Primary care-led survivorship care for patients with colon cancer and the use of eHealth: a qualitative study on perspectives of general practitioners

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ABSTRACT

Objectives: The aim of this study was to explore the perspectives of general practitioners (GPs) regarding their current and future role in survivorship care of patients with colon cancer, and to assess their perspectives on patients’ self-management capacities and the value of the eHealth application Oncokompas used by patients.

Setting: GPs from the central part of the Netherlands were interviewed at their location of preference.

Participants: 20 GPs participated (10 men, 10 women, age range 34–65 years, median age 49.5 years). The median years of experience as a GP was 14.5 years (range 3–44 years).

Results: GPs indicated attempting to keep in contact with patients after colon cancer treatment and mentioned being aware of symptoms of recurrent disease. Most participants would have liked to be more involved and expected to be able to provide survivorship care of colon cancer. Requirements mentioned were agreements with secondary care and a protocol. GPs considered Oncokompas, which stimulates patients to structure their own survivorship care, as a useful additional tool for a specific group of patients (ie, young and highly-educated patients).

Conclusions: Based on the perspectives of the GPs, survivorship care of colon cancer in primary care is deemed feasible and the use of an eHealth application such as Oncokompas is expected to benefit specific groups of patients after colon cancer treatment.

BACKGROUND

It is expected that, in 2020, more than 17 000 patients in the Netherlands will be diagnosed with colorectal cancer.1 After initial treatment, patients are included in a surgeon-led programme that mainly focuses on detection of recurrent disease and metachronous tumours. This so-called ‘follow-up’ includes periodical carcinoembryonic antigen blood testing, imaging of the abdomen and colonoscopy during the first five postoperative years.1

Scheduled follow-up is part of survivorship care, which also includes care to alleviate physical and psychosocial concerns, provision of information, evaluation of late and adverse effects due to treatment or disease, and lifestyle counselling after initial treatment.2

Currently, several aspects of survivorship care are not well addressed in secondary care. Only a small number of distressed patients are identified and supported.3,4 A cross-sectional survey among Dutch patients, surgeons and general practitioners (GPs), demonstrated that patients were satisfied with the current surgeon-led care concerning recurrent disease detection and identification of physical symptoms.2 However, only half of the patients were satisfied with the identification and treatment of psychosocial concerns.5 Care of a GP is suggested by the Health Council of the Netherlands, the Dutch Cancer Society and the Dutch College of General Practitioners, to improve survivorship care.6–8 The current role of GPs in survivorship care is not well defined.

Besides a more prominent role for GPs in survivorship care, the Dutch Federation of Cancer Patients Organizations and the Dutch Cancer Society recommend a more central role of patients in managing their medical care during the transition period.
own health. This is in line with the Chronic Care Model (CCM). Self-management is defined as the individual’s ability to manage symptoms, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition. Web-based interventions (eHealth) can have a positive effect on self-management in patients with a chronic disease such as cardiac failure, diabetes and chronic obstructive pulmonary disease (COPD). Also, after cancer treatment, eHealth is becoming more important to involve patients in structuring their own rehabilitation. An example of a self-management eHealth application to enable patients with cancer to positively influence their rehabilitation is Oncokompas (see online supplementary appendix A). In Oncokompas, cancer survivors can monitor their quality of life by means of patient-reported outcomes (‘Measure’), which is followed by automatically generated tailored feedback (‘Learn’) and personalised advice on supportive care services (‘Act’). According to various Dutch healthcare and patients’ organisations, both a more prominent role of GPs and patients’ self-management are important aspects to improve survivorship care of cancer. Therefore, it is important to explore the feasibility of these recommendations together. To date, combined research on these aspects in the survivorship care of patients with colon cancer is scarce. Therefore, the aim of this study was to explore the perspectives of GPs regarding their current and future role in survivorship care of patients with colon cancer, and to assess their perspectives on patients’ self-management capacities and the value of the eHealth application, Oncokompas.

**METHOD**

**Study sample**

In this qualitative study, GPs were interviewed. GPs were chosen to be the group of interest because their views can help in preparing GPs in case their role in survivorship care becomes more prominent. GPs were recruited through the network of the department of General Practice of the Academic Medical Centre (AMC) in Amsterdam. All selected GPs worked in cities and villages of three provinces around Amsterdam, in the Netherlands. First, GPs were invited by email with information about the study. Subsequently, the GPs were informed by one researcher (LAMD) by phone on details about the study and asked for agreement to participate. During recruitment, we used purposive sampling to achieve a wide sample of participants with respect to gender, age, years of experience as a GP, area of occupation (ie, urban vs rural) and employment (self-employed or employed).

