Appendix A: Overview of Measures

Variable	Instrument	Crohnbach's alpha	Measured at	Response format	Items
Cancer information seeking behavior (general)	Sources of information in the past 2 weeks	N/A	T0, T2	7-category multiple choice	o No, I have not looked up information about cancer o Yes, via family, friends, acquaintances, and/or colleagues o Yes, via other clinicians than the clinician with whom I will soon have a consultation (for example my GP, practice nurse, pharmacist, physiotherapist) o Yes, via traditional media (for example television, brochures, magazines, books, radio, newspapers) o Yes, via my electronic patient file o Yes, via the internet (for example websites of official organizations, online support groups, search engines such as Google or Bing, social media such as Twitter, Facebook, or Instagram) o Other:….
OHIS	Frequency	N/A	T0, T2	6-category answer options	o Never o Once in the past two weeks o Once a week o Several times a week, but less than once a day o Once a day o Several times a day
OHIS	Sources	N/A	T0, T2	13-category multiple choice	o Google, Microsoft Bing, or a similar search engine o My electronic patient file o Websites of official organizations (e.g., Kanker.nl, KWF.nl, NKI.nl, MijnGezondheid.net, Pallialine.nl) o Independent platforms (e.g. Gezondheidsplein.nl, Huisarts.nl, Thuisarts.nl) o The website of a hospital (such as the AMC, VUmc, Antoni van Leeuwenhoek or Erasmus MC) o Online forums and online support groups (websites with the aim of allowing visitors to communicate with each other and exchange information) o Websites where you come into contact with online clinicians, such as a website such as 'Ask a professional' o Wikipedia or another online encyclopedia o Blogs about cancer (websites where personal stories and experiences of usually one person are shared)

					o Social media (e.g., Facebook, Instagram, YouTube, Twitter, Podcasts or Reddit) o Digital scientific sources (e.g., Google Scholar, PubMed, EMBASE, MEDLINE) o The website of a patient organization (such as Hematon or Breast Cancer Association Netherlands) o Other:….
OHIS	Type of information	N/A	T0, T2	16-category multiple choice	Information about or experiences with… o Physical complaints (symptoms of the disease) o A possible diagnosis about the type of cancer I have/had o Possible causes for the type of cancer I have/had o The chance of recovery and life expectancy (information about the prognosis) o Common treatments (e.g., different treatment options, purpose and description of the treatments and possible side effects) o Certain medications and possible side effects o Alternative and/or complementary treatments (e.g., acupuncture, haptotherapy, herbal products, supplements) o Scientific research about new treatments and medications in which I may be able to participate o Possible long-term consequences of the disease and treatment on my quality of life (e.g., fatigue, concentration problems, sexuality/fertility, anxiety, effects on social life, effects on work or professional life) o Recovery (e.g., self-care during recovery, dealing with side effects at home, returning to work, promotion of healthy behavior) o Coping with the disease and treatments (e.g., through help from loved ones, via online support groups or through experiences of fellow sufferers, psychological help) o The impact of the disease and treatments on my partner, family, and friends o Cancer and genetic inheritance o Practical matters (e.g., about my treating clinician, my treating hospital, hospital routines) o Possibilities to prevent (the recurrence of) cancer o Other:…
OHIS	Reasons	N/A	T0, T2	13(T0)/20(T2) items rated on a 5-point Likert scale (Strongly disagree – Strongly agree)	• Preparation for the consultation “I want to know more about my disease/complaints and their consequences.” “I want to understand medical terms better.” “I want to prepare myself adequately for the conversation with my clinicians.”

