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Primary care-led survivorship care for colon cancer patients and the use of eHealth: perspectives of general practitioners

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4 **general practitioners**
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49 **Keywords**

50 Colon cancer, survivorship care, primary care, eHealth
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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 colon cancer patients and to assess their perspectives on patients' self-management capacities and the value of the eHealth application Oncokompas^{2.0}.

Setting

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

Participants

Twenty 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 3-34 years).

Results

GPs indicated to attempt to keep in contact with patients after colon cancer treatment and mentioned to be aware of symptoms of recurrent disease. Most participants would like to be more involved and expected that they can provide survivorship care of colon cancer. Requirements mentioned were agreements with secondary care and a protocol. GPs considered Oncokompas^{2.0} as a useful additional tool for a specific group of patients (i.e. young and highly-educated patients), which stimulates patients to structure their own survivorship care.

Conclusion

Based on the perspectives of the general practitioners, survivorship care of colon cancer in primary care is deemed feasible and the use of an eHealth application like Oncokompas^{2.0} is expected to be beneficial after colon cancer treatment for a specific group of patients.

Article summary

Strengths and limitations of this study

- This study shows GPs' perspectives on the current need to improve survivorship care of cancer by introducing GP-led survivorship care and stimulation of patients' self-management with an eHealth application
- Interviews took place at the location of preference of the participants which enabled them to speak freely about their experiences
- Screenshots used during the interview to introduce questions on eHealth might gave an abstract picture of the eHealth application Oncokompas^{2.0}

Background

It is expected that in 2020 more than 17.000 patients with colorectal cancer will be diagnosed in the Netherlands.¹ After initial treatment, patients are included in a surgeon-led programme which mainly focuses on detection of recurrent disease and metachronous tumours. This so-called 'follow-up' includes periodical carcino-embryonic antigen (CEA) 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 and 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.⁵ However, only half of the patients were satisfied with the identification and treatment of psychosocial concerns.⁵ Care of a GP is suggested to improve survivorship care.^{6,7}

Besides a more prominent role for GPs in survivorship care, a more central role of patients in managing their own health is emphasized by the Chronic Care Model.⁸ 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.⁹ Web-based interventions (eHealth) can have a positive effect on self-management in patients with a chronic disease like cardiac failure, diabetes and COPD.¹⁰ Also after cancer treatment, eHealth is becoming more important to involve patients in structuring their own rehabilitation.^{10,11} An example of a self-management eHealth application to enable cancer patients to positively influence their rehabilitation is Oncokompas^{2,0} (appendix A). In Oncokompas^{2,0} cancer survivors can monitor their quality of life by means of patient reported outcomes (PROs) ("Measure"), which is followed by automatically generated tailored feedback ("Learn") and personalized advice on supportive care services ("Act").¹²⁻¹⁴

To date, research on a more prominent role of GPs in combination with the use of eHealth applications in the survivorship care of colon cancer patients 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 colon cancer patients and to assess their perspectives on patients' self-management capacities and the value of the eHealth application Oncokompas^{2,0}.

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 will become more prominent. GPs were recruited from several cities and villages in the central part of the Netherlands. First, GPs were invited by e-mail with information about the study. Subsequently, the GPs were informed by one researcher (LD) 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 (i.e. urban versus rural), and employment (self-employed or employed).

In total, 10 men and 10 women participated in a semi-structured individual interview. Table 1 shows their characteristics. No GPs declined participation.

Procedure

Interviews were performed by one researcher (LD), who received training in qualitative methods and had conducted another qualitative study previously. Interviews took place at a location of preference of the participants, e.g. 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 literature and clinical expertise of the research team. The four topics that were discussed during the interview were: current involvement of the GP in survivorship care of colon cancer patients, 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^{2.0} (Table 2). Interviews were digitally recorded and transcribed verbatim and field notes were made during and after the interview. The duration of the interviews lasted between 39 and 66 minutes (median 48 minutes). The interviews started with an explanation of two key words, i.e. follow-up and survivorship care as defined in the introduction section. During the interview, questions concerning eHealth (Table 2) were preceded by an introduction of the application Oncokompas^{2.0} (appendix A). As many participants had difficulties conceptualizing the idea of a web-based intervention, six screenshots of Oncokompas^{2.0} were shown to the respondents.¹²⁻¹⁴

When no new information was found from four consecutive transcripts during the data analysis, we assumed that data saturation was reached.¹⁵

Data analysis

Data analysis was conducted by two coders (LD 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 were 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 (CvU or JW) was consulted. Related themes were combined and refined. The coders together created a framework, based on these 10 interviews. Subsequently, the remaining ten transcripts were analysed by one coder (LD) according to the prior refined framework. Transcripts containing quotes that did not reflect the framework were discussed with the second coder (TW) until consensus was reached. One coder (LD) re-examined all transcripts to ensure that the analysis was robust and to confirm that all data were reflected in the coding. The software MAXQDA version 11.0 was used to facilitate data analysis. Reporting of the data was done using the consolidated criteria for reporting qualitative research (COREQ).¹⁶

Results

GPs' current involvement in survivorship care of colon cancer patients

GPs mentioned various levels of involvement with colon cancer patients in survivorship care including follow-up (Table 3). GPs pointed out involvement with patients after initial colon cancer treatment in different ways. Some GPs stated to proactively initiate 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 GP's involvement in order to personalize 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 least, 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 they were requested by patients if they could perform follow-up instead of continuing follow-up in secondary care.

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3 Not all GPs felt involved, which they experienced as a shortcoming. GPs stated to lose
4 contact with their patients during cancer treatment. For example, some GPs experienced that
5 patients “disappear” in secondary care after the colon cancer diagnosis and they felt that updated
6 information was lacking since letters from medical specialists are often delayed or not received at all.
7 GPs also assumed that patients already had a lot of involved healthcare providers in secondary care
8 and did not need their GP in this phase. Some GPs had difficulties in answering the interview
9 question, since they were not often confronted with patients after colon cancer treatment.
10 Furthermore, GPs mentioned that their contact with these patients occurred randomly, depending
11 on their time available and their contact with patients before the cancer diagnosis.
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18 *‘There has to be a reason to get in contact, this can be information from the hospital like a*
19 *discharge letter that makes me realize: it has been a while, I am going to call this patient to hear how*
20 *he is doing. And you need sufficient time.’ (GP7, male)*
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24 Despite of varying levels of involvement, GPs said to be aware of a cancer history if these
25 patients consulted them. Some indicated to be especially aware in case patients presented with
26 symptoms that could indicate recurrent disease, e.g. weight loss, abdominal pain and paleness.
27 Others mentioned to pay specific attention to patients’ wellbeing if patients showed up for non-
28 cancer symptoms.
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35 **Future role of GPs in survivorship care for colon cancer patients**