In total, 10 men and 10 women participated in semi-structured individual interviews. Table 1 shows their characteristics. No GPs declined participation. All participants provided verbal consent, which was digitally recorded. The Research Ethics Committee of the AMC reviewed the protocol and assessed that the Medical Research Involving Human Subjects Act does not apply to this study. An official approval by the committee was therefore not required and written informed consent not obtained.

**Procedure**

Interviews were performed by one researcher (LAMD), who received training in qualitative methods and had previously conducted another qualitative study. Interviews took place at a location preferred by the participants, for example, at the researcher’s workplace (n=9), at the participant’s clinic (n=7) or at the participant’s home (n=4). Topics and questions were based on the literature and clinical expertise of the research team. The four topics discussed during the interview were: current involvement of the GP in survivorship care of patients with colon cancer, the possibility of a more prominent role in the future, the capability of patients’ self-management and the expected potential of the eHealth application, Oncokompas (table 2).

**Data analysis**

Data analysis was conducted by two coders (LAMD and TW), using thematic data analysis. The first 10 transcripts were independently analysed, in which citations regarding GPs’ views about the four topics were selected.
and key issues and themes identified (table 2). The two coders compared their key issues and themes, and discussed all discrepancies until consensus was reached. In case of disagreement, a third researcher (CFvU-K or JW) was consulted. Related themes were combined and refined. The coders together created a framework, based on these 10 interviews. Subsequently, the remaining 10 transcripts were analysed by one coder (LAMD) according to the framework as previously defined. Transcripts containing quotes that did not reflect the framework were discussed with the second coder (TW) until consensus was reached. One coder (LAMD) re-examined all transcripts to ensure that the analysis was robust and to confirm that all data were reflected in the coding. Data analysis was conducted using MAXQDA V.11.0 software. Reporting of the data was carried out using the consolidated criteria for reporting qualitative research (COREQ).17

RESULTS

GPs’ current involvement in survivorship care of patients with colon cancer
GPs mentioned various levels of involvement with patients with colon cancer in survivorship care, including follow-up (table 3). GPs pointed out involvement with patients after initial colon cancer treatment in different ways. Some GPs described proactively initiating contact with patients after treatment to monitor psychological symptoms and to offer support. During the initial contact, GPs discussed patient’s preferences regarding the degree of the GP’s involvement in order to personalise their contact.

What matters is: “How are you? Do you have any questions? Are there any uncertainties?” This is a reason for us to get in touch with patients. Because, in the acute phase, patients might be too busy with their disease and there will be a moment they’ll ask themselves: how do I proceed? We try to avoid this and arrange another appointment. At a minimum, we invite patients for a subsequent appointment. (GP6, male)

Other GPs said they only got involved after their patients initiated contact. Although a role for GPs in follow-up is not described in the national guideline, two GPs indicated that patients requested them to perform the continuation of follow-up in secondary care.

Not all GPs felt involved with survivorship care, which they experienced as a shortcoming (n=8). GPs mentioned losing contact with their patients during cancer treatment. For example, some GPs experienced patients ‘disappearing’ in secondary care after colon cancer diagnosis, and felt that updated information was lacking since letters from medical specialists are often delayed or not received at all. GPs also assumed that patients already had a lot of healthcare providers involved in secondary care and did not need their GP in this phase. Two GPs had difficulties in answering the interview question, since they were not frequently confronted with patients after colon cancer treatment. Furthermore, GPs mentioned that their contact with these patients occurred randomly, depending on their available time and their level of contact with patients before the cancer diagnosis.

There has to be a reason to get in contact, this can be information from the hospital like a discharge letter that makes me realize: it has been a while, I am going to call this patient to hear how he is doing. And you need sufficient time. (GP7, male)

Despite varying levels of involvement, GPs mentioned being aware of a cancer history if these patients consulted them. Some indicated being especially aware when patients presented with symptoms that could indicate recurrent disease, for example, weight loss, abdominal pain and paleness. Others mentioned paying specific attention to patients’ well-being if patients showed up for non-cancer symptoms.

