
SPAIN	21,4%	3,6%	33,9%	31,3%
POLAND	31,9%	17,8%	30,1%	12,9%
UK	18,9%	17,0%	20,8%	41,5%
BELGIUM	26,2%	6,2%	24,6%	36,9%
CYPRUS	12,3%	26,3%	17,5%	33,3%
ITALY	44,4%	8,3%	30,6%	13,9%
NETHERLANDS	20,0%	15,0%	25,0%	25,0%
TURKEY	30,8%	7,7%	15,4%	38,5%
PORTUGAL	29,2%	16,7%	41,7%	8,3%

■ Yes ■ No ■ I don't know ■ I don't know what this is

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In a few words…

Although an encouraging 60% of patients received treatment within a month after diagnosis, it is very worrying that ~3% of patients waited for at least a year before being treated. Not surprisingly, the most common treatments among patients with CRC across Europe were surgery and chemotherapy. However, not all patients were aware about the type of treatment they received, and half of the respondents were not informed about RAS testing, a biomarker that can guide decisions around treatment.[11,12]

Communication and information around treatment

Effective communication between patients and healthcare professionals contributes to patient well-being. Although 64% of patients agreed with the statement that their treatment had been discussed with the multidisciplinary team and they had been informed about the outcome, 25% were not sure (Figure 3-5). Patients from Poland showed lower levels of agreement with this statement (41%) and higher levels of uncertainty (43%) (Figure 3-5).
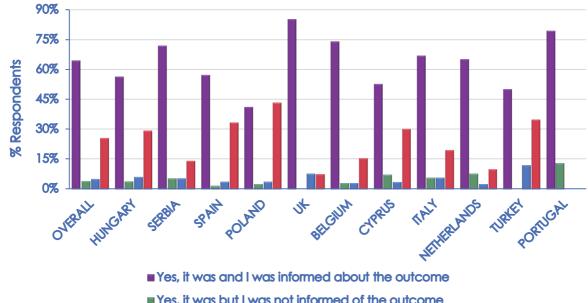
More than 50% of patients from most countries felt that their views were considered; however, only 29% of patients from Serbia and 11% from the UK shared this view (Figure 3-6).

In all countries the oncologist was the main contact person for medical-related information (~84% overall) (Figure 3-7).

The three most important information topics for patients were about the disease, treatment options and treatment side effects (Figure 3-8).

Overall, ~75% of all patients felt they were given clear information about the side effects of treatment (Figure 3-9), and the same percentage of patients felt that their treatment was as explained (Figure 3-10).

Figure 3-5. Was your treatment discussed with the multidisciplinary team?
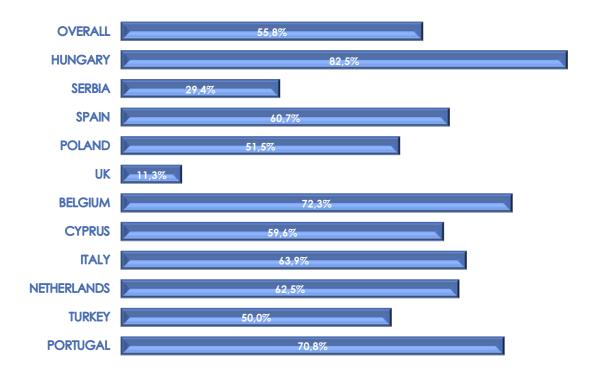
Legend:
- Yes, it was and I was informed about the outcome
- Yes, it was but I was not informed of the outcome
- No, as far as I am aware, it was not
- I don't know

Figure 3-6. Percentage of respondents who felt their views were considered

OVERALL	55,8%
HUNGARY	82,5%
SERBIA	29,4%
SPAIN	60,7%
POLAND	51,5%
UK	11,3%
BELGIUM	72,3%
CYPRUS	59,6%
ITALY	63,9%
NETHERLANDS	62,5%
TURKEY	50,0%
PORTUGAL	70,8%