					• Reduction of uncertainty "I hope that the online information can reassure me." "I have received conflicting information* (e.g. from different doctors and nurses, family, friends or via blogs or websites on the internet)." • Active contribution to one's own disease trajectory "I want to be in control when it comes to my disease and the choices involved." "I want to actively participate in the discussion of the best options for my disease." • Need for emotional support "I need emotional support." "I am curious about the experiences of others in a comparable situation." • Need for recognition "I am afraid to voice my concerns to my clinicians." "My clinicians hardly involve me in medical decisions (e.g. about treatment(s), medication)." "I am afraid to ask my questions to my clinicians." • Recommendation by the clinician "My clinicians referred me to the internet (e.g. in a conversation or via information material)." Only for T2: • Complementation of information from the consultation "I had new questions after the consultation with my clinician." "My clinician shared (too) little information with me." "I wanted to better understand what my clinician told me." • Validating information from the consultation "I wanted to verify that what my clinician said during the recorded consultation was correct." "I do not trust the information from my clinicians." • Challenging information from the consultation "I wanted to know what other options I have (e.g., about treatments or medication)." "I wanted to nuance the clinicians' information."
Age	Extracted from EPD Epic	N/A	T0	Continuous in years	18 years or older
Gender	Extracted from EPD Epic	N/A	T0	Dichotomous	o Male o Female

Level of education	What is your highest completed level of education?	N/A	T0	9-category answer option	• Low o None o Primary school (primary education, special education) o Lower vocational education (e.g., LTS, LHNO, LEAO, domestic science school) • Medium o Secondary general education (e.g. VMBO, ULO, MULO, MAVO) o Secondary vocational education (e.g., MTS, MEAO, INAS, MBO) o Higher general and preparatory scientific education (e.g., HAVO, VWO) • High o Higher vocational education (e.g., HBO, HTS, HEAO) o University (e.g., WO) o Other:….
Ethnic background	What ethnic group do you feel you belong to?	N/A	T0	8-category multiple choice	o Dutch o Moroccan o Turkish o Antillean/Aruban o Surinamese o Asian o Other:_____ o I would rather not say
Health literacy	Chew et al., 2004	α = 0.62	T0	5-point Likert scale (Never-Always/Very confident-Not confident at all)	"How often do you have difficulty understanding written information about disease and treatment?""How often does someone help you read information about disease and treatment?""How confident are you in your ability to fill out medical forms yourself?"
Monitoring coping style	TMSI (Bol et al., 2020)	α = 0.77	T0	5-points Likert scale (Not applicable at all- Very applicable)	"I planned to read about my disease." "I decided to deepen my understanding of the disease/treatment as much as possible." "I planned to ask the specialist as many questions as possible."
Trait anxiety	STAI-6 (van der Bij et al., 2003)	α = 0.89	T0	4-point Likert scale (Almost never-Almost always)	"I feel nervous and restless." "I feel that the difficulties are piling up so that I can no longer cope with them." "I worry too much about things that are not really important." "I am plagued by disturbing thoughts." "There are thoughts that I find very difficult to let go of." "I get tense and agitated when I think about my recent worries."
Uncertainty intolerance	IUS scale	α = 0.85	T0	5-point Likert scale	"Unforeseen events upset me greatly." "I find it frustrating not to have all the necessary information."

	(De Bruin et al., 2006)			(Strongly disagree–Strongly agree)	“One should always look ahead to avoid surprises.” “The smallest unforeseen event can ruin everything, despite the best planning.” “I always want to know what the future has in store for me.” “I can't stand being taken by surprise.” “I should be able to organize everything in advance.” “Uncertainty prevents me from getting the best out of life.” “When I have to take action, I feel paralyzed by uncertainty.” “When I am uncertain, I can't function properly.” “Even the smallest doubt can prevent me from taking action.” “I must avoid all uncertain situations.”
State anxiety	Bronner et al., 2017	α = 0.83-0.86	T0, T1, T2	4-point Likert scale (Not at all-Very much)	“I feel calm.” “I feel tense.” “I am confused.” “I am relaxed.” “I feel content.” “I am worried.”
Uncertainty	MUIS scale (Hagen et al., 2015)	α = 0.66-0.75	T0, T1, T2	5-point Likert scale (Not at all-Very much/Strongly disagree-Strongly agree)	“I have many unanswered questions.” “The clinicians told me things that could have different meanings.” “I understand everything that has been explained to me so far.” “There are so many different clinicians, it's unclear who's responsible.”

