

RESEARCH

Open Access



Awareness, use and perception of patient versions of clinical practice guidelines – a national cross-sectional survey among patients with a cancer diagnosis and healthcare providers

S. Blödt¹, S. Erstling¹, M. Becker², G. Carl³, M. Follmann⁴, S. Frenz⁵, C. Holmberg⁶, T. Langer⁴, A. Pachanov^{7,8}, D. Pieper^{2,7,8} and M. Nothacker^{1*}

Abstract

Background To investigate awareness, use, and perceptions of the patient guidelines (PGs) of the German Guideline Program in Oncology (GGPO) and to explore general preferences regarding cancer information among patients and healthcare providers (HCPs).

Methods Two cross-sectional surveys among patients with cancer (November 2020—May 2021) and among HCPs (April–June 2021) were set up as anonymised, self-administered, semi-structured online surveys, including open-ended questions. Data were analysed with descriptive statistics and qualitative thematic analysis. Patients were recruited from national self-help organisations and certified cancer centres located all over Germany. HCPs were recruited from cancer centres, scientific medical societies and guideline groups.

Results Of 816 participating patients, 45% were aware of the GGPO-PGs, while 55% of the 455 participating HCPs were aware of them. Of those aware of the GGPO-PGs, 65% of patients and 86% of HCPs perceived them as helpful, while 95% in both groups saw them as comprehensive. Seventy-five percent of patients and 85% of HCPs were satisfied with the GGPO-PGs, 22%/13% were partially satisfied, and 3%/2% were rather/not at all satisfied. In addition to self-help organisations, physicians and hospitals were perceived as central in distributing the GGPO-PGs. More patients (78%) than HCPs (56%) stated a preference for detailed information, although the wish for concise information – e.g. decision aids – was concurrently expressed by the majority of all participants. Thematic analysis showed that up-to-dateness, trustworthiness, and supportive messaging are important properties for PGs.

Conclusions HCPs found the GGPO-PGs helpful, but awareness was low, which suggests that dissemination should be improved. This is also true for patients; however, further research needs to be done to increase the helpfulness of PGs for patients. Oncological PGs seem to be needed in different formats according to patients' situational needs. Theory-driven research should investigate how to best frame patient information in a supportive way.

*Correspondence:

M. Nothacker

nothacker@awmf.org

Full list of author information is available at the end of the article



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

Keywords Clinical practice guidelines, Patient version, Oncology, Cancer, Healthcare providers, Self-help organisations, Formats, Dissemination, Implementation

Introduction

Information and the search for information is an important coping strategy for cancer patients [1]. In 2018, there were approximately 498,000 new cases of cancer diagnosed in Germany, and more than 220,000 people died of cancer [2]. Five-year relative survival rates differed among cancer entities between 90% for malignant melanoma and less than 10% for pancreatic cancer. Already in 2008, a national cancer plan (NCP) was established in Germany with the aim of improving the quality of cancer care [3]. The NCP comprises a certification system for cancer centres with defined quality standards [4]. As a further aim of the NCP, the German Guidelines Program in Oncology (GGPO) of the Association of the Scientific Medical Societies in Germany (AWMF), German Cancer Society, and German Cancer Aid was set up 2008 to support the development and implementation of high-quality oncological clinical practice guidelines (CPGs) to optimise patient care. The CPG recommendations should be informed by a systematic review of the evidence and an assessment of the benefits and harms of alternative care options [5]. With the German Patient Rights Act of 2013 [6], the duty to explain medical information and therapy options to patients in a comprehensible manner became legally mandatory.

Patient guidelines (PGs), an easy-to-understand version for patients of the related CPGs for clinicians, have been a mandatory part of the GGPO from the beginning and have been developed with a defined ‘translation’ and editorial process based on national and international methodological standards [7, 8]. Patient representatives and clinical experts from the CPG group are directly involved in the development of the PGs. The PGs (page range between 64 and 215 A5 pages) are produced in one format containing the CPGs’ recommendations and patient-relevant background information. According to professional guidelines, there is generally one PG covering all stages of the cancer disease, while for some entities (such as breast and prostate cancer) there are two PGs (one for prevention and early stage, and one for advanced stage).

In the last decade, interest in such ‘lay’ guidelines for patients and the public has steadily grown. Thus, freely accessible lay information or PGs are becoming increasingly available. For example, in the guideline program of the National Institute for Health and Care Excellence (NICE) in the United Kingdom, lay versions are regularly developed together with or after guidelines for

healthcare providers (HCPs) [9]. Similar programs exist in the American Society of Oncology [10].

There are international recommendations for the development and presentation of PGs, notably the ‘Public Toolkit’ of the Guidelines International Network (GIN) [8]. The section on patient information has been updated based on the international DECIDE (Developing and Evaluating Communication Strategies to support Informed Decisions and practice based on Evidence) project, which focused on the communication of guidelines to patients and further target audiences [11]. A systematic review conducted in 2014 by the DECIDE team on publications reflecting patients’ or public views of PGs found four overarching themes: applicability, purpose for patients, purpose for HCPs such as physicians, and the properties of PGs like format and trustworthiness. Awareness of PGs among the lay participants was generally low, with a wide span of 0–79%. There were critical perceptions about a rationing of care through guidelines and the individual ‘fit’ of recommendations [12]. Interviews and focus groups in the United Kingdom revealed that patients and the public mainly want information to help them choose between treatments, including information on harms, to support shared decision-making with HCPs [13].

A content analysis of PGs has suggested that they do not adequately address the needs of their target audience [14]. To overcome these barriers, the DECIDE project developed a layered format for guidelines, with recommendations on the front layer and more detailed information in further layers. This format has been implemented in digital guideline tools for HCPs [15, 16]. The layered format is also promoted for guideline information for patients and the public [8], but to date, no digital layer solution for patient or lay versions has been implemented.

In Germany, there are several patient information sources on cancer, in addition to the GGPO-PGs. Since 1994, the charitable foundation German Cancer Aid has produced so-called ‘blue guidebooks’ for most cancer entities and crosscutting issues, which are freely available in digital and print form, and since 2014 as videos [17]. The blue guidebooks are shorter than the GGPO-PGs, with more directive language and a focus on practical tips. Some self-help organisations distribute the GGPO-PGs and/or the blue guidebooks, while other organisations produce their own info material, predominantly short, illustrated brochures. Information is usually available

online (as pdf) and sometimes in print. While the blue guidebooks and self-produced materials are not formally evidence-based, the official portal informedhealth.de (www.gesundheitsinformation.de) provides cancer information on the basis of systematic evidence reviews, available as pdf via the website.

In addition, according to survey results undertaken on the occasion of cancer information sessions for patients, doctors and nurses were named as most important in terms of giving information to patients [18].

As of July 2022, 27 PGs have been published by the GGPO, 25 relating specifically to cancer and two addressing crosscutting topics. The oncological GGPO-PGs are freely available as print or digital versions [19]. In 2022, 220,863 oncological GGPO-PGs were downloaded, and 77,764 print versions were ordered, with increasing demand in 2023 (107,501 orders). Regarding user feedback, short comments from 156 users over time were available for a preliminary analysis 2015 [20].