Figure 3-7. Who is your most valuable contact for medical information?
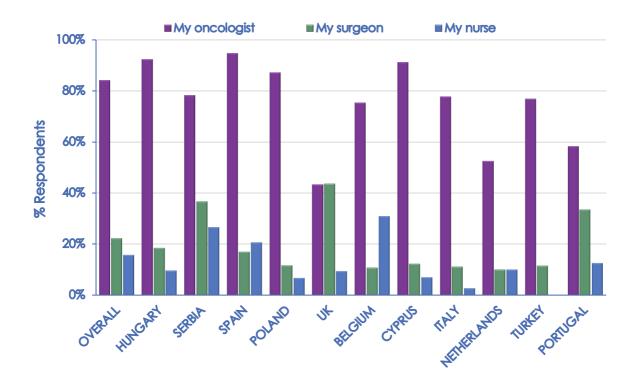
Figure 3-8. Information topics important for patients

Legend:
- Disease
- Treatment options
- Treatment side effects
- Clinical trials
- Physicians/hospitals/health-centers
- Patient support groups
- Telephone helplines
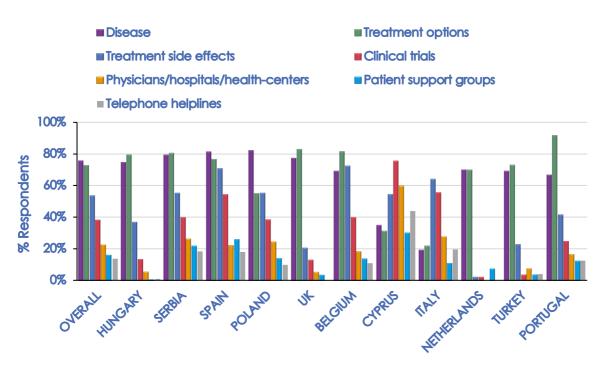
Figure 3-9. Were you given clear information regarding the side effects of your treatment?

	Yes	I am not sure	No
OVERALL	74,2%	13,2%	9,3%
HUNGARY	90,3%	4,9%	3,9%
SERBIA	48,2%	28,2%	14,7%
SPAIN	88,4%	6,3%	1,8%
POLAND	62,0%	17,8%	11,7%
UK	75,5%	13,2%	9,4%
BELGIUM	75,4%	6,2%	3,1%
CYPRUS	78,9%	3,5%	3,5%
ITALY	75,0%	8,3%	13,9%
NETHERLANDS	65,0%	10,0%	10,0%
TURKEY	65,4%	7,7%	19,2%
PORTUGAL	79,2%		12,5%

![Digestive Cancers Europe logo]
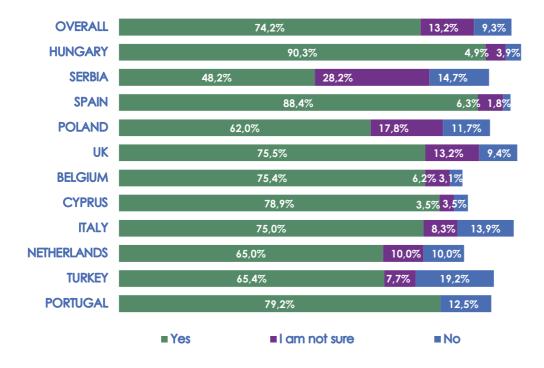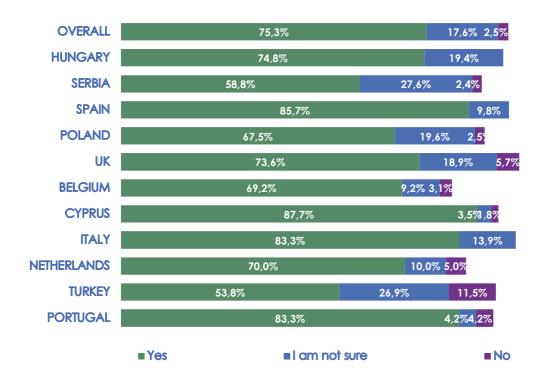
Figure 3-10. Was your treatment as explained?