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37 Participants were ambiguous about their future involvement in survivorship care including
38 follow-up. They preferred or did not prefer to be more involved. The majority of the GPs expected
39 patients to benefit from more involvement of the GP in survivorship care, because the GP’s practice
40 is closer to their homes and consulting their familiar GPs might decrease patients’ anxiety levels.
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45 *‘Of course there are a lot of people who experience a visit to the hospital as a burden. These*
46 *people will be pleased if they are able to visit their GP. Especially when they know that the same*
47 *diagnostic tests will be done.’ (GP13, female)*
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51 Eleven participants wanted to be more involved in survivorship care of colon cancer patients.
52 They mentioned several arguments (Table 3). They were willing to be the coordinator of survivorship
53 care in the future, including follow-up. According to them, coordination of survivorship care by GPs
54 will lead to more continuity of care for patients they are currently not in touch with in a structural
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3 way. GPs assumed they would be able to obtain an improved total overview of their patients when
4 being the coordinator of survivorship care.
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7 *'I think that psychological support will be easier to provide if you're also involved in the*
8 *physical part of survivorship care' (GP2, female)*
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11 Another argument of GPs to be willing to coordinate survivorship care, is that they felt they
12 are more aware of patients' context compared to medical specialists and therefore more capable to
13 deliver comprehensive care. Also, these participants believed that coordination could strengthen
14 their doctor-patient relationship. Although not all GPs indicated to be familiar with the content of the
15 follow-up guideline, they thought coordination by GPs will be feasible and expected it to be easy to
16 carry out.
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19 *'I wonder what the effort of a surgeon looks like. I mean, the patient visits the surgeon at the*
20 *outpatient clinic and the surgeon asks: "How are you?" "I'm doing fine." "The result of the blood test*
21 *was good, the ultrasound was normal". At last he examines the abdomen, they shake hands and that*
22 *is that. I don't think much of it.'* (GP1, male)
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25 Furthermore, GPs stated that care that can be delivered in primary care, should be delivered
26 in primary care.
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29 *'Well, I think there is a trend towards more care being transferred to GPs, because we have a*
30 *broad view and we are more conservative with respect to diagnostic tests.'* (GP5, female)
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33 Seven participants were satisfied with their current involvement and preferred to maintain
34 this role. Mainly because they believed that too many responsibilities have been transferred to
35 primary care and they felt unable to adopt another task.
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38 *'Well, the workload is increasing. I mean, first there was diabetes, then COPD and*
39 *cardiovascular risk management. We already integrated asthma and now care for elderly will be*
40 *added. It has to fit in the same practice. It all has to be done within the same 24 hours. There is a*
41 *limit if it comes to transferring tasks.'* (GP8, female)
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44 Another barrier mentioned by GPs was their assumption that survivorship care including
45 follow-up requires a different approach of GPs. They indicated that usually GPs deal with patients' ad
46 hoc problems. They were not willing to adapt another protocol as a guidance of a consult.
47 Furthermore, some GPs said to not feel confident due to lack of expertise. They also mentioned that
48 patients might think GPs lack expertise.
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3 The remaining two participants stated to have doubts concerning more involvement in
4 survivorship care. They only wanted to be more involved if they will be supported by nurses in their
5 practice, comparable to specialized nurses taking care of other chronic illnesses in primary care.
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9 Overall, GPs mentioned some requirements if survivorship care will be transferred. The most
10 important requirement mentioned was clear agreements with medical specialists in secondary care
11 including easy accessible consultations, to enable fast referrals to specialists and diagnostic testing in
12 the hospital. Furthermore, a follow-up protocol, a refresher course, a financial compensation by the
13 health care insurance and support within and beyond the practice by other health care providers
14 were mentioned as essential requirements. They requested a system to call patients for scheduled
15 visits, because they feared follow-up appointments would be forgotten by patients and/or
16 themselves. Finally, most participants suggested that time investment should be assessed in advance,
17 to determine whether it is feasible.
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27 **Patients' self-management after colon cancer treatment**

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29 Next, GPs were asked to provide their views on the role of self-management by patients with
30 regard to supportive care after colon cancer treatment (Table 4).
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33 Participants indicated to have reservations about the possibilities of patients' self-
34 management, because they considered not all patients willing to be more in charge.
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37 *'I think that some people are able to manage it well, but most of the time, people with cancer*
38 *want someone else to be in charge. Look, diabetes or COPD; that has to do with lifestyle. Cancer has*
39 *partly to do with lifestyle, but in most cases not. So, I think it's a different situation; it happens to*
40 *people.'* (GP4, male)
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45 Additionally, they assumed not everyone will be capable to take responsibilities in his/her
46 own survivorship care, like elderly, immigrants or poorly educated people.
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49 Although almost all participants had their reservations, most GPs believed that the role of
50 self-management should be expanded in survivorship care and they offered suggestions to achieve
51 this. First, patients should be more informed about physical symptoms that might indicate recurrent
52 disease and when to consult their doctor. Besides that, GPs wanted patients to participate in decision
53 making. They suggested to provide patients with the possibility to arrange their own care, by defining
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3 individual goals during rehabilitation and to stimulate patients to decide which supportive care they
4 desired. GPs believe that consequently patients will be more in charge of their own survivorship care.
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7 *'To what extent do you want to go on in case of recurrent disease? What do you want in that*
8 *scenario and what do you not want? You can also think of: what kind of care do you desire and what*
9 *type of care not?'* (GP3, male)
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12 A few GPs found it difficult to answer the question and could not imagine which specific parts
13 of survivorship care can be managed by patients.
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19 **The use of an eHealth application in survivorship care of colon cancer**

