

Recruitment for the Survey on the Unmet Needs of Patients Living with Metastatic Colorectal Cancer (mCRC) – Lessons from a European Study



#436

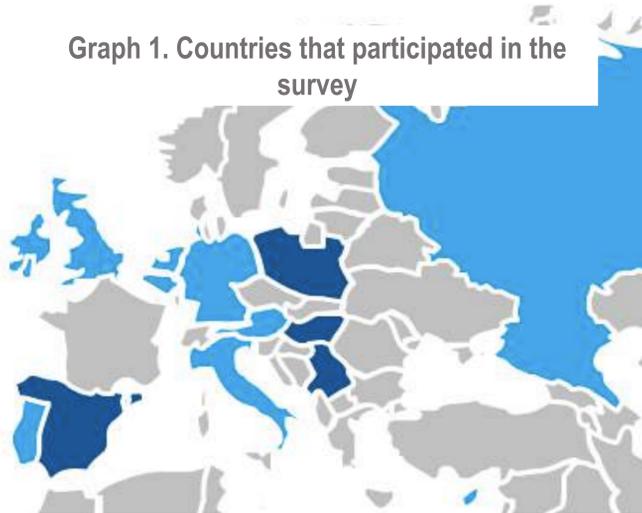
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BACKGROUND:

- Colorectal cancer is still a taboo for many patients and there is little information about the patient's experience in general practice. Much of what is known about their quality-of-life comes from clinical trials – that are not representative of everyday patient experience.
- EuropaColon, a European CRC patient organisation, planned and carried out a survey on the Unmet Needs of Patients Living with Metastatic Colorectal Cancer (mCRC).
- The aim of the survey was to better understand the challenges and needs of those living with mCRC as well as to understand their quality-of-life.

Graph 1. Countries that participated in the survey



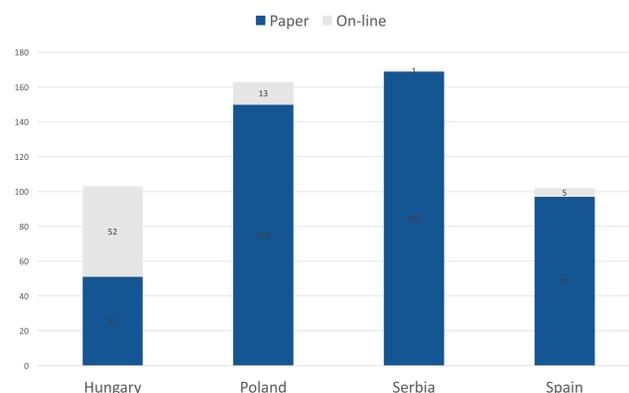
METHODS:

- The English survey was translated into 11 languages (German, Greek, Hungarian, Italian, Dutch, Serbian, Spanish, Polish, Portuguese and Turkish), for countries see Graph 1.
- Four sections of the survey covered demographics (12 questions), the illness (in total 53 questions on discovery, diagnosis, treatment and support), and health-related quality-of-life instruments: EORTC QLQ-C30 and EORTC QLQ-C29 (see Table 1).
- Institutional review board approval, where needed, was obtained at the local hospital level. Recruitment was planned by directly contacting nurses and clinicians in specific hospitals that volunteered to help recruit for the survey, or through EuropaColon partner groups (Portugal, Serbia, Poland and Turkey), or both recruitment strategies were used (Spain, Hungary, Netherlands and Hungary).
- Healthcare teams were asked to inform patients about the survey and provided them with an information leaflet and patients would need to make an effort to complete the survey by visiting a dedicated web-page (europacol.com/survey). They could either complete the survey on-line or download it, print it and complete on paper.

RESULTS:

- According to the initial plan, the majority of the surveys would be collected on-line.
- After 4 months of recruitment, because of low response, alternative strategies for patient recruitment had to be initiated. Different approaches were used in different countries. In Poland, Spain and Hungary, clinicians printed the survey to give paper copies to patients who would then complete on the spot.
- In Poland, 10 oncology departments recruited patients with two clinicians having the major role in recruitment majority of them. In Spain, four hospitals were involved with equal importance of nurses and clinicians having an active roles in recruiting patients for the survey while in Hungary, although two centers participated, one clinician and one nurse recruited majority of patients.
- In Serbia, Serbian CRC Patient Association printed and distributed 300 copies by mail to all centers treating mCRC patients with a pre-stamped envelope for the completed survey to be returned. A nurse from the Association made weekly calls to local clinicians in order to motivate them to recruit patients.
- By the end of February 2018, 719 patients had completed the survey. 202 patients (28%) completed the survey on-line while 517 patients (72%) completed the paper version. The majority of surveys came from Serbia (170), Poland (163), Spain (112) and Hungary (103), see Graph 2. Results of the questionnaire will be summarized overall and by country (see Maravic et al. ESMO WCGC, Barcelona, June 20-23,#432).

Graph 2. Number of Surveys Completed



ABOUT EUROPACOLON:

EuropaColon is a not-for-profit European organisation established in 2004 with the aim to unite patients, caregivers, healthcare professionals, politicians, the media and the public in the fight against digestive cancers. The Organisation works with 43 groups in 32 European countries and has been recognized as the voice of colorectal cancer patients in Europe.

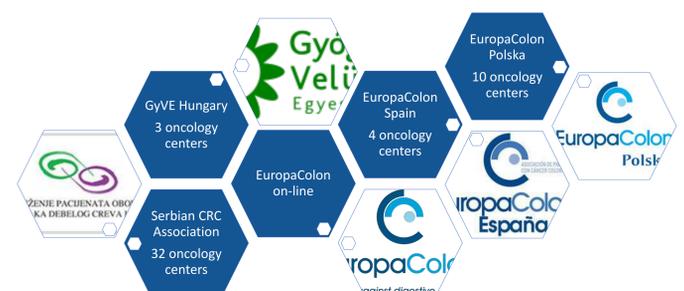
Table 1. Sections of the survey

	Demography 12 questions – age, sex, place of residence, highest degree earned, marital status, employment status, etc.)
	Your illness <ul style="list-style-type: none"> Discovery of your illness (16 questions) Your diagnosis (4 questions) Your treatment (21 questions) Support (12 questions)
	Health Related Quality of Life: EORTC QLQ C-30 and EORTC QLQ C-29

CONCLUSION:

- It is possible to reach patients outside of the clinical trial setting and they are interested in expressing their views.
- Paper versions of the survey were preferred, especially in Central and Eastern Europe. Social media (i.e. Twitter) as a recruitment platform worked only in few Western European countries e. g. Netherlands and UK. This may reflect the access to technology across the elderly population.
- Patients from Central and Eastern Europe are far better motivated to express their opinion whilst in the Western countries there is greater saturation with this type of research.
- The recruitment will continue until the number of 1'000 patients is reached.

Graph 3. Organisations that helped with survey completion



EuropaColon
united against digestive cancers