Country	Yes	I am not sure	No
OVERALL	75,3%	17,6%	2,5%
HUNGARY	74,8%	19,4%	
SERBIA	58,8%	27,6%	2,4%
SPAIN	85,7%	9,8%	
POLAND	67,5%	19,6%	2,5%
UK	73,6%	18,9%	5,7%
BELGIUM	69,2%	9,2%	3,1%
CYPRUS	87,7%	3,5%	1,8%
ITALY	83,3%	13,9%	
NETHERLANDS	70,0%	10,0%	5,0%
TURKEY	53,8%	26,9%	11,5%
PORTUGAL	83,3%	4,2%	4,2%

■ Yes ■ I am not sure ■ No

In a few words…

Patients mostly seek information on disease, treatments and side effects and the oncologist is the person they will primarily turn to for medical information. However, patient-HCP communication leaves a lot of room for improvement and is still poor in some European countries where the patient's voice is not particularly considered.
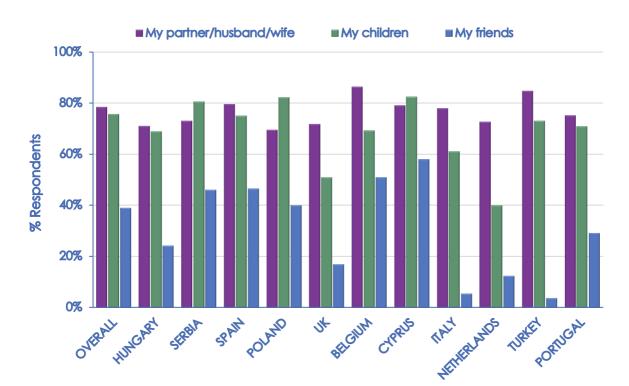
4. The patient journey – after diagnosis: support and obstacles

What is it we wanted to understand?

- **Who supports patients mostly?**
- **How satisfied are patients with the hospital care and the emotional support offered by HCPs?**
- **How can the relationship with the healthcare team become better?**
- **What are the principal gaps in patient support?**
- **To what extent do difficulties during examinations and treatments affect patients?**
- **What are the main side effects of treatment?**
- **What are the main financial difficulties patients encounter?**

Support levels and gaps

The main sources of support for all patients were their families (Figure 4-1), a finding consistent throughout all countries, which confirms the vital role that partners and children have in supporting CRC patients.

Figure 4-1. Who was your main source of support?

The majority of patients reported high levels of satisfaction with the care received in their hospital with only ~12% reporting fair or poor care (Figure 4-2). Similarly, in most countries more than 50% of patients felt they received adequate emotional support from their doctor and nurse (Figure 4-3), although the percentages varied in different countries.

When asked what would improve the relationship with the healthcare team, most patients (~37%) opted for "being spoken to in a language I can understand". Although the percentages of the different responses varied among groups, other popular responses included "being included in shared decision-making" (~25%) and "being treated as an individual and not as a number" (~25%) (Figure 4-4).

Patients were asked what would help that is not currently available to them; the five most popular responses included a psychologist (~26%), talking to other patients (25%), patient support programmes (~23%), mobile/tablet applications (apps) (~20%) and a telephone help-line (~17%)(Figure 4-5).
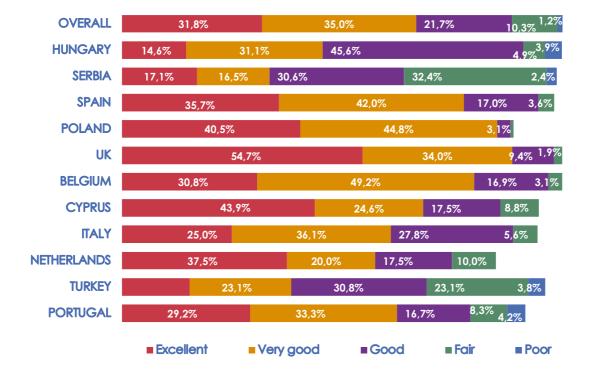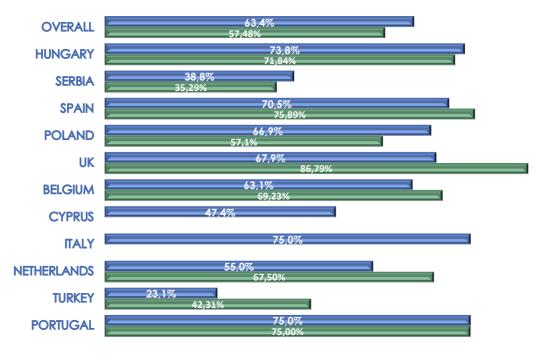
Figure 4-2. How would you rate the care received in your hospital?