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21 After an introduction (appendix A) including a demonstration of Oncokompas^{2.0}, a majority of
22 14 GPs had a positive attitude towards patients' use of Oncokompas^{2.0} and four participants were
23 partly positive. One of the motives of the positive GPs to provide Oncokompas^{2.0} was that it could
24 make patients feel more empowered. According to them, patients will not only be able to use the
25 application whenever it suits them, but also receive tailored advice and are able to consider which
26 advice is appropriate for them.
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32 *'We still keep patients dependent and now they will be forced to explore 'what suits me'. And*
33 *we have to adopt a different role as a coach and not as a father figure.'* (GP10, female)
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36 Other motives of GPs to provide Oncokompas^{2.0} to patients would be that patients will gain
37 insight into their symptoms and concerns. GPs said that it would be a relief for patients to be
38 informed on specific well-known late effects and to realize they are not the only ones suffering from
39 certain symptoms and concerns.
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43 Furthermore, GPs expected that patients will be better prepared when they use
44 Oncokompas^{2.0} before consulting them. They assumed Oncokompas^{2.0} will save GPs time in taking
45 the patient's medical history and finding appropriate support. The participants mentioned that the
46 eHealth application could be used as a supportive instrument that might stimulate self-management
47 of patients. However, they declared that it should be used in addition to standard survivorship care
48 and not as a replacement of it.
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54 Two participants did not support the use of eHealth in general as they found it impersonal
55 and preferred exploration of symptoms and concerns by themselves. These reservations were also
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3 mentioned by the GPs who supported the use of eHealth, who furthermore indicated that eHealth
4 would only be suitable for specific groups of patients who are highly educated and young. Elderly,
5 poorly educated people, people with no computer skills, illiterates and immigrants who are not able
6 to understand Dutch were not considered as target groups. Some GPs feared that the use of
7 Oncokompas^{2.0} could cause arousal in patients, by showing them a list of problems that could occur.
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12 *'Of course, you can ask a lot of questions, but that can also give patients ideas what might go*
13 *wrong. So, for example an anxious patient reads: "Do you have symptoms of ...?" They might think: Is*
14 *that also possible after colon cancer?' (GP5, female)*
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18 GPs had different ideas about how to incorporate the use of Oncokompas^{2.0}. Overall, the
19 participants who had a positive attitude towards the use of Oncokompas^{2.0} preferred to be informed
20 about the general content of Oncokompas^{2.0}, to be prepared if patients have questions. A majority of
21 the GPs wanted to be a consultant when patients use Oncokompas^{2.0} and leave the initiative to
22 patients whether they want to discuss the results.
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26 *'I think if someone is able to use it, he is able to manage it for himself. In that case it should*
27 *not make him dependent.'* (GP17, female)
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31 The GPs who preferred to be a consultant stated that in case Oncokompas^{2.0} advises patients
32 to take action for which a referral of the GP is needed, they preferred to discuss the results first.
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35 *'If I have to make a referral on request, I always want to talk to my patient. I have been asked*
36 *to write referral letters, like: 'Do you want to write a letter to the physical therapist?' Well, I refuse. I*
37 *first want to see patients and have a look, because I'm not an administrator and that doesn't change*
38 *in this case.'* (GP12, male)
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42 A few participants wished to be involved intensively when their patients would use
43 Oncokompas^{2.0}. They wanted to have insight in their patients' Oncokompas^{2.0} results and discuss
44 them routinely, especially when the coordination of survivorship care will be transferred to primary
45 care. These participants also suggested to receive an alert if a patient had a low score on specific
46 well-being items assessed by Oncokompas^{2.0}.
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50 51 52 **Discussion**

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55 This study explored the perspectives of GPs regarding their current and future role in
56 survivorship care of colon cancer patients. Furthermore, their perspectives with respect to eHealth to
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3 stimulate self-management among cancer patients was assessed.

4 Our results showed that part of the GPs is not (routinely) involved in survivorship care of
5 colon cancer patients. Jabaaij et al., however, showed that patients who have been treated for
6 cancer consult their GP more often compared to patients without a history of cancer.¹⁷ These results
7 indicate that GPs are supposed to be in touch with patients after cancer treatment. Several GPs
8 interviewed indicated to lose contact. Others mentioned not to keep in touch with patients actively,
9 but decided their involvement based on their patients' preferences. These GPs seem to adapt a
10 reactive attitude after their patients have been treated for cancer.¹⁸ In contrast, a review study on
11 cancer survivors' general practice needs showed that cancer survivors preferred to have a proactive
12 GP after treatment, supporting them in their needs on psychosocial issues, medical issues and
13 information.¹⁹

14 As the number of cancer survivors is increasing, a programmatic approach in survivorship
15 care is required to meet patients' needs.² Furthermore, more generalist care is suggested.^{6,7} Dutch
16 surgeons have declared to lack sufficient time to provide psychosocial survivorship care and stated
17 that GPs are better equipped with respect to time and skills to tackle these problems.⁵ Our study
18 showed that most of the interviewed GPs are willing to have a more central role in survivorship care.
19 They expected a better doctor-patient relationship and more continuity of care. Aspects that have
20 shown to be of great importance to patients also.³ Two randomized controlled trials demonstrated
21 that GP-led survivorship care including follow-up was comparable with respect to quality of life,
22 efficiency of recurrence detection, and anxiety levels.^{20,21} Barriers mentioned by the interviewed GPs
23 were having already a high workload and a lack of expertise.

24 The vast majority of GPs in our study were positive on more patient involvement in future
25 survivorship care by letting patients define their own goals during rehabilitation and letting them
26 decide on what kind of supportive care is best for them. These are among the main targets of
27 Oncokompas^{2.0} and conform the Chronic Care Model.^{8,12,13} According to our participants, with
28 Oncokompas^{2.0} patients could receive more knowledge of their problems and their independency is
29 expected to be stimulated. Previous research showed that patients had a positive attitude towards
30 eHealth after cancer treatment²² and were satisfied with the use of Oncokompas^{2.0}.¹² Almost all
31 interviewed GPs who were positive, wanted to be supportive if their patients wish to use
32 Oncokompas^{2.0}. They either see a reactive (patients' initiative to discuss their results) or an active
33 (GPs' initiative to discuss patients' results) role for themselves. Both possible roles were also
34 mentioned by health care providers engaged in the follow-up of head- and neck cancer patients and
35 involved in the development of Oncokompas.²³ An obstacle mentioned by GPs, was that eHealth
36 might be less suitable in elderly compared to younger patients. This is in line with previous research

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3 on eHealth.^{12 23 24} Furthermore, the interviewed GPs considered poorly educated patients not capable
4 of understanding the feedback and personalized advice on their reported outcomes in
5 Oncokompas^{2.0}. Gee et al. suggested that both patients and health care providers should be trained
6 before using eHealth to let it be successful, because according to them an informed patient with the
7 skills and knowledge to use eHealth is a key element of the Chronic Care model.²⁵ In future studies
8 the additional value of eHealth should be explored in colon cancer survivors with appropriate
9 support.
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14 Strengths and limitations

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16 The interviews with GPs in this study took place at the location of preference of the
17 participants which enabled them to feel comfortable and speak freely about their experiences.
18 Although we tried to achieve a wide sample of GPs by using purposive sampling, only a small group
19 of GPs were working in rural areas. It could be expected that GPs working in rural areas felt more
20 involved in patients who have been treated for cancer. Another limitation was that some of the GPs
21 were not often confronted with patients after colon cancer treatment and had difficulties in
22 answering the questions. In general, they based their answers on cancer overall to make their
23 perspectives clear. Questions on eHealth were preceded with an introduction of Oncokompas^{2.0}
24 supported by screenshots. Although this stimulates participants to visualize Oncokompas^{2.0} and
25 provides an idea how it works, the screenshots only gave an abstract picture and the interactive
26 nature of Oncokompas^{2.0} might not always have become clear.
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37 In conclusion, based on the perspectives of the interviewed Dutch GPs, survivorship care of colon
38 cancer in primary care is deemed feasible. However, GPs mentioned arrangements with secondary
39 care and a protocol to be required if they will be the future coordinator of survivorship care. An
40 eHealth application like Oncokompas^{2.0} is expected to be beneficial. According to GPs,
41 Oncokompas^{2.0} should be considered as additional and is expected to stimulate patient
42 empowerment and awareness in supporting patients to structure their own survivorship care. GPs
43 were open to discuss Oncokompas^{2.0}, results and supportive care options with patients.
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45 Nevertheless, according to the GPs, eHealth will not be appropriate for all patients.
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Contributorship statement

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

Competing interests

There are no competing interests.