An in-depth evaluation of overall awareness of the oncological GGPO-PGs and the perceived usefulness of the information needs of patients with a cancer diagnosis and their HCPs has been missing up to now. Therefore, the aims of this study were threefold:

1. To assess awareness of the GGPO-PGs;
2. To evaluate the use and perceptions (e.g. understandability, satisfaction) of the GGPO-PGs;
3. To explore sources of information used regarding a cancer diagnosis/disease.

These aims related to both patients with a cancer diagnosis and HCPs in Germany.

Methods

Target group

The target group of this study were adult patients (≥ 18 years) with a cancer diagnosis and HCPs treating and caring for cancer patients in Germany in an outpatient or hospital-based setting.

Study design

Two national anonymised, cross-sectional, and self-administered online surveys were conducted, one among adult cancer patients and the other among HCPs. The survey included closed and open questions [21]. Participation was voluntary and participants gave informed consent before starting the survey.

Data collection

SB and MN developed the draft questionnaire for the two surveys based on pre-existing knowledge of clinical guidelines and PGs and a review of the literature, notably

[1, 8, 10–12, 18]. First, the patient version of the survey was drafted and discussed with the research team, which involved experts on guideline development, healthcare research, physicians, and patient representatives from two national self-help organisations. Following the discussions, the questions were refined and regrouped, and the survey was shortened by prioritising aspects. After considering the comments of the author team, including those of the patient representatives, no further piloting was deemed necessary. The survey for HCPs was developed according to the same procedure.

The surveys comprised 34 questions for patients and 35 questions for HCPs on the same aspects, with specific differences as appropriate (for the questionnaires, see E-Supplements 1 and 2). Surveys were hosted on the electronic platform Survey Monkey. Questionnaires were divided into three sections: 1) characteristics of participants (11/12 questions), 2) awareness, knowledge, and perception of disease-specific GGPO-PGs (20 questions), and 3) general preferences in terms of cancer information (three questions). In section two, survey participants were first asked whether they knew of the GGPO-PGs. If they had used at least one PG, further questions followed. For patients, data on information transfer was collected using a modified self-developed scale on knowledge transfer and information [8]. In section three, participants could indicate what sources of cancer information they had used so far, with preferences on format and information type and open-ended questions on the expectations of health information among cancer patients, on layout, understandability, missing information (topics or single aspects), and requests for changes of existing information.

Recruitment

Survey for patients with a cancer diagnosis

Fourteen of the 17 cancer self-help organisations that were contacted – all of which had participated in the development of the GGPO – distributed a link to the patient survey among their network of members and group leaders and advertised the survey on their websites, reaching approximately 2,550 members. Forty hospital or outpatient departments agreed to lay out information material for the study, including thirteen (of fifteen) cancer centres of excellence [22] and seven (of 31 contacted) certified cancer centres, covering all regions in Germany. Reasons for not taking part were a lack of resources or no response. Moreover, the study was advertised through the newsletter of the German Cancer Society, which is sent out to 121 of the 133 certified cancer centres in Germany. Thus, more than 50,000 patients were potentially reached during the period that the online survey was open: November 2020 to May 2021.

Survey for healthcare providers

Information on the survey for HCPs was sent out via e-mail to the 62 scientific medical member societies of the AWMF and ten additional organisations, which were involved in the multi-professional guideline development groups of the GGPO. Ten scientific medical societies were willing to promote the survey for HCPs through their networks and e-mail distribution lists. Additionally, all participating clinics and guideline coordinators from the patient survey received the invitation to participate in the survey for HCPs, which means that potentially more than 45,000 members were reached. The online survey for HCPs ran from April until June 2021.

Sample size

In recognition of a possible wide range of awareness and perceptions of the GGPO-PGs and considering the uncertainty of people's willingness to engage in the study during the COVID-19 pandemic, we pragmatically set a minimum sample size of >385 participants per survey to be reached within the study periods. This was based on a calculation for awareness as critical outcome, with at least 385 participants needed per survey to reach a 95% confidence level of $\pm 5\%$ error with an assumption of at least 50%.

Statistical analysis

Analyses were done using SPSS Version 20. T-tests and chi-squared tests were used to assess bivariate relations between independent variables (personal characteristics) and the outcome variable awareness about the GGPO-PGs. Tests were two-sided, and statistical significance was set to $p < 0.05$. The sum score on information transfer was computed by adding the scores of each answer. Statistical tests were done for variables we assumed to be relevant for differences according to our expert knowledge. We applied stratified analysis using the Mantel–Haenszel (MH) method to explore whether the association between HCPs' profession and awareness about the GGPO-PGs was affected by their workplace (i.e. certified versus non-certified cancer centre). Therefore, we dichotomised participants into physicians versus other HCPs. We calculated crude, adjusted (MH), as well as stratum-specific odds ratios (OR) with 95% confidence intervals.

Additionally, we did an analysis for participants with the two most frequent cancer types: women with breast cancer and men with prostate cancer. No relevant differences in relation to all patients occurred, and therefore the results are not reported separately. All other results are reported in a descriptive manner.

Qualitative analysis of open-ended questions

Answers to open-ended questions were entered into Excel files per participant group. Analysis was started after the surveys were closed and was conducted using thematic analysis according to Braun and Clarke [23]. The first author (SB) and last author (MN) read all answers to familiarise themselves with the data. Then, thematic codes were developed inductively from the material and sorted into meaningful groups in consensus. Resulting themes and sub-themes were discussed in a subsequent round between SB, MN, and CH to ensure intersubjectivity and grounding in the data. No further changes in themes and sub-themes were made.

Results

Sample characteristics

Overall, the sample size for the patient questionnaire was 920 persons, and for the HCPs 626 persons. The statistical quorum for the endpoint 'awareness' was reached. As the surveys were distributed very widely, to approximately 50,000 potential patients and 45,000 potential HCPs, we assume an overall absolute response rate of 1.8% for patients and 1.4% for HCPs. Survey participants were located in all parts of Germany, though predominantly central Germany (see Tables 1 and 2).

Patients with a cancer diagnosis

The final study sample consisted of 816 patients, with 501 women, 314 men, and one person of diverse gender (see Table 1). These participants were included as they answered at least one question concerning the GGPO in addition to socioeconomic and disease-specific data. Of the 920 people who participated in the patient survey, 712 participants (435 women and 276 men) finished the survey. One hundred and four responses were deleted, seven because participants did not have a cancer diagnosis and 97 because of missing answers on any question concerning the GGPO. The mean age was 68 years in men and 55 years in women. Men were mostly diagnosed with prostate cancer and women with breast cancer. Diagnosis in men was less often current compared to women, and more men than women were retired (see E-Supplement 6). Of the patients, 463 (57.7%) stated being a member or participant of a self-help organisation, with 124 (29.7%) being associated with the German Prostate Cancer Support Group and 115 (27.5%) with the Women's Self-Help Association Cancer (see Table 1).