Figure 4-3. Percentage of respondents who felt very satisfied with the emotional support offered by clinicians and nurses

Country	Clinicians	Nurses
OVERALL	63,4%	57,48%
HUNGARY	73,8%	71,84%
SERBIA	38,8%	35,29%
SPAIN	70,5%	75,89%
POLAND	66,9%	57,1%
UK	67,9%	86,79%
BELGIUM	63,1%	69,23%
CYPRUS	47,4%	
ITALY	75,0%	
NETHERLANDS	55,0%	67,50%
TURKEY	23,1%	42,31%
PORTUGAL	75,0%	75,00%

■ Clinicians   ■ Nurses

Figure 4-4. Areas for improving the relationship with the healthcare team

Legend:
- Being spoken to in a language I can understand - a less technical approach
- Sharing the decision-making
- Being considered a valued member of the team
- Being treated as an individual
- Recommendations about how to improve my emotional feelings
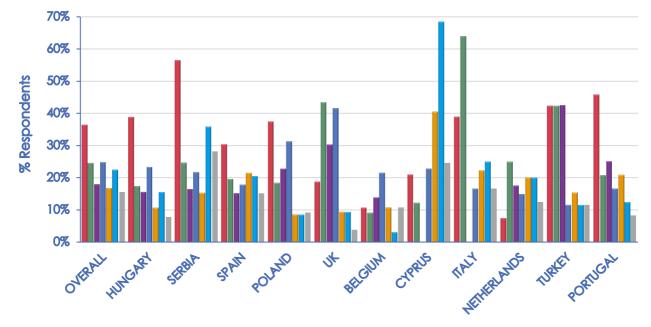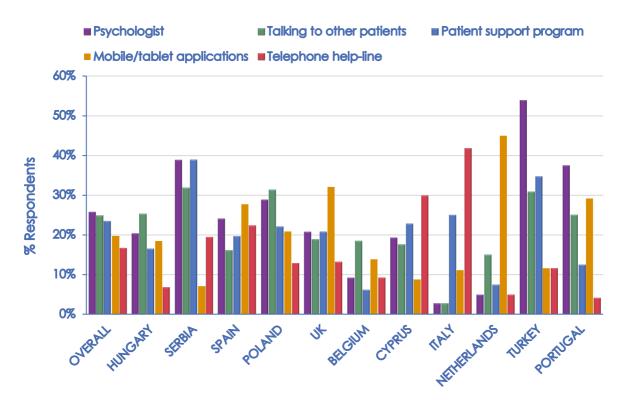- Helping me through my ups and downs
- More empathy - I am not a number!

Figure 4-5. Patient support gaps

DIGESTIVE CANCERS
EUROPE

In a few words…

Families are the main sources of support for patients across Europe. This aligns with previous reports that estimated that family caregivers provide over half of the care needed by cancer patients,[13] and that cancer patients want medical decisions to be made in conjunction with family members.[14,15]

Patients expressed high levels of satisfaction with hospital care and ~50% or more found adequate the emotional support provided by doctors and nurses. However, improving the communication between patients and HCPs is necessary and the use of a less technical language when transmitting information is crucial.

Additional psychological support is the main unmet need of support that patients called for. Patients agree that talking to other patients and having patient support programmes in place would help, unveiling the need for an increase in patient-patient interactions. In addition, the ask for specific apps highlights the importance that technology can play in supporting patients.
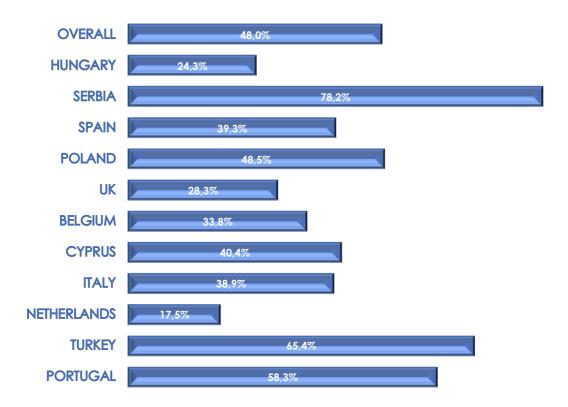
Obstacles

The survey revealed that ~48% of overall respondents encountered examination- or treatment-related difficulties (Figure 4-6). Patients experienced a variety of side effects, among which the most prominent ones were peripheral neuropathy (~38%) and emotional side effects (~36%) (Figure 4-7).

