



The impact of cancer information services

A deep dive into the benefits of My Cancer Navigator

White paper



Introduction

Cancer patients and their families frequently seek information related to treatment, preferring one-on-one discussions with healthcare professionals (HCPs) [1-3]. However, when HCPs fail to meet these needs, patients turn to alternative sources like family, books, media, or the internet. Unfortunately, these sources can often be inaccurate or misleading. In contrast, cancer information services (CISs) provide personalized, one-on-one cancer information and are regarded as more reliable [4]. Studies show that CISs positively impact users' knowledge, emotions, communication with HCPs, decision-making abilities, and disease management [5-7]. While CISs are seen as valuable tools in improving cancer-related knowledge and decision-making, their direct role in facilitating shared decision-making remains underexplored [8].

Shared decision-making (SDM) is defined by the National Cancer Institute as a collaborative process where patients and healthcare professionals work together to decide the best care plan [9]. Elwyn et al. expands on this by emphasizing that SDM involves sharing the best available evidence with patients, allowing them to make informed choices [10]. SDM has been shown to improve cancer patients' outcomes and is considered a key patient right according to the European Code of Cancer Practice [11].

The benefits of SDM include improved treatment satisfaction, better health outcomes, and potentially lower healthcare costs [12]. However, various barriers hinder its implementation, such as poor communication between patients and healthcare providers, insufficient patient health literacy, and unmet information needs. Additionally, patients may feel emotionally overwhelmed, anxious, or too ill to engage fully in the decision-making process [13]. A combination of these factors often leads to patients' information needs going unmet [14].

This white paper explores the unmet information needs of cancer patients, and discusses the beneficial impact of a specific cancer information service, i.e. My Cancer Navigator (MCN), on known factors of SDM such as emotions, knowledge and disease-related communication.

Addressing unmet information needs

Cancer patients and their caregivers frequently encounter unmet information needs and communication barriers, contributing to inefficiencies in healthcare. Medical literature highlights several key challenges:

Information gaps

Cancer patients and their caregivers wish to receive comprehensive details on the disease, symptoms, treatment options, potential side effects, and self-care [4]. This need for information spans various stages of the disease, from diagnosis to treatment and beyond [15]. Patients report that their needs are not fully met by healthcare providers due to time constraints during consultations, complex medical terminology, and cultural or language differences [3]. As a result, many patients turn to alternative sources like the internet, which can offer inaccurate, misleading, or overwhelming information [1].

Emotional toll

In addition to the impact of the diagnosis itself, the lack of crucial information can intensify feelings of anxiety, depression, and uncertainty among cancer patients and their caregivers [16]. These emotional burdens can affect their ability to manage their health and adhere to treatment plans. Effective communication and access to reliable information are critical for mitigating these emotional strains and helping patients feel more in control their health [17-18].

Shared decision-making (SDM)

The concept of SDM, a process where patients and healthcare providers make informed healthcare decisions together, is preferred in oncology. However, SDM's implementation is often hampered by low health literacy of patients and poor communication with healthcare providers [13; 19]. Patients must be well-informed and emotionally prepared to engage effectively in SDM.

Healthcare provider constraints

Healthcare providers face their own set of challenges, including limited time for patient consultations and high workloads, complicating their ability to meet the information needs of patients adequately [20]. The diversity and often complex nature of cancer-related information required by patients add to these constraints.

These dynamics underscore the essential role of services like MCN, which aim to bridge information gaps and facilitate effective communication between patients and healthcare providers. By delivering personalized, evidence-based information, MCN addresses these unmet needs, promoting emotional well-being and participation in SDM.

Elevating patient care with My Cancer Navigator

My Cancer Navigator (MCN) is a **free** and **personalised** service of the Anticancer Fund, aiming to address information needs and contribute to informed and shared decision-making (SDM). To this end, a team of scientists and physicians, answers therapy-related questions of cancer patients and their relatives in an evidence-based manner. The service is available in Dutch, French and English and provides the following:

- Reliable information about the type of cancer
- Clarifications about test results
- Clear explanations on treatment options
- An overview of clinical trials patients may be eligible for
- Nuanced reviews of unregulated therapies
- Support to prepare questions to discuss with the treating doctor



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An explorative and descriptive cross-sectional study was conducted to assess the perceived impact of MCN on users' emotions, knowledge level and communication with HCPs, all factors contributing to SDM [21].