Healthcare providers

The final sample comprised 455 HCPs (232 women, 167 men, and one person of diverse gender), with 400 HCPs completing the survey (see Table 2). Of the 626 total

Table 1 Characteristics of the study sample of patients with a cancer diagnosis

	816 patient participants ^{a,b}	
	Women n = 501 (61.4%)	Men n = 314 (38.5%)
Age		
18–30	20 (4)	5 (1.6)
31–65	419 (83.6)	128 (40.8)
66–85	62 (12.4)	181 (57.6)
Highest education level		
< 11 years of school education	219 (43.8)	126 (40.3)
≥ 11 years of school education	143 (28.6)	82 (26.2)
University degree	137 (27.4)	101 (32.3)
Other	2 (0.4)	0
Place of living in Germany		
South	132 (26.6)	112 (35.9)
Middle	236 (47.6)	133 (42.6)
North	124 (25.0)	67 (21.5)
Other	4 (0.8)	1 (0.3)
Cancer diagnosis		
Current cancer	239 (47.8)	142 (45.2)
In the last 5 years	155 (31.3)	68 (21.7)
> 5 years	104 (20.8)	104 (33.1)
Having a relapse	119 (24.2)	113 (36.1)
Type of cancer		
Breast	231 (46.5)	5 (1.6)
Other gynaecological	24 (4.8)	-
Prostate	-	152 (48.6)
Skin (melanoma)	101 (20.3)	29 (9.3)
Lung	38 (7.6)	18 (5.8)
Thyroid gland	18 (3.6)	5 (1.6)
Gastro-intestinal	15 (3.0)	14 (4.5)
Head-neck tumour	11 (2.2)	13 (4.2)
Lymphoma	12 (2.4)	23 (7.3)
Bladder	2 (0.4)	15 (4.8)
Other	46 (9.2)	36 (11.5)
Member/participant of a self-help organisation	253 (51.6)	209 (67.6)

^a There was one additional person of diverse gender, aged 72 years, ≥ 11 years of school education, living in central Germany, who was diagnosed with prostate cancer > 5 years ago, until now without a relapse and was a member of a self-help organisation

^b Due to missing values on single variables n differs between 801–817

respondents to the HCP survey, 71 had to be excluded due to not being an HCP, 19 for not treating cancer patients, and 81 because they did not answer any question concerning the GGPO-PGs. The mean age was 52 years with a range from 23 to 75 years. More men than women were physicians (87% versus 37.8%; 57.6% in total) and in a leading position (85.7% versus 56.6%;

68.6% in total). More men compared to women worked in a certified centre and were working together with a self-help organisation (see Table 2).

The majority of HCPs (77.3%) were offering care to adults with different types of cancer. A minority worked with children/adolescents (5.7%). Some stated that they consult women and men with a specific cancer type such as breast (12.8%), lung and bronchial (7%), brain (0.9%), and several others (6.4%) (see Table 2).

Thematic findings from open-ended questions

Patients with a cancer diagnosis and HCPs gave answers to the open-ended questions on what they expected and desired from written information on cancer, particularly from PGs. More than 80% of study participants in each group gave answers to the question on expectations of cancer information. The remaining open-ended questions were answered by between 1.9% and 18.6% of participants (see E-Supplement 3).

Answers to the open-ended questions related to themes comprising ‘public awareness and availability of GGPO-PGs’, ‘wishes regarding properties’ for health information (and in particular for PGs), ‘reasons for using PGs’, and ‘limitations’ of PGs and written cancer information. These themes are presented below, following the respective quantitative results.

Awareness of the GGPO-PGs

Patients with a cancer diagnosis

Of the 816 patients with a cancer diagnosis, 44.6% were aware of the GGPO-PGs. Awareness was higher among participants of a self-help organisation compared to those with no participation (56.2% versus 28.9%, $p < 0.001$), among patients with a cancer diagnosis in the past compared to those with a current cancer diagnosis (52.9% versus 35.2%, $p < 0.001$), and among patients with higher education compared to those with lower education (university degree: 53%, ≥ 11 years: 44.7%, < 11 years: 38.3%, $p < 0.001$).

Patients received the GGPO-PGs most frequently from a self-help organisation (46.3%) and through an internet search (34.1%). Fewer people named a health institution (17.4%), their physician (13.1%), a conference for cancer patients (10.4%), private recommendation (3.5%), or others (6.0%) as the source of the recommendation.

Healthcare providers

Of the HCPs, 55.4% were aware of the GGPO-PGs. Awareness was higher among nurses (78.6%), psychologists (77.8%), and physicians (65.6%) than among physiotherapists (21.6%) and other HCPs (38.4%). It was also higher among those in training (65%) and in leading positions (59.7%) compared to those without a leading

Table 2 Characteristics of the study sample of HCPs

	455 HCP participants ^{a,b}	
	Women n = 270 (59.3%)	Men n = 184 (40.4%)
Age		
18–30	18 (6.7)	3 (1.6)
31–65	241 (89.3)	164 (89.6)
66–85	11 (4.1)	16 (8.7)
Profession		
Physician	102 (37.8)	160 (87.0)
Nurse	24 (8.9)	4 (2.2)
Psychologist	16 (5.9)	2 (1.1)
Physiotherapist	64 (23.7)	9 (4.9)
Other	64 (23.7)	9 (4.9)
Position		
In training	28 (10.5)	7 (3.8)
No leadership function	82 (30.8)	19 (10.4)
Leadership function	156 (56.6)	156 (85.7)
Workplace		
University hospital	54 (20)	67 (36.4)
Non-university hospital	77 (28.5)	70 (38.0)
Outpatient care	123 (45.6)	38 (20.7)
Other	16 (5.9)	9 (4.9)
Experience with cancer patients (years)		
< 3	19 (7.0)	3 (1.6)
3–10	53 (19.6)	20 (10.9)
> 10	192 (71.1)	161 (87.5)
Place of living in Germany		
South	82 (31.2)	57 (31.7)
Middle	117 (44.5)	85 (47.2)
North	64 (24.3)	38 (21.1)
Working in a certified cancer centre recognised by the German Cancer Society (DKG)		
	116 (43.1)	122 (67.0)
Working together with a self-help organisation		
	141 (52.2)	141 (76.6)

^a There was one additional HCP with diverse gender, aged 38 years, living in the south of Germany, working as a physiotherapist in an outpatient facility in a leading position with more > 10 years of experience in dealing with cancer patients, and was neither working together with self-help organisations nor aware of the GGPO-PGs

^b Due to missing values on single variables, n differs between 443–454

position or not in training (both 39.6%). Furthermore, awareness was higher in HCPs with more compared to less working experience (59.3% > 10 years versus 42.1% ≤ 10 years, $p=0.003$) and in those working in a certified cancer centre compared to those not working in such a centre (66.4% versus 43.5%, $p=0.001$). Additionally, the centre-stratified MH analysis revealed that physicians were more likely to be aware of the GGPO-PGs than other HCPs (OR=2.02; CI: 1.34–3.06), although this association was less strong than that observed in the crude analysis (OR=2.67; CI: 1.80–3.87). However,

analysis for the certified centre stratum showed no association between being a physician and awareness about the GGPO-PGs (OR=0.95; CI: 0.50–1.80).

Of the 252 HCPs who knew about the GGPO-PGs, most knew about them through the internet (38.5%) or by participation in GGPO guidelines (38.1%). Fewer people became knowledgeable through display in their healthcare facility (24.2%), via an HCP recommendation (14.7%), through a conference (13.9%), through participation in GGPO-PG development (13.1%), and via other sources (7.1%).

Participants' perception of public awareness and the availability of GGPO-PGs

Survey participants mentioned that, in their view, few people know about the GGPO-PGs, and they wished to increase awareness and availability. Aside from self-help organisations, physicians and hospitals were perceived as central in distributing the PGs. In this theme, no sub-themes were identified.