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Data sharing statement

No additional data are available.

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For peer review only

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Table 1 Participants' characteristics (n=20)

Age in years, median (range)	49.5	(34-65 years)
Gender, n (%)		
Male	10	(50)
Female	10	(50)
Experience as a GP in years, median (range)	14.5	(3-34 years)
Area of occupation, n (%)		
Urban	15	(75)
Rural	5	(25)
Health care practice, n (%)		
Self-employed GP	14	(70)
Employed GP	6	(30)

Table 2 Interview topics

Topics	Key questions
GPs' current involvement in survivorship care of colon cancer patients	<ul style="list-style-type: none"> • What is your current involvement in survivorship care of patients who have been treated for colon cancer?
Future role of GPs in survivorship care for colon cancer patients	<ul style="list-style-type: none"> • To what extent would you like to be involved after treatment of colon cancer with curative intent? • Are you willing to coordinate survivorship care of colon cancer? • Under what condition(s) are you willing to provide survivorship care, including follow-up of colon cancer?
Patients' self-management after colon cancer treatment	<ul style="list-style-type: none"> • What could be the role of self-management by patients in survivorship care of colon cancer?
The use of Oncokompas ^{2.0} in survivorship care of colon cancer	<ul style="list-style-type: none"> • What is the value of Oncokompas^{2.0} regarding the future role of patients in survivorship care of colon cancer? • To what extent do you want to be involved if your patient uses Oncokompas^{2.0}?

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	<ul style="list-style-type: none"> - Initiates periodic contact with the patient - Involved after patient initiated contact - Awareness if patient has a history of colon cancer
	The GP has a limited role when patients have been treated for colon cancer	<ul style="list-style-type: none"> - Loses contact with the patient - Contact with patients at random - Not often confronted with patients who have been treated for colon cancer
Desired role of the GP in survivorship care	The GP wants to be more involved in coordination of colon cancer survivorship care	<ul style="list-style-type: none"> - Opportunity to improve continuity in care - Familiarity with patients - Improvement of doctor-patient relationship - Follow-up is easy to carry out - All care aspects that can be done in primary care should be transferred
	The GP does not want more involvement	<ul style="list-style-type: none"> - Too many responsibilities have already been shifted from secondary to primary care - Survivorship care requires a different approach - Lack of expertise - Lack of trust of patients in expertise of GP
	Requirements of the GP to coordinate survivorship care of colon cancer	<ul style="list-style-type: none"> - Agreements with medical specialist in secondary care - Follow-up protocol - Refresher course - Financial compensation by insurance - Support within and beyond the practice (e.g. by a nurse) - System to schedule patient visits - Assessment of feasibility

Table 4. Overview of involvement and key issues and themes concerning patient's self-management and the use of Oncokompas^{2.0} in survivorship care of colon cancer according to GPs

	KEY ISSUES	THEME
Patients' self-management in survivorship care	Reservations of the GP concerning patients' responsibilities in survivorship care	<ul style="list-style-type: none"> - Patients are not willing to be responsible for own care - Patients are not capable to take responsibility
	Patients should be more involved in survivorship care	<ul style="list-style-type: none"> - Patients should be informed about physical symptoms that could indicate recurrent disease and when to consult a doctor - Involvement in decision making
Use of Oncokompas ^{2.0} in survivorship care of colon cancer	The GP had a positive attitude towards the use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - Oncokompas^{2.0} makes patients more empowered - Patients will obtain insight into their symptoms and concerns - Oncokompas^{2.0} will relieve the workload of GPs - Increased insight for both GP and patients in case of vague symptoms and problems
	Reservations of the GP concerning the use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - Impersonal - Not suitable for all patients - Increase patients' awareness of problems
	Involvement of the GP during patient's use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - GPs as a consultant <ul style="list-style-type: none"> o Leave the initiative to the patient to discuss Oncokompas^{2.0} results o Estimate if a referral, suggested by Oncokompas^{2.0}, is appropriate - Intensive involvement of the GP <ul style="list-style-type: none"> o Receive a message if the patient has a serious symptom or concern, detected by Oncokompas^{2.0} o Discuss results of Oncokompas^{2.0} routinely with the patient

Appendix Oncokompas^{2.0}

The eHealth application Oncokompas^{2.0} is a personal and interactive application to support patients who have been treated for cancer. Oncokompas^{2.0} consists of three steps; “Measure”, “Learn” and “Act”.

In the “Measure” component patients can monitor their quality of life (QOL) with patient reported outcomes (PROs). The QOL domains used in Oncokompas^{2.0} include physical functioning in general but also specific physical symptoms and concerns after colon cancer, psychological functioning, social functioning, healthy lifestyle and existential issues. Patients decide which domain(s) they want to explore. A clickable demo and an animation video are available on the website www.oncokompas.nl. PROs on colon cancer were selected by a team of experts together with the project team of Oncokompas^{2.0} and based on the national guideline of colorectal cancer and literature.¹

Subsequently, patients receive automatically generated tailored feedback on data from their PROs in the “Learn” component, which are based on algorithms. These algorithms are based on existing Dutch guidelines and discussed by the expert team until consensus was reached. Feedback is shown using three colours, red (seriously elevated wellbeing risks), orange (elevated wellbeing risks) and green (no elevated wellbeing risks). Additional personalized information about the specific PROs will be provided. Furthermore self-support advice is shown in the “Learn” component, which is tailored to the individual outcomes of the patients.