Future role of GPs in survivorship care for patients with colon cancer
Participants were ambiguous about their future involvement in survivorship care, including follow-up. They
preferred or did not prefer to be more involved. The majority of the GPs expected patients to benefit from more involvement of the GP in survivorship care, because the GP’s practice was closer to their homes and consulting their familiar GPs might decrease patients’ anxiety levels.

Of course, there are a lot of people who experience a visit to the hospital as a burden. These people will be pleased if they are able to visit their GP. Especially when they know that the same diagnostic tests will be done. (GP13, female)

Eleven participants wanted to be more involved in survivorship care of patients with colon cancer. They mentioned several arguments for this enhanced involvement (table 3). They were willing to be the coordinator of survivorship care in the future, including follow-up. According to them, coordination of survivorship care by GPs will lead to more continuity of care for patients. GPs assumed they would be able to obtain an improved total overview of their patients, compared with the current situation.

I think that psychological support will be easier to provide if you’re also involved in the physical part of survivorship care (GP2, female)

Another argument of GPs to be willing to coordinate survivorship care is that they felt they were more aware of patients’ contexts than were medical specialists and therefore more capable to deliver comprehensive care. Also, these participants believed that coordination could strengthen their doctor–patient relationship. Although not all GPs indicated being familiar with the content of the follow-up guideline, they thought coordination by GPs would be feasible and expected it to be easy to carry out.

I wonder what the effort of a surgeon looks like. I mean, the patient visits the surgeon at the outpatient clinic and the surgeon asks: “How are you? “I’m doing fine”. “The result of the blood test was good, the ultrasound was normal”. At last, he examines the abdomen, they shake hands and that is that. I don’t think much of it. (GP1, male)

Furthermore, GPs stated that care that can be delivered in primary care should be delivered in primary care.

Table 3 Overview of involvement and key issues and themes concerning the current and future role in survivorship care of colon cancer according to GPs

| Key issues | Theme |
|------------|-------|
| Current role of the GP | |
| The GP experiences involvement in patients who have been treated for colon cancer | ▶ Initiates periodic contact with the patient |
| The GP has a limited role when patients have been treated for colon cancer | ▶ Involved after patient initiated contact |
| Desired role of the GP in survivorship care | ▶ Awareness if patient has a history of colon cancer |
| The GP wants to be more involved in coordination of colon cancer survivorship care | ▶ Loses contact with the patient |
| The GP does not want more involvement | ▶ Contact with patients at random |
| Requirements of the GP to coordinate survivorship care of colon cancer | ▶ Not often confronted with patients who have been treated for colon cancer |

GPs, general practitioners.
Well, I think there is a trend towards more care being transferred to GPs, because we have a broad view and we are more conservative with respect to diagnostic tests. (GP5, female)

Seven participants were satisfied with their current involvement and preferred to maintain this role—mainly because they believed that too many responsibilities have been transferred to primary care and they felt unable to adopt another task.

Well, the workload is increasing. I mean, first there was diabetes, then COPD and cardiovascular risk management. We already integrated asthma and now care for elderly will be added. It has to fit in the same practice. It all has to be done within the same 24 hours. There is a limit if it comes to transferring tasks. (GP8, female)

Another barrier mentioned by GPs was their assumption that survivorship care including follow-up requires a different approach from GPs. They indicated that, usually, GPs deal with patients' ad hoc problems. They were not willing to adapt another protocol as a guidance of a consult. Furthermore, some GPs did not feel confident due to lack of expertise. They also mentioned that patients might think GPs lack expertise.

The remaining two participants stated having doubts concerning more involvement in survivorship care. They only wanted to be more involved if they would be supported by nurses in their practice, comparable to specialist nurses taking care of other chronic illnesses in primary care.

Overall, GPs mentioned some requirements if survivorship care were to be transferred. The most important requirement mentioned was clear agreements with medical specialists in secondary care, including easily accessible consultations, to enable fast referrals to specialist care were to be transferred. The most important requirement was that if it comes to transferring tasks. (GP8, female)

The majority of 14 GPs had a positive attitude towards the possibility of patients being more involved in survivorship care and they offered suggestions to achieve this. First, patients should be more informed about physical symptoms that might indicate recurrent disease and when to consult their doctor. Besides that, GPs wanted patients to participate in decision-making. They suggested providing patients with the possibility of arranging their own care, by defining individual goals during rehabilitation and stimulating patients to decide which supportive care they desired. The GPs believed that patients would consequently be more in charge of their own survivorship care.