"More 'advertising' needs to be done for the patient guidelines. I just typed in 'breast cancer and now?' and went to page 4 on Dr. Google but didn't find any reference to these guidelines anywhere. Who is supposed to find them who is just getting into the topic and doesn't even know what to look for yet?" (patient, ID 27)

"Quickly hand out the PGs to patients via physicians, display/distribution in waiting rooms, and via self-help organisations." (patient, ID 451)

"Better availability of the booklets in the outpatient clinics." (HCP, ID 248)

"Advertise new patient guidelines better so that they are perceived more quickly." (HCP, ID 342)

Sources of information on cancer

When asked about their general cancer information use, more than half of the 693 patients (393, 56.6%) used information from self-help organisations to find out more about their cancer. The GGPO-PGs and the related CPGs were used by about a third each (27.7% and 29.4% respectively). Only 9.8% of patients used other PGs, but more

than 85.9% stated using information from further organisations, mainly the so-called blue guidebooks from German Cancer Aid.

The 390 HCPs most often referred patients to information from other organisations (73.1%), followed by references to information from self-help organisations (42.5%) and the GGPO-PGs (40.9%). Less often, they referred to the medical guidelines (CPGs) of the GGPO (17.4%) and other PGs (40.9%).

The majority of participants stated that they prefer printed and internet-based information (>60% for both) over videos and apps (<20% for both). More patients (78.1%) than HCPs (56.3%) stated a preference for detailed information. However, the wish for short information on important decisions was also expressed by the majority of participants (patients: 65.3%; HCPs: 70.8%), with a little fewer than half of both patients and HCPs expressing an interest in a single page of information (see Table 3). Concerning 'other' information types, patients mentioned most often personal consultations with HCPs or self-help organisations and HCPs addressed mainly scientific articles and congresses.

Which properties should a patient guideline have

Survey participants had specific wishes regarding the properties that PGs should have (see Table 4). We

Table 3 Sources of information on cancer among patients with a cancer diagnosis and healthcare providers

	Patients with a cancer diagnosis n = 694–712	Healthcare providers n = 390–402
What information or decision-making tools do you use/refer (your patients) to?^a		
Self-help organisation	393 (56.6)	166 (42.5)
Medical guidelines (CPGs) of the GGPO	204 (29.4)	68 (17.4)
GGPO-PGs	192 (27.7)	160 (40.9)
Other PGs	68 (9.8)	48 (12.3)
Information from other organisations (e.g. German Cancer Aid's blue guidebooks)	595 (85.9%)	285 (73.1)
Preference for (n = 712)^a		
Print information	473 (66.4)	347 (86.3)
Internet-based information	447 (62.8)	273 (67.9)
Internet and information tailored to my needs	382 (53.7)	n.a
Videos	132 (18.5)	73 (18.2)
Apps	108 (15.2)	53 (13.2)
Other	46 (6.5)	18 (4.5)
Preferred information type^a		
Detailed information ^b	556 (78.1)	225 (56.3)
Short (on important decisions)	465 (65.3)	283 (70.8)
One page (most important disease information)	309 (43.4)	168 (42.0)
Other	32 (4.5)	41 (10.3)

^a More than one answer possible

^b Due to missing values on single variables, n differs between 694–712 in patients with a cancer diagnosis and between 390–402 in HCPs. n.a. not applicable

identified applicability, language, up-to-dateness, quality, information framing, and format as sub-themes. Participants addressed their desire for the use of easy-to-understand language and up-to-date information. Outdated PGs and missing updates on innovative treatment options were major criticisms. A high-quality PG that is reliable, trustworthy, evidence-based, and without the influence of pharmaceutical or medicinal

products industry was considered essential by survey participants. They acknowledged the need for honest but also encouraging information, and mentioned how important it is that information gives hope and takes away fears. Being a cancer patient was perceived as a journey that requires different information and information formats depending on the phase of the disease or individual needs.

Table 4 Properties of patient guidelines: themes and sub-themes

Applicability

Patient-related (specific), individual; starting simple and deepening for interested people

"I wanted to know more and go into more depth. The patient guideline was a good start, but when you are sitting at home on sick leave with cancer, have secondary diagnoses, and internet access, you can always think of something else you absolutely have to know." (patient, ID 788)

"Keeping different patient needs in mind – desire for detailed information versus being overwhelmed by too much information, different prerequisites, e.g. to understand data or scientific considerations, different focus on complementary therapies." (healthcare provider, ID 292)

Language

Easy to understand, normal font, comprehensible wording, avoidance or explanation of technical medical terms, translation in several languages

"More understandable language, even for people without a higher degree. Also for older people. That you understand it without many foreign words." (patient, ID 406)

"The information is presented too 'technically' for me." (healthcare provider, ID 189)

Up-to-dateness

Up-to-date information containing updates on innovative treatment options; no outdated patient guidelines

"The S3 guidelines are not always up to date with the current state of science, i.e. an update should also take place outside the five-year cycle if new data and recommendations are available. Unfortunately, the guidelines are usually already out of date when they are published. Thus, the latest therapy findings were missing..." (patient, ID 47)

"Rapid changes in treatment mean that guidelines are often not up to date. More frequent updates." (healthcare provider, ID 463)

Quality

Evidence-based (S3¹ classification), scientifically sustained, reliable, accuracy of information; comprehensible, factual, objective, not promoting anything, trustworthy; link to the medical guidelines (CPGs)

"Neutrality of the experts, no influence of the pharmaceutical industry." (patient, ID 216)

"It would be important to me that the information is independent, neutral, and without advertising for drug companies." (healthcare provider, ID 423)

Information framing

Honest and unembellished, but also encouraging; giving empathic and optimistic, not frightening or **overwhelming**, **words of comfort**; taking away fears, motivating

"It is difficult for me to say specifically what information I was missing. Perhaps it was also due to my personal situation at the time of diagnosis. I had received little information from my urologist around the time of diagnosis. I then searched for information on the internet myself and understood this information to mean that, with a PSA value greater than ten, I was probably terminally ill and therefore a case for palliative care. In fact, I was diagnosed with initial metastases, but thanks to good treatment, I have a good prognosis and can live a virtually symptom-free life. In retrospect, I would like to see patient guidelines that also show an optimistic outlook on life in this sense." (patient, ID 636)

"Easing fears, dispelling common misconceptions. Empathic." (healthcare provider, ID 230)

Format

Short, but also comprehensive and detailed; clearly structured, key messages clearly presented; glossary to explain technical terms; supported by pictures, videos, and graphs

"For clarity, the text statements should be summarised in graphs, tables, and illustrations. Summary chapters should be placed at the beginning for patients who do not want to read everything at once. Some patients are no longer used to reading a brochure or downloadable pdf file. They want to read everything online immediately and decide for themselves how deeply they want to go into the details." (patient, ID 36)

"The graphic presentation in the DKG brochures would have to be more appealing/modern. Pure text format is difficult for patients... interactive solutions would be ideal." (healthcare provider, ID 211)

(bold: only mentioned by a person with a cancer diagnosis)

¹ In the GERMAN AWMF Guideline Register, guideline classification starts from S1 (recommendations of expert groups) to S3 (formally evidence- and consensus-based guideline)

Use of GGPO-PGs

Patients with a cancer diagnosis

Of the 355 patients who had used at least one GGPO-PG, the guidelines on early breast cancer (29.9%), psycho-oncology (29.3%), melanoma (22%), prostate local (19.7%), prostate advanced (16.6%), advanced breast cancer (16.6%), supportive care (15.5%), and palliative care (12.4%) were the most frequently used. Patients used the GGPO-PGs to search for information about their disease, e.g. symptoms or course of disease (77.8%), therapy and side-effects (79%), support for decision making (43.7%), preparation for physician consultation (41.3%), and other reasons (8.3%). The latter included practical tips such as finding addresses and specific information to advise other patients in self-help contexts.