- Online surveys consisted of quantitative (Likert scale, multiple choice) and qualitative (open-ended) questions, based on a structured literature review.
- Surveys were disseminated in February–March 2023 via email to adult patients and their relatives who used the MCN service in the previous year.
- Patient demographics were extracted from the MCN case files obtained as part of the standard procedure to which all service users consented.
- The ethics committee of the Catholic University of Leuven approved the study.

97%

(Very) satisfied users

86%

Increased knowledge

77%

Improved emotional well-being

60%

Better communication with treating team

52%

Well-considered changes in disease management

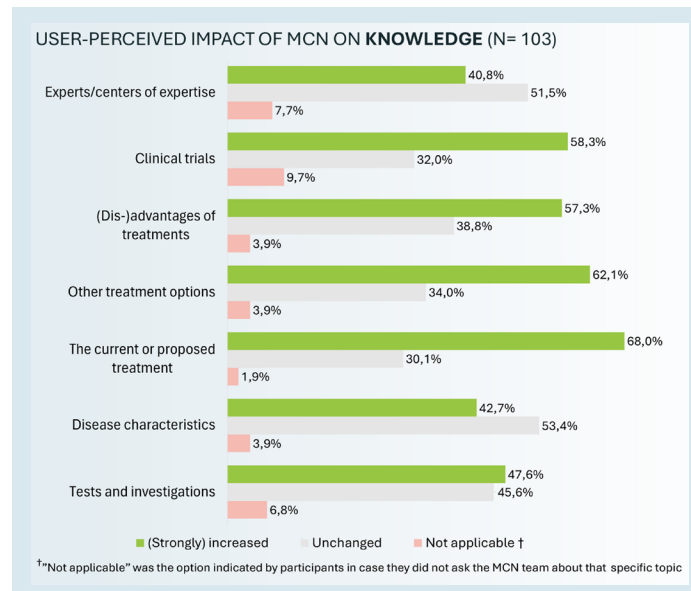
PATIENT CHARACTERISTICS		N (%)
SEX	Male	54 (49.5%)
	Female	54 (49.5%)
	Unknown	1 (0.9%)
CANCER TYPE	Gastrointestinal	24 (22.0%)
	Breast	21 (19.3%)
	Genitourinary	14 (12.8%)
	CNS [†]	10 (9.2%)
	Gynaecological	9 (8.3%)
	Lung	9 (8.3%)
	Sarcoma	7 (6.4%)
	Haematological	6 (5.5%)
	Other (n<5)	9 (8.3%)
COUNTRY OF RESIDENCE	Belgium	64 (58.7%)
	The Netherlands	12 (11.0%)
	UK	10 (9.0%)
	USA	5 (4.6%)
	France	5 (4.6%)
	Other (n<5)	13 (11.8%)

[†]Central Nervous System

Of the 253 invitees, 109 submitted the survey, among which 70 patients (64.2%) and 39 relatives (35.8%). Although 10 submitted surveys were incomplete, they were used for data analysis. Response rate was 43.1% and completion rate 90.8%. Patient characteristics are summarized in the table at the left.

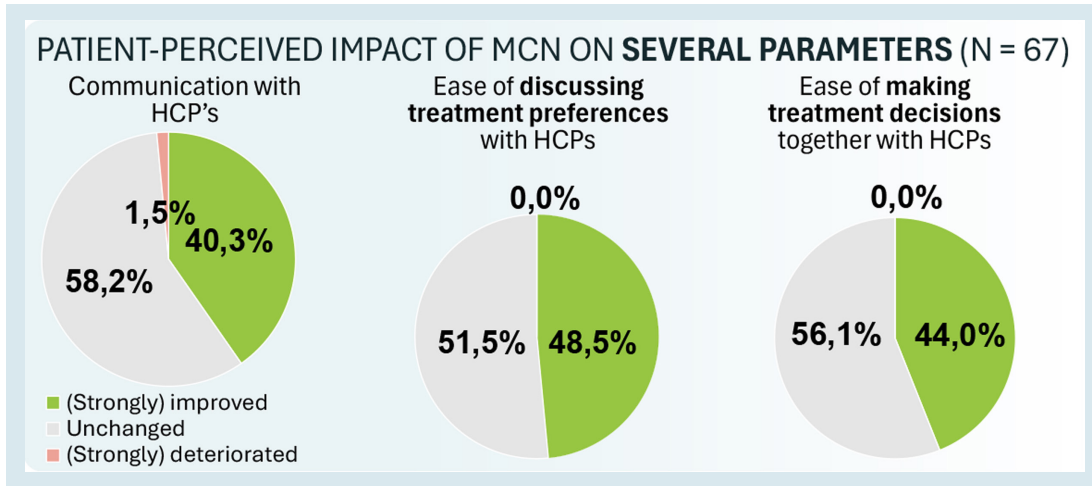
Knowledge

MCN effectively increased users' knowledge about their disease and treatment options. Specifically, 86.3% of users reported a positive impact on their overall knowledge level, covering topics such as the proposed or current treatment, other treatment options, clinical trials, and (dis-)advantages of treatment.