To what extent do you want to go on in case of recurrent disease? What do you want in that scenario and what do you not want? You can also think of: which sort of care do you desire and what type of care not? (GP3, male)

A few GPs found it difficult to answer the question and could not imagine which specific parts of survivorship care can be managed by patients.

The use of an eHealth application in survivorship care of colon cancer

After an introduction (see online supplementary appendix A) including a demonstration of Oncokompas 2.0, a majority of 14 GPs had a positive attitude towards patients' use of Oncokompas 2.0 and four participants were partly positive. One of the motives of the positive GPs to provide Oncokompas 2.0 was that it could make patients feel more empowered. According to them, patients would be able to use the application whenever it suited them, would receive tailored advice and would be able to consider which advice was appropriate for them.

We still keep patients dependent and now they will be forced to explore 'what suits me'. And we have to adopt a different role, as a coach and not as a father figure. (GP10, female)

Another motive of GPs to provide Oncokompas 2.0 to patients would be that patients would gain insight into their own symptoms and concerns. GPs said it would be a relief for patients to be informed on specific well-known late effects and to realise they are not the only ones suffering from certain symptoms and concerns.

Furthermore, GPs expected that patients would be better prepared if they used Oncokompas 2.0 before

Patients’ self-management after colon cancer treatment

Next, GPs were asked to provide their views on the role of self-management by patients with regard to supportive care after colon cancer treatment (table 4).

Participants indicated having reservations about the possibility of patients’ self-management, because they did not consider all patients to be willing to be more in charge.

I think that some people are able to manage it well, but most of the time, people with cancer want someone else to be in charge. Look, diabetes or COPD; that has to do with lifestyle. Cancer has partly to do with lifestyle, but in most cases not. So, I think it’s a different situation; it happens to people. (GP4, male)

Additionally, they assumed not everyone would be capable of taking responsibility of his/her own survivorship care, for example, among the elderly, immigrants or poorly educated people.

Although almost all participants had reservations, most GPs believed that the role of self-management should be expanded in survivorship care and they offered suggestions to achieve this. First, patients should be more informed about physical symptoms that might indicate recurrent disease and when to consult their doctor. Besides that, GPs wanted patients to participate in decision-making. They suggested providing patients with the possibility of arranging their own care, by defining individual goals during rehabilitation and stimulating patients to decide which supportive care they desired. The GPs believed that patients would consequently be more in charge of their own survivorship care.

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consulting their GP. They assumed Oncokompas\textsuperscript{2,0} would save the GPs’ time spent in the patient’s medical history taking and would provide appropriate support. The participants mentioned that the eHealth application could be used as a supportive instrument that might stimulate self-management of patients. However, they declared that it should be used in addition to standard survivorship care and not as a replacement for it.

Two participants did not support the use of eHealth in general as they found it impersonal, and preferred exploration of symptoms and concerns by themselves. These reservations were also mentioned by the GPs who supported the use of eHealth, who furthermore indicated that eHealth would only be suitable for patients who are highly educated and young. The elderly, poorly educated people, people with no computer skills, illiterates and immigrants who are not able to understand Dutch were not considered as target groups. Some GPs feared that the use of Oncokompas\textsuperscript{2,0} could cause arousal in patients, by showing them a list of problems that could occur.

Of course, you can ask a lot of questions, but that can also give patients ideas about what might go wrong. So, for example an anxious patient reads: “Do you have symptoms of...?” They might think: Is that also possible after colon cancer? (GP5, female)

GP\s had different ideas about how to incorporate the use of Oncokompas\textsuperscript{2,0}. Overall, the participants who had a positive attitude towards the use of Oncokompas\textsuperscript{2,0} preferred to be informed about the general content of Oncokompas\textsuperscript{2,0}, in order to be prepared if patients had questions. A majority of the GPs wanted to be a consultant when patients used Oncokompas\textsuperscript{2,0} and to leave the initiative to patients on whether or not they wanted to discuss the results.

I think if someone is able to use it, he is able to manage it for himself. In that case it should not make him dependent. (GP17, female)

The GPs who preferred to be a consultant stated that, in case Oncokompas\textsuperscript{2,0} advises patients to take action for which a referral of the GP is needed, they preferred to discuss the results first.