Healthcare providers

Of the 252 HCPs who were aware of the GGPO-PGs, 80.2% had used at least one. The most frequently used GGPO-PGs were for breast cancer early (45.5%) and breast cancer late (43.6%), followed by the PG for palliative care (37.6%), supportive care (38.6%), and psycho-oncological care (35.1%) (E-supplement 4). Of the 202 HCPs who had used the GGPO-PGs, they did so for their own information (42.6%), as an information tool in their communication with patients (54.5%), as a hand-out to patients (38.6%), as an information service in the waiting room (26.2%), and as a decision aid (24.3%).

In the answers to the open-ended questions, survey participants mentioned lung and bronchial cancer, head and neck tumours, thyroid gland, gastrointestinal stromal tumour, and sarcomas as missing topics for PGs. Additionally, HCPs named brain tumours, paediatric cancers, and patients with a diagnosis of breast carcinoma in situ as further topics they wished to be addressed in CPGs and PGs.

Reasons for using patient versions of clinical guidelines

Analysis of the answers to the open-ended questions shows that survey participants had clear ideas regarding the reasons for using PGs. For the identified theme 'reasons for using PGs', we defined the sub-themes 'education and being informed', 'guidance', 'getting empowered', 'learning what one can do in daily life', and 'getting support'.

Education and being informed

Most survey participants saw PGs as a tool to learn about cancer disease. Therefore, in their view, information on the causes of the disease and diagnosis, as well as treatment possibilities and aftercare, including rehabilitation, should be included in PGs. Providing information on the benefits and harms of treatment alternatives, including side-effects and possible long-term consequences,

was also deemed very important. Moreover, information on complementary medicine was seen as valuable and thus should be included. Some patients and a few HCPs desired information on experimental and latest therapy options in PGs. Some patients mentioned a wish to be informed about ongoing studies. Furthermore, survey participants mentioned that self-help organisations should be named in PGs as supportive in the cancer disease journey.

"Expect honest education about all relevant treatment options, including wait-and-see, about the likelihood of benefit for survival, discomfort, side-effects, quality of life, occupational and social outcomes." (patient, ID 36)

"Reference to self-help groups and their extraordinary benefits." (patient, ID 683)

"Healthcare provider and comprehensible information about diagnoses, therapies, risks, and side-effects, as well as rehabilitation measures." (healthcare provider, ID 321)

"Increase of the understanding of the disease, risk factors, diagnostics, therapy, typical courses of the disease (from cure to palliation), info on long-term consequences after surgery / chemo / radiation..." (healthcare provider, ID 347)

Guidance

Survey participants perceived PGs as a 'roadmap' that led them through the cancer disease journey. Information was deemed as helping people with cancer and their relatives to orient themselves within the health system and making cancer patients knowledgeable about the next steps in their disease journey as well as on life after the treatment phase. Survey participants thus mentioned that information on prognosis, the meaning of the diagnosis for their future life, and long-term side-effects was essential in order to contextualise the impact of the disease on their life.

"I would like to have information from patient guidelines on a cancer disease that enables me to assess my disease: what further course should I expect as a patient?" (patient, ID 636)

"I wish that people with a cancer experience can access ALL information on a protected internet platform. (Information of all professions involved, at best, the collected knowledge worldwide). Still, people have to search for the information themselves." (patient, ID 59)

"The information should accompany the patient step-by-step. What examinations are required, how pathology findings are to be understood, what treatment options are available, including the advantages and disadvantages, and finally, what examinations are to be performed at what time during follow-up care." (healthcare provider, ID 505)

"Helping people to navigate through the healthcare system." (healthcare provider, ID 436)

The majority of survey participants considered it essential to assist patients with a cancer diagnosis by providing addresses and links for psycho-oncological, legal (e.g. getting a second opinion), and social affairs support, as well as information on self-help organisations.

Getting empowered

Survey participants stated that PGs function as a tool to empower people with cancer and their relatives to “*be prepared for the consultation*”. PGs should help people with cancer be able to raise questions in their communication with HCPs and thus influence their situation. HCPs used terms like ‘health literacy’ to describe what they wished for from health information, i.e. enabling patients to influence their situation. Furthermore, participants expected that PGs should enable cancer patients to make decisions on the available treatment options. Decision aids as part of cancer information were seen as essential by some.

“Clear statements that allow me to decide on a therapy that I will be proposed.” (patient, ID 717)

“To give me an overview of the possible manifestations of the disease and the treatment methods available and [be] advised in each case, so that I know where I currently stand and can ask my doctor the right questions if necessary (or give thoughtful answers).” (patient, ID 788)

“... It is intended to provide important information so that patients go into their discussions with doctors well prepared and know what options are available so that they can make their own decisions about their therapy.” (patient, ID 27)

“...empowered to ask questions.” (healthcare provider, ID 480)

“...self-determined and informed patients.” (healthcare provider, ID 382)

“...Better communication with treating physicians.” (healthcare provider, ID 589)

Another reason mentioned for the use of PGs was that cancer information enables patients to review and verify the information they receive from physicians or other HCPs.

“Verifiability of individual treatment by physicians; patients must be able to see whether they are being treated in accordance with the guidelines.” (patient, ID 414)

“Reminder after interview.” (healthcare provider, ID 58)

“Opportunity to review at leisure the information received during a patient education interview and to check whether topics relevant to the disease + therapy were not or not sufficiently discussed.” (healthcare provider, ID 434)

Learning what one can do in daily life

A concrete expectation of PGs was that they should offer information on how affected people can influence their disease journey, improve their daily life, and avoid a relapse. Many participants stated the importance of information on what patients can do on their own and how they can actively participate in their recovery. This includes recommendations on lifestyle, such as knowledge on nutrition, self-directed exercise, and stress management, but also supportive therapy options against treatment side-effects. Moreover, several patients wished to get useful tips for daily life.

“What can I contribute to my recovery?” (patient, ID 627)

“Comprehensive recommendation on sport and nutrition and lifestyle.” (patient, ID 901)

“Information on a healthy lifestyle that goes beyond conventional medicine and pharmaceuticals (soft skills). What can the patient do himself in the palliative phase, e.g. sport, exercise, nutrition, stress avoidance?” (patient, ID 245)

“... Information [on] what one can do, e.g. concerning physical activity, active daily life.” (healthcare provider, ID 270)

“Patients miss general information on lifestyle.” (healthcare provider, ID 427)

Getting support

A sub-theme that was important for many patients with a cancer diagnosis was getting information on how to deal with the illness and cope with their new situation. PGs were used to give hope and offer mental and psychological support. Furthermore, HCPs and patients addressed the need to mention psycho-oncological support and provide addresses where cancer patients can receive psychological support.