Afterwards, personalized supportive care options (care professionals and self-management options) are provided in the “Act” component, which are based on individual PROs and patients’ preferences. When patients receive a red score (seriously elevated wellbeing risks) in the “Learn” component, the advice in the “Act” component includes to consult their GP or medical specialist.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Laura Duineveld (page 4)
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD student, MD (not mentioned in the manuscript)
3.	Occupation	What was their occupation at the time of the study?	PhD student and GP trainee (In the correspondence, page 1, the 'Department of Primary Care' is mentioned and 'researcher' is mentioned, page 4)
4.	Gender	Was the researcher male or female?	Female (not mentioned in the method section)
5.	Experience and training	What experience or training did the researcher have?	Previous observational study and course 'Qualitative research' (Academic Medical Centre, Amsterdam) (Page 4)
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	The interviewer knew 50% of the participants by face and never met the other 50% of the participants prior to the study (not mentioned in the manuscript)
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	The interviewer sent an e-mail before the interview took place this reasons for doing the interview study (page 4)
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	The interviewer introduced herself by telling that she was a PhD student of the Department of Primary Care and a GP trainee. (not mentioned in the manuscript)
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (page 5)
Participant selection			
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Purposive (page 4)
11.	Method of approach	How were participants	Initial contact via e-mail (page

		approached? <i>e.g. face-to-face, telephone, mail, email</i>	4)
12.	Sample size	How many participants were in the study?	20 (page 4)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	0 (page 4)
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	at the researcher's workplace in the Academic Medical Centre (n=9), at the participant's clinic (n=7) or at the participant's home (n=4) (page 4)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No (page 4)
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	10 men and 10 women, with 3 to 34 years of experience as a GP (page 4 and 16)
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	A pre-defined topic list was used during the interviews. Questions and topics were based on literature and expertise of the research team. After the first two interviews, the topic list was refined and sharpened but no major changes in the questions were made. (page 4 and 17)
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No (not explained in method section)
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording (page 4)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, during and after the interviews (page 4)
21.	Duration	What was the duration of the interviews or focus group?	between 39 and 66 minutes (page 4)
22.	Data saturation	Was data saturation discussed?	Yes (page 4)
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No (not explained in method section)
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two coders coded the first 10 interviews. Subsequently, one coder coded the remaining 10 interviews according to the prior refined framework. (page 5)
25.	Description of the coding tree	Did authors provide a description	Yes (page 18 and 19)

		of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data (page 5)
27.	Software	What software, if applicable, was used to manage the data?	MaxQDA version 11 (page 5)
28.	Participant checking	Did participants provide feedback on the findings?	No (not explained in the method section)
	Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>	Yes. Each quotation was identified. (page 5-10)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes (page 5-10)
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes (page 5-10 and 18-19)
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes (page 5-10 and 18-19)

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

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3 **Primary care-led survivorship care for colon cancer patients and the use of eHealth: a qualitative**
4 **study about perspectives of general practitioners**
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49 **Keywords**

50 Colon cancer, survivorship care, primary care, eHealth
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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 colon cancer patients and to assess their perspectives on patients' self-management capacities and the value of the eHealth application Oncokompas^{2.0} used by patients.

Setting

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

Participants

Twenty 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 3-34 years).

Results

GPs indicated to attempt to keep in contact with patients after colon cancer treatment and mentioned to be aware of symptoms of recurrent disease. Most participants would like 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^{2.0} as a useful additional tool for a specific group of patients (i.e. young and highly-educated patients), which stimulates patients to structure their own survivorship care.

Conclusion

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 like Oncokompas^{2.0} is expected to benefit specific groups of patients after colon cancer treatment.

Article summary

Strengths and limitations of this study

- This study shows GPs' perspectives on the current need to improve survivorship care of cancer by introducing GP-led survivorship care and stimulation of patients' self-management with an eHealth application
- Interviews took place at the location of preference of the participants which enabled them to speak freely about their experiences
- Screenshots used during the interview to introduce questions on eHealth might give an abstract picture of the eHealth application Oncokompas^{2.0}

Background

It is expected that in 2020 more than 17.000 patients will be diagnosed with colorectal cancer in the Netherlands.¹ After initial treatment, patients are included in a surgeon-led programme which mainly focuses on detection of recurrent disease and metachronous tumours. This so-called 'follow-up' includes periodical carcino-embryonic antigen (CEA) 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.⁵ 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 own health.⁷ This is in line with the Chronic Care Model (CCM).⁹ 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.¹⁰ Web-based interventions (eHealth) can have a positive effect on self-management in patients with a chronic disease like cardiac failure, diabetes and COPD.¹¹ Also after cancer treatment, eHealth is becoming more important to involve patients in structuring their own rehabilitation.^{11,12} An example of a self-management eHealth application to enable cancer patients to positively influence their rehabilitation is Oncokompas^{2.0} (appendix A). In Oncokompas^{2.0} cancer survivors can monitor their quality of life by means of patient reported outcomes (PROs) ("Measure"), which is followed by automatically generated tailored feedback ("Learn") and personalized advice on supportive care services ("Act").¹³⁻¹⁵

According to various Dutch health care and patients organizations, both a more prominent role of GPs and patients' self-management are important aspects to improve survivorship care of cancer.⁶⁻⁸ Therefore, it is important to explore the feasibility of these recommendations together. To date, combined research on these aspects in the survivorship care of colon cancer patients is scarce. Therefore, the aim of this study was to explore the perspectives of GPs regarding their current and

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3 future role in survivorship care of colon cancer patients and to assess their perspectives on patients'
4 self-management capacities and the value of the eHealth application Oncokompas^{2,0}.
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7 8 **Method**

9 **Study sample**

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11 In this qualitative study GPs were interviewed. GPs were chosen to be the group of interest,
12 because their views can help in preparing GPs in case their role in survivorship care will become more
13 prominent. GPs were recruited through the network of the department of General Practice of the
14 Academic Medical Centre (AMC) in Amsterdam. All selected GPs worked in cities and villages of three
15 provinces in the Netherlands around Amsterdam. First, GPs were invited by e-mail with information
16 about the study. Subsequently, the GPs were informed by one researcher (LD) by phone on details
17 about the study and asked for agreement to participate. During recruitment we used purposive
18 sampling to achieve a wide sample of participants with respect to gender, age, years of experience as
19 a GP, area of occupation (i.e. urban versus rural), and employment (self-employed or employed).
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22 In total, 10 men and 10 women participated in a semi-structured individual interview. Table 1
23 shows their characteristics. No GPs declined participation. All participants provided verbal consent,
24 which was digitally recorded. The Research Ethics Committee of the AMC reviewed the protocol and
25 assessed that the Medical Research Involving Human Subjects Act does not apply to this study. An
26 official approval by the committee was therefore not required and written informed consent was not
27 obtained.
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30 **Procedure**

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32 Interviews were performed by one researcher (LD), who received training in qualitative
33 methods and had previously conducted another qualitative study. Interviews took place at a location
34 preferred by the participants, e.g. at the researcher's workplace (n=9), at the participant's clinic (n=7)
35 or at the participant's home (n=4). Topics and questions were based on literature and clinical
36 expertise of the research team. The four topics that were discussed during the interview were:
37 current involvement of the GP in survivorship care of colon cancer patients, the possibility of a more
38 prominent role in the future, the capability of patients' self-management, and the expected potential
39 of the eHealth application Oncokompas^{2,0} (Table 2). Interviews were digitally recorded and
40 transcribed verbatim and field notes were made during and after the interview. The duration of the
41 interviews lasted between 39 and 66 minutes (median 48 minutes). The interviews started with an
42 explanation of two key words, i.e. follow-up and survivorship care as defined in the introduction
43 section. During the interview, questions concerning eHealth (Table 2) were preceded by an
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3 introduction of the application Oncokompas^{2.0} (appendix A). As many participants had difficulties
4 conceptualizing the idea of this web-based intervention, six screenshots of Oncokompas^{2.0} were
5 shown to the respondents.¹³⁻¹⁵
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8 When no new information was found from four consecutive transcripts during the data
9 analysis, we assumed that data saturation was reached.¹⁶
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12 Data analysis