If I have to make a referral on request, I always want to talk to my patient. I have been asked to write referral letters, like: ‘Do you want to write a letter to the physical therapist?’ Well, I refuse. I first want to see patients and have a look, because I’m not an administrator and that doesn’t change in this case. (GP12, male)

| Table 4 Overview of involvement, and key issues and themes concerning patient’s self-management and the use of Oncokompas\textsuperscript{2,0} in survivorship care of colon cancer according to GPs |
|-----------------------------------------------|-----------------------------------------------|-----------------------------------------------|
| **Key issues** | **Theme** | **Key points** |
| **Patients’ self-management in survivorship care** | Reservations of the GP concerning patients’ responsibilities in survivorship care | ▶ Patients are not willing to be responsible for own care |
| | Patients should be more involved in survivorship care | ▶ Patients are not capable of taking responsibility |
| | | ▶ Patients should be informed about physical symptoms that could indicate recurrent disease and about when to consult a doctor |
| **Use of Oncokompas\textsuperscript{2,0} in survivorship care of colon cancer** | The GP had a positive attitude towards the use of Oncokompas\textsuperscript{2,0} | ▶ Involvement in decision-making |
| | Reservations of the GP concerning the use of Oncokompas\textsuperscript{2,0} | ▶ Oncokompas\textsuperscript{2,0} makes patients more empowered |
| | Involvement of the GP during patient’s use of Oncokompas\textsuperscript{2,0} | ▶ Patients will obtain insight into their symptoms and concerns |
| | | ▶ Oncokompas\textsuperscript{2,0} will relieve the workload of GPs |
| | | ▶ Increased insight for both GP and patients in case of vague symptoms and problems |
| | | ▶ Impersonal |
| | | ▶ Not suitable for all patients |
| | | ▶ Increases patients’ awareness of problems |
| | | ▶ GPs as consultants |
| | | – Leave the initiative to the patient to discuss Oncokompas\textsuperscript{2,0} results |
| | | – Estimate if a referral, suggested by Oncokompas\textsuperscript{2,0}, is appropriate |
| | | ▶ Intensive involvement of the GP |
| | | – Receive a message if the patient has a serious symptom or concern detected by Oncokompas\textsuperscript{2,0} |
| | | – Discuss results of Oncokompas\textsuperscript{2,0} routinely with the patient |

GPs, general practitioners.
A few participants wished to be involved intensively when their patients used Oncokompas2.0. They wanted to have insight into their patients’ Oncokompas2.0 results and to discuss them routinely, especially if the coordination of survivorship care were to be transferred to primary care. These participants also suggested receiving an alert if a patient had a low score on specific well-being items assessed by Oncokompas2.0.

DISCUSSION
This study explored the perspectives of GPs regarding their current and future role in survivorship care of patients with colon cancer. Furthermore, their views towards the use of eHealth to stimulate self-management among patients with cancer were assessed.

Our results show that part of the GPs role is not (routinely) involved in survivorship care of patients with colon cancer. However, it has been shown that patients who have been treated for cancer consult their GP more often compared to patients without a history of cancer. This indicates that GPs are supposed to be in touch with patients after cancer treatment. Several GPs interviewed reported losing contact. Others mentioned not keeping in touch with patients actively, but decided their level of involvement was based on their patients’ preferences. These GPs seemed to adapt a reactive attitude after their patients were treated for cancer. In contrast, a review study on cancer survivors’ general practice needs showed that cancer survivors preferred to have a proactive GP after treatment, supporting them in their needs on psychosocial issues and medical issues, and for their information requirements.

As the number of cancer survivors is increasing, a programmatic approach in survivorship care is required to meet patients’ needs. Furthermore, more generalist care is suggested. Dutch surgeons have acknowledged lacking sufficient time to provide psychosocial survivorship care, and have stated that GPs are better equipped with respect to time and skills to tackle these problems. Our study showed that most of the interviewed GPs were willing to have a more central role in survivorship care. They expected a better doctor–patient relationship and more continuity of care—aspects that have shown to be of great importance to patients. Two randomised controlled trials demonstrated that GP-led survivorship care including follow-up was comparable with respect to quality of life, efficiency of recurrence detection and anxiety levels. Barriers mentioned by the interviewed GPs were the already high workload and lack of expertise. An instrument to enable the transition of survivorship care to primary care is a survivorship care plan. This care plan contains an individualised, comprehensive care summary of and follow-up plan for the patient. It provides GPs with the required information and might improve communication between GPs and specialists. Survivorship care plans are recommended by the Institute of Medicine, and advocated by patients and the Dutch College of General Practitioners.