“Support during the disease journey in the form of encouragement.” (patient, ID 155)

“Help and emotional support.” (patient, ID 560)

“... and to feel that you are not alone.” (patient, ID 910)

“Psychological support.” (healthcare provider, ID 83)

“Addressing the fears of those being affected and their relatives.” (healthcare provider, ID 625)

Perception of the GGPO-PGs

The GGPO-PGs were rather well evaluated by those who had used them (Table 5). The sum score (MD, SD) of the question on information transfer among patients was 12.2 ± 2.9 in women (range 5–18) and 12.90 ± 3.5 in men (range 4–18), with no significant difference between the groups ($p=0.078$). More HCPs than patients perceived the GGPO-PGs as helpful and trustworthy, but patients and HCPs would equally recommend them to others.

Limitations of patient guidelines and written cancer information

Survey participants described the feelings of fear and anxiety experienced by people when facing a cancer diagnosis. A feeling of being left alone with information or when organising daily needs was mentioned by others. Furthermore, survey participants described that the cancer disease trajectory is not as streamlined as it appears in the PGs. The desire for caring support was something that was present in many answers. Therefore, time with the physician – for receiving answers and psychological support – was seen as important, and something that cannot be replaced by PGs.

Table 5 Perception of GGPO-PGs (quantitative assessment)

	Patients with a cancer diagnosis <i>n</i> = 288–322 <i>n</i> (%)	Healthcare providers <i>n</i> = 169–190 <i>n</i> (%)
Did you perceive the patient guideline as...		
Helpful?		
Yes	216 (64.7)	163 (85.8)
Partially	111 (33.2)	2 (1.1)
No	7 (2.1)	25 (13.2)
Clearly arranged? (designed)		
Yes	293 (91.6)	176 (94.6)
Understandable?		
Yes (for themselves)	302 (95.9)	n.a
Yes (for patients)	n.a	176 (95.1)
With the received information, I'm		
Very/satisfied	241 (74.8)	156 (85.2)
Partially satisfied	72 (22.4)	24 (13.1)
Less/not at all satisfied	9 (2.8)	3 (1.6)
Of the information I have searched, I have received		
All/most	230 (78.5)	
A part	56 (19.1)	
Little/no	7 (2.4)	
information		
The received information meets my needs/the needs of the patients		
Fully/mostly (yes)	222 (76.3)	142 (80.7)
A part	61 (21)	30 (17)
Little/not at all (no)	8 (2.7)	4 (2.3)
The information of the PGs...		
I (fully) trust	118 (40%)	160 (87.5)
Partially trust	125 (42.4%)	24 (12.5)
I rather do not trust/not at all	17.6%	0 (0%)
Would you recommend the PGs?		
Yes	284 (98.6)	162 (95.6)

"Everything is presented smoothly. In reality, the patient encounters obstacles that are not found in the guidelines, e.g. making appointments for mammography must be done oneself, one must find the institutions that are important for follow-up care by oneself, the brochures present a smooth course, which, from my experience, does not take place in this way." (patient, ID 157)

"Illness management is probably not something a guideline can do." (patient, ID 271)

"More time to talk to the doctor, as described in the guideline." (patient, ID 892)

"Cancer patients have a lot of anxiety about their diagnosis. This is not sufficiently dealt with, nor are ways of dealing with it shown." (healthcare provider, ID 407)

"What is sometimes missing in practice is that the patients are not left alone with the guidelines, but that their needs and requirements, which arise when reading the guidelines, are not systematically taken up in supportive and helpful discussions – this is particularly the case when it is a matter of very personal, real-life issues for which the guidelines do not provide any answers." (healthcare provider, ID 167)

"The link [up] of guidelines brochures, hearsay e.g. in waiting rooms, and direct communication with physicians – that's what I would like to see. Patients need at different times different communication or methods of information transfer." (healthcare provider, ID 570)

Patients with a cancer diagnosis additionally named the exchange with other affected people as something they missed, especially at the beginning of their disease trajectory.

"I missed the exchange with others in the beginning." (patient, ID 660)

Discussion

The two national surveys on awareness and perceptions of the GGPO-PGs were conducted among patients – mostly with breast or prostate cancer – and HCPs – mostly physicians. Participants came from all parts of Germany, though predominantly from central Germany. We largely reached our minimum sample size in both surveys concerning the awareness rate of the GGPO-PGs. In both groups – patients and HCPs – overall awareness of the GGPO-PGs was low (45% and 55% respectively). The results from patients with a breast or prostate cancer

diagnosis did not differ from those with another cancer diagnosis. For the HCPs, we found that awareness was higher among professionals working in certified cancer centres compared to those in non-certified cancer centres. The open-ended questions revealed ‘public awareness and availability’, ‘wishes regarding properties’, ‘reasons for using PGs’, and ‘limitations’ as themes.

Awareness of cancer information requires active and strategic dissemination and evaluation

Our survey results are in line with the conclusions of the systematic review of Loudon et al. [12], that “awareness of guidelines is generally low and guideline producers cannot assume that the public has a more positive perception of their material than of alternative sources of health information” [12]. The low awareness of oncological PGs in Germany after more than a decade of production, and the fact that in the open-ended questions participants addressed the need to better advertise the GGPO-PGs, underline the need for a strategic dissemination and evaluation of PG use [24]. A ‘marketing strategy’ could be one approach. To enhance visibility, the GIN toolkit promotes multiple active dissemination strategies, including media releases with the participation of patients and the public, digital tools such as apps, and the provision of copies of the PGs in public places [25]. Distribution of PGs by self-help organisations was perceived as one cornerstone in our survey. This activity should be enhanced.

Our results suggest, furthermore, that working in a certified cancer centre might be one determining factor for PG awareness among physicians and other HCPs. Thus, the distribution of GGPO-PGs in certified cancer centres could become part of the obligatory requirements. In non-certified hospitals or ambulant cancer care, being a physician (compared to other HCPs) was associated with higher awareness of PGs. Patients mentioned physicians and hospitals as central for distribution, aside from self-help organisations. Actively distributing print and online PGs to hospitals and physicians outside of certified cancer centres might be beneficial to further increase awareness.

A structured discussion with representatives of self-help organisations and HCPs on how to improve identification with GGPO-PGs and to create an attractive brand could additionally be useful. Furthermore, an exchange with the producers of the most-used lay oncological guidelines in Germany, the blue guidebooks of German Cancer Aid, could reveal further synergies.

PG producers in other countries should explore and evaluate specific dissemination approaches appropriate to their specific healthcare systems. GIN could provide a platform to exchange experiences concerning successful

information dissemination strategies and could initiate international surveys for evaluation.

Information should fulfil different and specific needs

To enhance use by fulfilling the specific needs of the target population also means strategic marketing. Our results add to our knowledge regarding the properties that PGs should have. Patients and HCPs wish for PGs that are individualised and specific to their needs, easy to understand, and up to date. Furthermore, PGs should adhere to specific quality and format standards – short as well as detailed – and frame information in an encouraging way.

Of major critique among survey participants were missing updates on innovative treatment options and outdated PGs. The GGPO-PGs are developed after the completion of the CPGs for HCPs and thus generally require one-and-a-half to two years until publication. To overcome the problem of outdated PGs, a ‘living guideline’ approach [26] that provides yearly updates – as established in several CPGs – could help.