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15 Data analysis was conducted by two coders (LD and TW) using thematic data analysis. The
16 first 10 transcripts were independently analysed in which citations regarding GPs' views about the
17 four topics were selected and key issues and themes were identified (Table 2). The two coders
18 compared their key issues and themes and discussed all discrepancies until consensus was reached.
19 In case of disagreement, a third researcher (CvU or JW) was consulted. Related themes were
20 combined and refined. The coders together created a framework, based on these 10 interviews.
21 Subsequently, the remaining ten transcripts were analysed by one coder (LD) according to the
22 framework as previously defined. Transcripts containing quotes that did not reflect the framework
23 were discussed with the second coder (TW) until consensus was reached. One coder (LD) re-
24 examined all transcripts to ensure that the analysis was robust and to confirm that all data were
25 reflected in the coding. Data analysis was done using the software MAXQDA, version 11.0. Reporting
26 of the data was done using the consolidated criteria for reporting qualitative research (COREQ).¹⁷
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37 Results

38 GPs' current involvement in survivorship care of colon cancer patients

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41 GPs mentioned various levels of involvement with colon cancer patients in survivorship care
42 including follow-up (Table 3). GPs pointed out involvement with patients after initial colon cancer
43 treatment in different ways. Some GPs stated to proactively initiate contact with patients after
44 treatment to monitor psychological symptoms and to offer support. During the initial contact, GPs
45 discussed patient's preferences regarding the degree of the GP's involvement in order to personalize
46 their contact.
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52 *'What matters is: "How are you? Do you have any questions? Are there any uncertainties?"*
53 *This is a reason for us to get in touch with patients. Because, in the acute phase, patients might be*
54 *too busy with their disease and there will be a moment they'll ask themselves: how do I proceed? We*
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3 *try to avoid this and arrange another appointment. At a minimum, we invite patients for a*
4 *subsequent appointment.’ (GP6, male)*
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7 Other GPs said they only got involved after their patients initiated contact. Although a role
8 for GPs in follow-up is not described in the national guideline, two GPs indicated that patients
9 requested them to perform the continuation of follow-up in secondary care.
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12 Not all GPs felt involved with survivorship care, which they experienced as a shortcoming
13 (n=8). GPs stated to lose contact with their patients during cancer treatment. For example, some GPs
14 experienced that patients “disappear” in secondary care after the colon cancer diagnosis and they
15 felt that updated information was lacking since letters from medical specialists are often delayed or
16 not received at all. GPs also assumed that patients already had a lot of healthcare providers involved
17 in secondary care and did not need their GP in this phase. Two GPs had difficulties in answering the
18 interview question, since they were not frequently confronted with patients after colon cancer
19 treatment. Furthermore, GPs mentioned that their contact with these patients occurred randomly,
20 depending on their time available and their level of contact with patients before the cancer
21 diagnosis.
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25 *‘There has to be a reason to get in contact, this can be information from the hospital like a*
26 *discharge letter that makes me realize: it has been a while, I am going to call this patient to hear how*
27 *he is doing. And you need sufficient time.’ (GP7, male)*
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31 Despite of varying levels of involvement, GPs said to be aware of a cancer history if these
32 patients consulted them. Some indicated to be especially aware in case patients presented with
33 symptoms that could indicate recurrent disease, e.g. weight loss, abdominal pain and paleness.
34 Others mentioned to pay specific attention to patients’ wellbeing if patients showed up for non-
35 cancer symptoms.
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38 **Future role of GPs in survivorship care for colon cancer patients**

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40 Participants were ambiguous about their future involvement in survivorship care including
41 follow-up. They preferred or did not prefer to be more involved. The majority of the GPs expected
42 patients to benefit from more involvement of the GP in survivorship care, because the GP’s practice
43 is closer to their homes and consulting their familiar GPs might decrease patients’ anxiety levels.
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3 *'Of course there are a lot of people who experience a visit to the hospital as a burden. These*
4 *people will be pleased if they are able to visit their GP. Especially when they know that the same*
5 *diagnostic tests will be done.'* (GP13, female)
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Eleven participants wanted to be more involved in survivorship care of colon cancer patients. 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 to 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 are more aware of patients' context compared to 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 to be familiar with the content of the follow-up guideline, they thought coordination by GPs will be feasible and expected it to be easy to apply.

'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.

'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

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3 *added. It has to fit in the same practice. It all has to be done within the same 24 hours. There is a limit*
4 *if it comes to transferring tasks.'* (GP8, female)
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7 Another barrier mentioned by GPs was their assumption that survivorship care including
8 follow-up requires a different approach of GPs. They indicated that usually GPs deal with patients' ad
9 hoc problems. They were not willing to adapt another protocol as a guidance of a consult.
10 Furthermore, some GPs said not to feel confident due to lack of expertise. They also mentioned that
11 patients might think GPs lack expertise.
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16 The remaining two participants stated to have doubts concerning more involvement in
17 survivorship care. They only wanted to be more involved if they would be supported by nurses in
18 their practice, comparable to specialized nurses taking care of other chronic illnesses in primary care.
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21 Overall, GPs mentioned some requirements if survivorship care would be transferred. The
22 most important requirement mentioned was clear agreements with medical specialists in secondary
23 care including easily accessible consultations, to enable fast referrals to specialists and diagnostic
24 testing in the hospital. Furthermore, a follow-up protocol, a refresher course, a financial
25 compensation by the health care insurance and support within and beyond the practice by other
26 health care providers were mentioned as essential requirements. They requested a system to call
27 patients for scheduled visits, because they feared follow-up appointments would be forgotten by
28 patients and/or themselves. Finally, most participants suggested that time investment should be
29 assessed in advance, to determine whether it is feasible.
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39 **Patients' self-management after colon cancer treatment**