Although a recent study showed that Dutch GPs have a positive attitude towards introduction of a survivorship care plan, it has not been introduced systematically nationwide. Furthermore, evidence of improved patients’ outcomes associated with the introduction of survivorship care plans is limited.

The Comprehensive Cancer Centre advises implementing the CCM in survivorship care of cancer and advocates that research be conducted in order to redesign survivorship care. The vast majority of GPs in our study were positive towards more patient involvement in future survivorship care by letting patients define their own goals during rehabilitation and letting them decide on what kind of supportive care is best for them. These are the main targets of Oncokompas2.0, and they are expected to receive more knowledge of their problems and their self-dependence is expected to increase. Previous research has shown that patients had a positive attitude towards eHealth after cancer treatment and were satisfied with the use of Oncokompas2.0. Furthermore, GPs are responsible for the majority of care for patients with COPD and cardiovascular disease in the Netherlands. Care for these patients is conformable to the CCM guidelines. Therefore, implementation of survivorship care of cancer according to the CCM in primary care seems feasible.

Almost all interviewed GPs who were positive wanted to be supportive if their patients were to use Oncokompas2.0. They saw either a reactive (patients’ initiative to discuss their results) or an active (GPs’ initiative to discuss patients’ results) role for themselves. Both roles were also mentioned by healthcare providers engaged in the follow-up of patients with head and neck cancer, and involved in the development of Oncokompas2.0. An obstacle mentioned by GPs was that eHealth might be less suitable in the elderly compared with in younger patients. This is in line with previous research on eHealth. However, more recently, progress has been made in the development of eHealth applications suitable for the elderly. Studies have shown that eHealth can be used by older patients, without difficulties, for example, by older men with prostate cancer. Furthermore, the interviewed GPs considered poorly educated patients not capable of understanding the feedback and personalised advice on their reported outcomes in Oncokompas2.0. As patients with breast cancer with low incomes and low education levels have been shown to use eHealth to a similar extent as more advantaged counterparts, Oncokompas2.0 might reach more patients than our participants assumed. Gee et al. suggested that patients and healthcare providers should both be trained before using eHealth for it to be successful, because, according to them, an informed patient with the skills and knowledge to use eHealth is a key element of the CCM. In future
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studies, the additional value of eHealth should be explored in colon cancer survivors with appropriate support.

Strengths and limitations

The interviews with GPs in this study took place at the location of preference of the participants, which enabled them to feel comfortable and speak freely about their experiences. Although we tried to achieve a wide sample of GPs by using purposive sampling, only a small group of GPs were working in rural areas. It could be expected that GPs working in rural areas feel more involved with patients who have been treated for cancer, because of geographic distances to secondary care. Another limitation was that some of the GPs were not often confronted with patients after colon cancer treatment and had difficulties in answering the questions. In general, they based their answers on cancer overall, to make their perspectives clear. Questions on eHealth were preceded with an introduction to Oncokompas, supported by screenshots. Although this stimulates participants to visualise Oncokompas and provides an idea of how it works, the screenshots gave only an abstract picture and the interactive nature of Oncokompas might have not become completely clear.

In conclusion, based on the perspectives of the interviewed Dutch GPs, survivorship care of colon cancer in primary care is deemed feasible. However, GPs mentioned arrangements with secondary care and a protocol to be required if they were to become coordinators of survivorship care. An eHealth application such as Oncokompas is expected to be beneficial. According to GPs, Oncokompas should be considered additional and is expected to stimulate patient empowerment and awareness in supporting patients to structure their own survivorship care. GPs were open to discuss Oncokompas, results and supportive care options with patients. Nevertheless, according to the GPs, eHealth will not be appropriate for all patients.

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Contributors

LAMD conducted the interviews. TW and LAMD analysed the data. JW and CFvU-K served as scientific advisors during data analysis and interpretation. All the authors were involved in the conception and design of the study. LAMD wrote the manuscript and all the authors critically reviewed the manuscript.

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Competing interests

None declared.

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Medical Ethics Review Committee of the AMC, Amsterdam.

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Data sharing statement

No additional data are available.

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