We found that participants use PGs as a tool to get education and be informed, to be guided in their cancer journey, to get empowered, to learn what they can do in daily life, and to get support. Individualised formats seem to be needed by patients in different stages of their cancer journey. To support decisions, short, focused formats might be helpful in addition to long formats for people who want to fully understand their disease. The GIN public toolkit also recommends decision aids as one pillar of patient information, in addition to other formats.

While the themes ‘getting knowledgeable’ and ‘preparing for communication and decision-making’ overlap with the findings of Fearn et al. [13], the wish for encouraging information and the use of PGs as a tool to get support on how to deal with the illness and cope with their new situation were new aspects of our research. Moreover, we found that written information has its limitations and needs to be embedded within personal time with the physician or other HCPs. Although cancer survival rates have increased in the last years, the diagnosis of cancer is in most cases a life-threatening event [27], bringing deep uncertainty into the life of the affected person [28]. Information is part of the process of normalising life after a shattering cancer diagnosis [29]. Satisfaction with information might be influenced by a trustful relationship with the physician [30] and/or other HCPs and being embedded in a network with emotional support. Thus, physicians and other health professionals need to keep in mind that ‘care receiving’ is central for people diagnosed with cancer [30, 31].

Our results indicate that more highly educated people had a better awareness of the PGs than those with less

education. There was a general wish for easy-to-understand and not-too-technical language. Easy-to-understand language and formats like short films with little text might also help to extend the target group of PGs to less educated or illiterate people. This could be one facilitating factor as part of a broader plan to reach more equity for the care of all patients. An online layer presentation – as suggested by Fearn et al. (1026) [13] – could be a digital solution to realise different formats.

Digitalisation and the use of AI tools may support the presentation of PGs, also in terms of language aspects, for instance, with connected translation tools, and with individualised graphical illustrations. On the other hand, digital versions exclude patients and HCPs who do not use digital devices. In our sample, more than half of participants expressed a wish for written (printed) information. This also correlated with age.

It would be also interesting to know the extent to which information needs of younger patients with a cancer diagnosis are satisfied by evolving digital products only or when and how they too wish for additional personal support to be empowered. There is a need for research into what kind of support is helpful at what time and in what setting, to strengthen patients and fulfil their needs.

Limitations of this study

Our study has some methodological limitations. We did not carry out a pre-test for the surveys, though the drafts were commented on by all co-authors, including the two patients representing two large patient organisations. Another limitation is that we did not plan purposive sampling beyond contacting the professional and patient organisations that have participated in oncological guideline projects. We also did not establish a definition of data saturation.

Survey invitations were widely spread among patients with a cancer diagnosis and HCPs via email, flyers, and posters, yet we do not know how many people were finally reached. We can only indicate an approximate response rate, which is in absolute terms very low. We largely reached our statistical goal, but we did not reach a fully representative sample concerning different cancer types or the characteristics of patients and HCPs. Patients active in self-help groups are overrepresented in our sample. We had a high rate of male doctors in leading positions as HCPs who had participated in guideline development. Our sample was thus not representative of the predominantly female clinical gender reality and the range of professions in healthcare. The study design included an open invitation to participate; there were no further processes to avoid selection bias among respondents. It is thus also likely that the participating patients

and HCPs had an above-average interest in or knowledge of oncological patient guidelines.

Conclusion

For the participating HCPs, while awareness of oncological PGs was low, those who were aware found them helpful. This suggests the need for improved – in particular, more strategic – dissemination. The same was true for patients; however, further research needs to be done on how to improve the overall helpfulness of PGs for patients. Patient information in the form of oncological PGs seems to be required in different formats, according to patients' individual information needs, and depending on individual and disease-related factors. In-depth interviews and/or focus groups in a heterogeneous population of patients with a cancer diagnosis, their partners, and members of self-help organisations might be helpful in meeting these needs. Beyond the purpose of education and knowledge, patients and HCPs should keep in mind the personal burden of a cancer diagnosis. To strengthen patients, information needs to be framed in a supportive way and embedded in a relationship. Additional theory-driven research should investigate how this can be done best.

Abbreviations

ASCO	American Society of Clinical Oncology
AWMF	Association of the Scientific Medical Societies in Germany
AWMF-IMWi	AWMF-Institute for Medical Knowledge Management
COVID-19	Coronavirus Disease 2019
CPG	Clinical practice guideline
DECIDE	Developing and Evaluating Communication Strategies to support Informed Decisions and practice based on Evidence – project funded by the European Union to develop user-specific guideline formats
DKG	German Cancer Society
GGPO	German Guideline Program in Oncology
GIN	Guidelines International Network
ID	Identification (number)
IFOM	Institute for Research in Operative Medicine
MD	Median
MH	Mantel–Haenszel
NCP	National cancer plan
NICE	National Institute for Health and Care Excellence (UK)
OR	Odds ratio
PG	Patient guideline (patient version of the CPG)
SD	Standard deviation
SPSS	Statistical Package for the Social Sciences

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11563-2>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.
Supplementary Material 5.
Supplementary Material 6.

Acknowledgements

The authors thank all survey participants – patients with a cancer diagnosis as well as healthcare providers, the self-help organizations, the supporting staff in the cancer centres and the scientific medical societies who distributed the information to the survey in their networks and clinics.

Data sharing statement

Data are shared on request.

Authors' contributions

M.N. and S.B.L. planned the surveys, analysed the data and interpreted the quantitative study results. S.E. organized the survey. D.P. and A.P. added to statistical analysis. S.B.L., M.N. and C.H. interpreted the qualitative study results. S.B.L. and M.N. wrote the first draft of the manuscript. All authors - (S.B.L., M.B., G.C., S.E., S.F., M.F., C.H., T.L., A.P., D.P., M.N.) reviewed and discussed the questionnaires and contributed, reviewed and commented to the final manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Availability of data and materials

All of the material is owned by the authors and/or no permissions are required.

Data availability

Data on survey results are stored by the authors and are shared on request.

Declarations

Ethics approval and consent to participate

No ethical approval was needed for this survey, which used anonymised data in accordance with the Berlin chamber of physicians' medical code of conduct §15 section 1.

Participation in the survey was voluntary and participants gave informed consent before starting the survey.

Consent for publication

Not applicable.

Competing interests

Susanne Blödt, Monika Nothacker and Sabine Erstling are employed at the Institute for Medical Knowledge Management of the Association of the Scientific Medical Societies in Germany (AWMF-IMWi). The AWMF-IMWi receives institutional third-party funding from the German Cancer Aid for methodological support of the German Guideline Program in Oncology. Markus Follmann and Thomas Langer are employed at the German Cancer Society and are partially funded by the German Cancer Aid for coordinating the GGPO and providing methodological support for the guideline groups developing patient versions. Monika Becker and Dawid Pieper received institutional funding for the development of oncological patient versions of guidelines in Germany. Ernst-Günther Carl, Stefanie Frenz, Christine Holmsberg and Alexander Pachanov did not report any competing interests.

Author details

¹AWMF (Association of the Scientific Medical Societies in Germany)-Institute for Medical Knowledge Management (IMWi), c/o Philipps-University, Marburg, Germany. ²Institute for Research in Operative Medicine (IFOM), Witten/Herdecke University, Cologne, Germany. ³German Prostate Cancer Support Group, Bonn, Germany. ⁴Office of the German Guideline Program in Oncology (GGPO), c/o German Cancer Society, Berlin, Germany. ⁵Women's Self-Help Association Cancer, Bonn, Germany. ⁶Institute of Social Medicine and Epidemiology, Brandenburg Medical School Theodor Fontane, Brandenburg an der Havel, Germany. ⁷Faculty of Health Sciences Brandenburg, Brandenburg Medical School Theodor Fontane, Institute for Health Services and Health System Research, Rüdersdorf, Germany. ⁸Centre for Health Services Research, Brandenburg Medical School Theodor Fontane, Rüdersdorf, Germany.