Appendix B. Overview of online sources consulted by patients two weeks before and after the consultation

Web resources	**T0 (pre-consultation), *N* = 110, *n* (% of cases)**	**T2 (2-w-post-consultation), *N* = 82, *n* (% of cases)**
Search engine (e.g., Google, Microsoft Bing, …)	90 (82%)	56 (68%)
Websites of official institutions (e.g., the Dutch Cancer Society)	45 (41%)	38 (46%)
Hospital websites (e.g., Amsterdam UMC)	45 (41%)	25 (31%)
Independent platforms (e.g., Thuisarts.nl, …)	26 (24%)	11 (13%)
Wikipedia or another encyclopedia	13 (12%)	7 (9%)
Websites of patient organizations (e.g., Hematon)	11 (10%)	5 (6%)
Personal blogs	9 (8%)	5 (6%)
Digital scientific sources (e.g., PubMed)	8 (7%)	10 (12%)
Online forums and online support groups	7 (6%)	6 (7%)
Social media	7 (6%)	5 (6%)
Other	4 (4%)	6 (7%)
Total number of responses	265	174

Note. Multiple responses were possible.

Appendix C. Overview of topics searched for by patients two weeks before and after the consultation

Topics	**T0 (pre-consultation), *N* = 108, *n* (% of cases)**	**T2 (2-w-post-consultation), *N* = 81, *n* (% of cases)**
Physical complaints	62 (57%)	41 (51%)
The chance of recovery and life expectancy	52 (48%)	38 (47%)
Common treatments	46 (43%)	27 (33%)
A possible diagnosis about the type of cancer	44 (41%)	20 (25%)
Possible long-term consequences of the disease and treatment on quality of life	40 (37%)	21 (26%)
Recovery chances and life expectancies	28 (26%)	11 (14%)
Certain medications and possible side effects	27 (25%)	18 (22%)
Possible causes for the disease	24 (22%)	13 (15%)
Scientific research about new treatments and medications to possible participate in	22 (20%)	16 (20%)
Practical matters	18 (17%)	9 (11%)
Impact of the disease and treatments on partner, family, and/or friends	15 (14%)	7 (9%)
Cancer and genetic inheritance	13 (12%)	8 (10%)
Possibilities to prevent (the recurrence of) cancer	10 (9%)	5 (6%)
Coping with the disease and treatment (e.g., through help from loved ones)	9 (8%)	10 (12%)
Alternative and/or complementary treatments	6 (6%)	5 (6%)
Other	3 (3%)	8 (10%)
Total answers	419	256

Multiple responses were possible.

Appendix D. Overarching reasons for OHIS

Overarching reasons	T0: M (SD), range (*n* = 110)	T2: M (SD), range (*n* = 82)
Preparation for the consultation	3.49 (0.89), 2-5	3.77 (0.64), 2-5
Reduction of uncertainty	2.46 (0.82), 1-4.5	2.56 (0.65), 1-4.5
Active contribution to one's own disease trajectory	3.69 (1.04), 1-5	3.81 (0.89), 1-5
Need for emotional support	2.58 (0.93), 1-5	3.09 (0.81), 1.5-4.5
Need for recognition	1.66 (0.72), 1-3.33	1.71 (0.58), 1-3
Recommendation by the clinician	1.86 (0.97), 1-4	1.69 (0.88), 1-4
Complementation of information from the consultation	n.a.	2.73 (0.66), 1-4
Validating information from the consultation	n.a.	2.01 (0.75), 1-4
Challenging information from the consultation	n.a.	2.54 (0.98), 1-4.5

Note. Possible response range: 1-5. Last three items were only measured after the consultation (T2).