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42 Next, GPs were asked to provide their views on the role of self-management by patients with
43 regard to supportive care after colon cancer treatment (Table 4).
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45 Participants indicated to have reservations about the possibilities of patients' self-
46 management, because they did not consider all patients to be willing to be more in charge.
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50 *'I think that some people are able to manage it well, but most of the time, people with cancer*
51 *want someone else to be in charge. Look, diabetes or COPD; that has to do with lifestyle. Cancer has*
52 *partly to do with lifestyle, but in most cases not. So, I think it's a different situation; it happens to*
53 *people.'* (GP4, male)
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3 Additionally, they assumed not everyone will be capable to take responsibilities in his/her
4 own survivorship care, like elderly, immigrants or poorly educated people.
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7 Although almost all participants had their reservations, most GPs believed that the role of
8 self-management should be expanded in survivorship care and they offered suggestions to achieve
9 this. First, patients should be more informed about physical symptoms that might indicate recurrent
10 disease and when to consult their doctor. Besides that, GPs wanted patients to participate in decision
11 making. They suggested to provide patients with the possibility to arrange their own care, by defining
12 individual goals during rehabilitation and to stimulate patients to decide which supportive care they
13 desired. GPs believe that patients will be more in charge of their own survivorship care consequently.
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19 *'To what extent do you want to go on in case of recurrent disease? What do you want in that*
20 *scenario and what do you not want? You can also think of: which sort of care do you desire and what*
21 *type of care not?'* (GP3, male)
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25 A few GPs found it difficult to answer the question and could not imagine which specific parts
26 of survivorship care can be managed by patients.
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31 **The use of an eHealth application in survivorship care of colon cancer**

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33 After an introduction (appendix A) including a demonstration of Oncokompas^{2.0}, a majority of
34 14 GPs had a positive attitude towards patients' use of Oncokompas^{2.0} and four participants were
35 partly positive. One of the motives of the positive GPs to provide Oncokompas^{2.0} was that it could
36 make patients feel more empowered. According to them, patients will be able to use the application
37 whenever it suits them, will receive tailored advice and are able to consider which advice is
38 appropriate for them.
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44 *'We still keep patients dependent and now they will be forced to explore 'what suits me'. And*
45 *we have to adopt a different role as a coach and not as a father figure.'* (GP10, female)
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48 Other motives of GPs to provide Oncokompas^{2.0} to patients would be that patients will gain
49 insight into their symptoms and concerns. GPs said it would be a relief for patients to be informed on
50 specific well-known late effects and to realize they are not the only ones suffering from certain
51 symptoms and concerns.
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3 Furthermore, GPs expected that patients will be better prepared when they use
4 Oncokompas^{2.0} before consulting them. They assumed Oncokompas^{2.0} will save GPs time in taking
5 the patient's medical history and in providing appropriate support. The participants mentioned that
6 the eHealth application could be used as a supportive instrument that might stimulate self-
7 management of patients. However, they declared that it should be used in addition to standard
8 survivorship care and not as a replacement of it.
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13 Two participants did not support the use of eHealth in general as they found it impersonal
14 and preferred exploration of symptoms and concerns by themselves. These reservations were also
15 mentioned by the GPs who supported the use of eHealth, who furthermore indicated that eHealth
16 would only be suitable for patients who are highly educated and young. Elderly, poorly educated
17 people, people with no computer skills, illiterates and immigrants who are not able to understand
18 Dutch were not considered as target groups. Some GPs feared that the use of Oncokompas^{2.0} could
19 cause arousal in patients, by showing them a list of problems that could occur.
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26 *'Of course, you can ask a lot of questions, but that can also give patients ideas about what*
27 *might go wrong. So, for example an anxious patient reads: "Do you have symptoms of ...?" They*
28 *might think: Is that also possible after colon cancer?' (GP5, female)*
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32 GPs had different ideas about how to incorporate the use of Oncokompas^{2.0}. Overall, the
33 participants who had a positive attitude towards the use of Oncokompas^{2.0} preferred to be informed
34 about the general content of Oncokompas^{2.0}, to be prepared if patients have questions. A majority of
35 the GPs wanted to be a consultant when patients use Oncokompas^{2.0} and leave the initiative to
36 patients whether they want to discuss the results.
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41 *'I think if someone is able to use it, he is able to manage it for himself. In that case it should*
42 *not make him dependent.'* (GP17, female)
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45 The GPs who preferred to be a consultant stated that in case Oncokompas^{2.0} advises patients
46 to take action for which a referral of the GP is needed, they preferred to discuss the results first.
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50 *'If I have to make a referral on request, I always want to talk to my patient. I have been asked*
51 *to write referral letters, like: 'Do you want to write a letter to the physical therapist?' Well, I refuse. I*
52 *first want to see patients and have a look, because I'm not an administrator and that doesn't change*
53 *in this case.'* (GP12, male)
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3 A few participants wished to be involved intensively when their patients would use
4 Oncokompas^{2.0}. They wanted to have insight in their patients' Oncokompas^{2.0} results and discuss
5 them routinely, especially when the coordination of survivorship care will be transferred to primary
6 care. These participants also suggested receiving an alert if a patient had a low score on specific well-
7 being items assessed by Oncokompas^{2.0}.
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11 Discussion