Received: 21 December 2023 Accepted: 9 September 2024

Published online: 09 October 2024

References

- Blödt S, Kaiser M, Adam Y, Adami S, Schultze M, Müller-Nordhorn J, et al. Understanding the role of health information in patients' experiences: secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany. *BMJ Open*. 2018;8(3):e019576.
- Robert Koch-Institute. Krebs in Deutschland für 2017/2018: Zentrum für Krebsregisterdaten Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V.; 2021 [13.]. Available from: https://www.krebsdaten.de/Krebs/DE/Content/Publikationen/Krebs_in_Deutschland/kid_2021/krebs_in_deutschland_2021.pdf?__blob=publicationFile.
- Ministry of Health. Ziele des Nationalen Krebsplans - NKP 2008. Available from: <https://www.bundesgesundheitsministerium.de/themen/praevention/nationaler-krebsplan/handlungsfelder/ziele-des-nationalen-krebs-plans.html>. Cited 2022 August.
- German Cancer Society e.V. . Certification 2022. Available from: <https://www.krebsgesellschaft.de/gcs/german-cancer-society/certification.html>. Cited 2022 August.
- Institute of Medicine. Clinical practice guidelines we can trust. Graham R, Mancher M, Wolman DM, Greenfield S, Steinberg E, editors. Washington, DC: The National Academies Press; 2011:290.
- Bundesministerium für Gesundheit. Gesetz zur Verbesserung der Rechte von Patientinnen und Patienten Bonn. 2013. Cited 2013 Februar 20.
- Ärztliches Zentrum für Qualität in der Medizin (ÄZQ), Office des Leitlinienprogramms Onkologie (OL), AWMF-Institut für Medizinisches Wissensmanagement (AWMF-IMWi). Erstellung von Patientenleitlinien zu S3-Leitlinien/NVL im Rahmen der Leitlinienprogramme 2016 Letzter Zugriff am 02.09.2020; Beta-Version 2. Available from: www.patienteninformation.de/patientenleitlinien.
- Graham K, Schaefer C, Santesso N. G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines 2015 [Guidelines International Network (GIN)]. Available from: <https://g-i-n.net/chapter/patient-information/>.
- National Institute for Health and Care Excellence (NICE). Research recommendations process and methods guide. 2015. Available from: <https://www.nice.org.uk/Media/Default/About/what-we-do/Research-and-development/Research-Recommendation-Process-and-Methods-Guide-2015.pdf>.
- American Society of Clinical Oncology. ASCO answers patient education materials: ASCO. 2022. Available from: <https://www.cancer.net/about-us/asco-answers-patient-education-materials>.
- Treweek S, Oxman AD, Alderson P, Bossuyt PM, Brandt L, Brozek J, et al. Developing and Evaluating Communication strategies to support Informed Decisions and practice based on Evidence (DECIDE): protocol and preliminary results. *Implementation Sci*. 2013;8:6.
- Loudon K, Santesso N, Callaghan M, Thornton J, Harbour J, Graham K, et al. Patient and public attitudes to and awareness of clinical practice guidelines: a systematic review with thematic and narrative syntheses. *BMC Health Serv Res*. 2014;14:321.
- Fearn N, Kelly J, Callaghan M, Graham K, Loudon K, Harbour R, et al. What do patients and the public know about clinical practice guidelines and what do they want from them? A qualitative study. *BMC Health Serv Res*. 2016;16:74.
- Santesso N, Morgano GP, Jack SM, Haynes RB, Hill S, Treweek S, et al. Dissemination of clinical practice guidelines: a content analysis of patient versions. *Med Decis Making*. 2016;36(6):692–702.
- McMaster University and Evidence Prime Inc. GRADEpro. 2019. Available from: <https://gradepro.org/>.
- MAGIC Evidence Ecosystem Foundation, Oslo, Norway. Available from: <https://app.magicapp.org/#/guidelines>.
- Krebshilfe. Blaue ratgeber. 2024.
- Keinki C, Seilacher E, Ebel M, Ruetters D, Kessler I, Stellamanns J, et al. Information needs of cancer patients and perception of impact of the disease, of self-efficacy, and locus of control. *J Cancer Educ*. 2016;31(3):610–6.
- Patient Guidelines of the German Guidelines Program in Oncology (GGPO-PG): German guidelines program in oncology; 2024. Available from: <https://www.leitlinienprogramm-onkologie.de/patientenleitlinien/uebersicht>.
- Schaefer C, Zowalla R, Wiesner M, Siebert S, Bothe L, Follmann M. Patient guidelines in oncology: objectives, procedures and first experiences with this format. *Z Evid Fortbild Qual Gesundheitswes*. 2015;109(6):445–51.

21. Becker M, Buhn S, Meyer N, Blödt S, Carl G, Follmann M, et al. Investigating the role and applicability of patient versions of guidelines in oncology and deriving recommendations for the development, dissemination and implementation of patient versions in Germany: protocol for multiphase study. *BMJ Open*. 2022;12(3):e059040.
22. Heiligenhaus A, Michels H, Schumacher C, Kopp I, Neudorf U, Niehues T, et al. Evidence-based, interdisciplinary guidelines for anti-inflammatory treatment of uveitis associated with juvenile idiopathic arthritis. *Rheumatol Int*. 2012;32(5):1121–33.
23. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3:77–101.
24. Collins N. Strategic marketing plans. Minneapolis: Walden University; 2014.
25. Graham K, Schaefer C, Santesso N. G-I-N PUBLIC Toolkit: patient and public involvement in guidelines- dissemination. 2015. Available from: <https://g-i-n.net/toolkit/dissemination-of-guidelines/>.
26. Akl E, Meerpohl J, Elliot J. Living systematic reviews: 4. Living guideline recommendations. *J Clin Epidemiol*. 2017;91:47–53.
27. Nanton V, Docherty A, Meystre C, Dale J. Finding a pathway: information and uncertainty along the prostate cancer patient journey. *Br J Health Psychol*. 2009;14(Pt 3):437–58.
28. Holmberg C. Eine ethnographische Studie über Krankheit und Krankheitserleben [Diagnosis Breastcancer: An ethnographic study on disease and illness experience]. Frankfurt/new York: Campus Verlag; 2005.
29. Kaiser M, Adami S, Lucius-Hoene G, Müller-Nordhorn J, Goerling U, Breuning M, et al. Learning-by-doing: the importance of experiential knowledge sharing for meeting the information needs of people with colorectal cancer in Germany-a qualitative study. *BMJ Open*. 2021;11(2):e038460.
30. Blödt S, Müller-Nordhorn J, Seifert G, Holmberg C. Trust, medical expertise and humaneness: a qualitative study on people with cancer' satisfaction with medical care. *Health Expect*. 2021;24(2):317–26.
31. Kleinman A. Care: in search of a health agenda. *Lancet*. 2015;386(9990):240–1.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.