In addition, patients faced financial-related difficulties; mainly, 23% had their income negatively affected as a result of their illness, 18% faced serious financial hardship, and 13% had to use their savings (Figure 4-8).

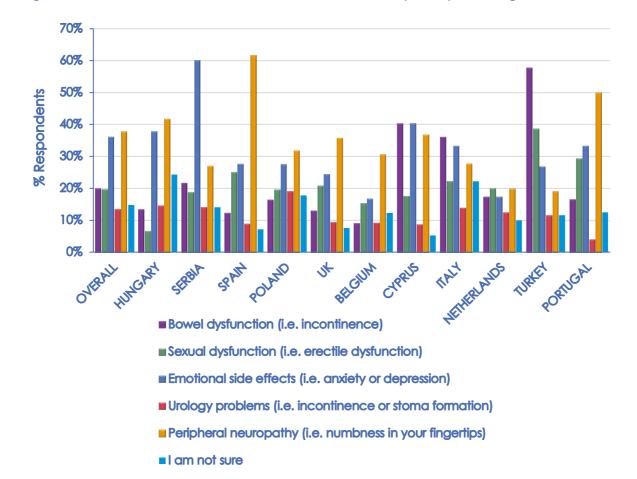**Figure 4-6. Percentage of respondents who encountered difficulties during examinations or treatment**

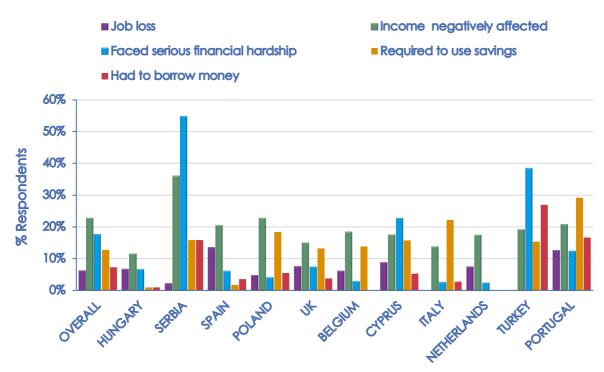|	
OVERALL	48,0%
HUNGARY	24,3%
SERBIA	78,2%
SPAIN	39,3%
POLAND	48,5%
UK	28,3%
BELGIUM	33,8%
CYPRUS	40,4%
ITALY	38,9%
NETHERLANDS	17,5%
TURKEY	65,4%
PORTUGAL	58,3%

Figure 4-7. Which medical side effects of the treatment are you experiencing?

Legend:
- ■ Bowel dysfunction (i.e. incontinence)
- ■ Sexual dysfunction (i.e. erectile dysfunction)
- ■ Emotional side effects (i.e. anxiety or depression)
- ■ Urology problems (i.e. incontinence or stoma formation)
- ■ Peripheral neuropathy (i.e. numbness in your fingertips)
- ■ I am not sure

Figure 4-8. Types of financial difficulties encountered

In a few words…

The number of patients (~50%) who faced difficulties during examinations and treatments is substantial, calling for a mechanism to be set in place to support patients during the difficult times of examinations and treatment.

Overall, patients' most common treatment-related side effects were emotional effects and peripheral neuropathy.

In terms of financial hardship, although a low percentage of patients (~6%) lost their job, more than 20% of patients saw their income negatively affected because of their illness.

Conclusions

Our survey reveals several areas in the journey of patients with mCRC that call for improvement. In the pre-diagnosis stage, awareness about the disease itself as well as its symptoms seems to be lacking across Europe. Screening practices should become the norm among people over 50 years of age; formal population CRC screening programmes with adequate participation rates for those in the 50–74 age group should be implemented across Europe.

In the diagnostic stage, although most patients are diagnosed promptly, an important degree of initial misdiagnosis is observed calling for greater information on CRC at the primary healthcare level. Patients receive adequate information on some aspects of the disease but information provision around the disease origin, stages and progression is still poor.

After diagnosis, in general, patients undergo treatment promptly, although a percentage of them have limited knowledge around the treatments they receive, even though the majority agree that they receive adequate information around treatments and treatment-related side effects. However, patients from nearly all countries agree that they would like information to be presented in a simpler, more easy-to-understand language, highlighting the need to develop better communication strategies between the patient and the HCP. Finally, most patients across Europe agree that the psychological support they receive is inadequate, emphasising the need to take better care of patients' emotional well-being.

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