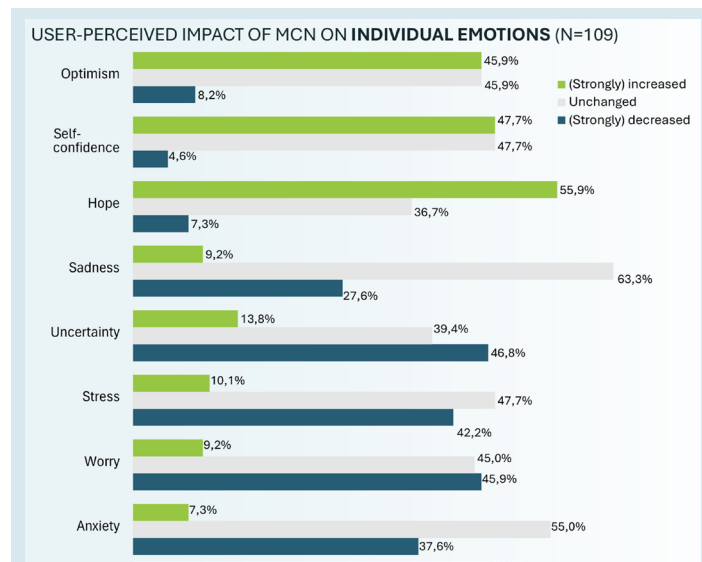
Communication

The service improved overall communication about the disease for 53.4% of users, enabling better discussions with healthcare providers and family members. Additionally, 48.5% of patients found it easier to discuss treatment preferences and 44.0% found it easier to make treatment decisions together with their treating team.



Emotional well-being

A substantial 72.5% of MCN users experienced improvements in emotional well-being, with significant reductions in worry and uncertainty, and increases in optimism, self-confidence, and hope. Furthermore, 68.5% of patients reported an increased ability to cope with their disease, while 76.4% of caregivers felt better equipped to support the patient.



These improvements collectively enhance the SDM process, where patients and clinicians collaborate to make informed healthcare decisions. This was illustrated by a direct impact on disease management, as reported by 52% of users*:

- the patient was able to decide about treatment, which they couldn't before (34.0%)
- the patient received a different treatment or participated in a clinical trial (41.5%)
- the patient went to a different hospital/centre of expertise (45.2%)
- the patient did not seek a second opinion, even though they planned on doing so initially (13.2%)
- the patient underwent an additional test or investigation (11.3%)
- other reasons (35.8%)

* Patients could give more than one impact

Empowering patients with shared-decision making

Extensive research from various other groups confirms that shared-decision making leads to better healthcare outcomes, including [12]:

Higher patient satisfaction

Patients engaged in SDM report greater satisfaction with their care [22]. They feel more respected and valued in the decision-making process. Research shows that patient navigation programs, such as those provided by cancer information services, significantly contribute to this satisfaction by offering personalized support [23].

Better health outcomes

SDM is associated with improved health outcomes, such as better adherence to treatment plans, fewer hospital readmissions, and enhanced quality of life [24-25]. Studies have shown that patient navigation services deepen patients' confidence in managing their disease and their understanding of diagnosis and treatments [26].

Reduced healthcare costs

Effective SDM can also contribute to cost savings by preventing unnecessary treatments and hospital stays [27-28]. The integration of patient navigators into care pathways has been linked to increased patient satisfaction and reduced overall healthcare expenses [12].

Delivering benefits for patients, HCPs and society

My Cancer Navigator brings substantial advantages to three key stakeholders:

1. **Patients:** By fulfilling previously unmet information needs and improving emotional well-being, MCN empowers patients to take an active role in their care, leading to better health outcomes and greater overall satisfaction.
2. **Healthcare providers:** Enhanced patient knowledge and communication skills facilitate consultations, contribute to a conscious choice of therapy, easing the burden on healthcare providers and improving all together the efficiency of care delivery.
3. **Society:** The societal benefits of MCN include potential reductions in healthcare expenses and improved public health outcomes through more informed and actively involved patients.

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