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14 This study explored the perspectives of GPs regarding their current and future role in
15 survivorship care of colon cancer patients. Furthermore, their views towards the use of eHealth to
16 stimulate self-management among cancer patients were assessed.
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19 Our results show that part of the GPs is not (routinely) involved in survivorship care of colon
20 cancer patients. However, it has been shown that patients who have been treated for cancer consult
21 their GP more often compared to patients without a history of cancer.¹⁸ This indicates that GPs are
22 supposed to be in touch with patients after cancer treatment. Several GPs interviewed reported to
23 lose contact. Others mentioned not to keep in touch with patients actively, but decided their level of
24 involvement based on their patients' preferences. These GPs seem to adapt a reactive attitude after
25 their patients have been treated for cancer.¹⁹ In contrast, a review study on cancer survivors' general
26 practice needs showed that cancer survivors preferred to have a proactive GP after treatment,
27 supporting them in their needs on psychosocial issues, medical issues and information.²⁰
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34 As the number of cancer survivors is increasing, a programmatic approach in survivorship
35 care is required to meet patients' needs.² Furthermore, more generalist care is suggested.^{6,7} Dutch
36 surgeons have declared to lack sufficient time to provide psychosocial survivorship care and stated
37 that GPs are better equipped with respect to time and skills to tackle these problems.⁵ Our study
38 showed that most of the interviewed GPs are willing to have a more central role in survivorship care.
39 They expected a better doctor-patient relationship and more continuity of care. Aspects that have
40 shown to be of great importance to patients.³ Two randomized controlled trials demonstrated that
41 GP-led survivorship care including follow-up was comparable with respect to quality of life, efficiency
42 of recurrence detection, and anxiety levels.^{21,22} Barriers mentioned by the interviewed GPs were the
43 already high workload and the lack of expertise. An instrument to enable the transition of
44 survivorship care to primary care is a survivorship care plan. This care plan contains an individualized,
45 comprehensive care summary and follow-up plan of a patient.²³ It provides GPs with the required
46 information and might improve communication between GPs and specialists.²⁴ Survivorship care
47 plans are recommended by the Institute of Medicine and advocated by patients and the Dutch
48 College of General Practitioners.^{8,23} Although a recent study showed that Dutch GPs have a positive
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3 attitude towards introduction of a survivorship care plan, it has not been introduced systematically
4 nation-wide.²⁴ Furthermore, evidence of improved patients' outcomes associated with the
5 introduction of survivorship care plans, is limited.^{25, 26}
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8 The Comprehensive Cancer Centre advises to implement the CCM in survivorship care of
9 cancer and advocates that research should be done in order to redesign survivorship care.² The vast
10 majority of GPs in our study were positive towards more patient involvement in future survivorship
11 care by letting patients define their own goals during rehabilitation and letting them decide on what
12 kind of supportive care is best for them. These are the main targets of Oncokompas^{2.0} and are
13 conform the CCM.^{9, 13, 14} According to our participants, with Oncokompas^{2.0} patients could receive
14 more knowledge of their problems and their self-dependence is expected to be increased. Previous
15 research has shown that patients had a positive attitude towards eHealth after cancer treatment²⁷
16 and were satisfied with the use of Oncokompas^{2.0}.¹³ Furthermore, GPs are responsible for the
17 majority of care for patients with COPD and cardiovascular disease in the Netherlands. Care for these
18 patients is conformable the CCM.²⁸ Therefore, implementation of survivorship care of cancer
19 according to the CCM in primary care seems feasible.
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27 Almost all interviewed GPs who were positive, wanted to be supportive if their patients
28 would like to use Oncokompas^{2.0}. They either see a reactive (patients' initiative to discuss their
29 results) or an active (GPs' initiative to discuss patients' results) role for themselves. Both roles were
30 also mentioned by health care providers engaged in the follow-up of head- and neck cancer patients
31 and involved in the development of Oncokompas^{2.0}.²⁹ An obstacle mentioned by GPs, was that
32 eHealth might be less suitable in elderly compared to younger patients. This is in line with previous
33 research on eHealth.^{13, 29, 30} However, more recently, progress has been made in the development of
34 eHealth applications suitable for elderly.³¹ Studies showed that eHealth can be used by older patients
35 without difficulties, for example by old men with prostate cancer.³² Furthermore, the interviewed
36 GPs considered poorly educated patients not capable of understanding the feedback and
37 personalized advice on their reported outcomes in Oncokompas^{2.0}. As breast cancer patients with
38 low incomes and low education levels have shown to use eHealth to a similar extent as more
39 advantaged counterparts,³³ Oncokompas^{2.0} might reach more patients than our participants
40 assumed. Gee et al. suggested that both patients and health care providers should be trained before
41 using eHealth for it to be successful, because according to them an informed patient with the skills
42 and knowledge to use eHealth is a key element of the CCM.³⁴ In future studies the additional value of
43 eHealth should be explored in colon cancer survivors with appropriate support.
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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 in 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 of Oncokompas^{2.0} supported by screenshots. Although this stimulates participants to visualize Oncokompas^{2.0} and provides an idea how it works, the screenshots only gave an abstract picture and the interactive nature of Oncokompas^{2.0} 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 would become the coordinator of survivorship care. An eHealth application like Oncokompas^{2.0} is expected to be beneficial. According to GPs, Oncokompas^{2.0} 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^{2.0}, results and supportive care options with patients. Nevertheless, according to the GPs, eHealth will not be appropriate for all patients.

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Contributorship statement

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

Competing interests

There are no competing interests.

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Data sharing statement

No additional data are available.

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Table 1 Participants' characteristics (n=20)

Age in years, median (range)	49.5	(34-65 years)
Gender, n (%)		
Male	10	(50)
Female	10	(50)
Experience as a GP in years, median (range)	14.5	(3-34 years)
Area of occupation, n (%)		
Urban	15	(75)
Rural	5	(25)
Health care practice, n (%)		
Self-employed GP	14	(70)
Employed GP	6	(30)

Table 2 Interview topics

Topics	Key questions
GPs' current involvement in survivorship care of colon cancer patients	<ul style="list-style-type: none"> • What is your current involvement in survivorship care of patients who have been treated for colon cancer?
Future role of GPs in survivorship care for colon cancer patients	<ul style="list-style-type: none"> • To what extent would you like to be involved after treatment of colon cancer with curative intent? • Are you willing to coordinate survivorship care of colon cancer? • Under what condition(s) are you willing to provide survivorship care, including follow-up of colon cancer?
Patients' self-management after colon cancer treatment	<ul style="list-style-type: none"> • What could be the role of self-management by patients in survivorship care of colon cancer?
The use of Oncokompas ^{2.0} in survivorship care of colon cancer	<ul style="list-style-type: none"> • What is the value of Oncokompas^{2.0} regarding the future role of patients in survivorship care of colon cancer? • To what extent do you want to be involved if your patient uses Oncokompas^{2.0}?

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	<ul style="list-style-type: none"> - Initiates periodic contact with the patient - Involved after patient initiated contact - Awareness if patient has a history of colon cancer
	The GP has a limited role when patients have been treated for colon cancer	<ul style="list-style-type: none"> - Loses contact with the patient - Contact with patients at random - Not often confronted with patients who have been treated for colon cancer
Desired role of the GP in survivorship care	The GP wants to be more involved in coordination of colon cancer survivorship care	<ul style="list-style-type: none"> - Opportunity to improve continuity in care - Familiarity with patients - Improvement of doctor-patient relationship - Follow-up is easy to carry out - All care aspects that can be done in primary care should be transferred
	The GP does not want more involvement	<ul style="list-style-type: none"> - Too many responsibilities have already been shifted from secondary to primary care - Survivorship care requires a different approach - Lack of expertise - Lack of trust of patients in expertise of GP
	Requirements of the GP to coordinate survivorship care of colon cancer	<ul style="list-style-type: none"> - Agreements with medical specialist in secondary care - Follow-up protocol - Refresher course - Financial compensation by insurance - Support within and beyond the practice (e.g. by a nurse) - System to schedule patient visits - Assessment of feasibility

Table 4. Overview of involvement and key issues and themes concerning patient's self-management and the use of Oncokompas^{2.0} in survivorship care of colon cancer according to GPs

	KEY ISSUES	THEME
Patients' self-management in survivorship care	Reservations of the GP concerning patients' responsibilities in survivorship care	<ul style="list-style-type: none"> - Patients are not willing to be responsible for own care - Patients are not capable to take responsibility
	Patients should be more involved in survivorship care	<ul style="list-style-type: none"> - Patients should be informed about physical symptoms that could indicate recurrent disease and when to consult a doctor - Involvement in decision making
Use of Oncokompas ^{2.0} in survivorship care of colon cancer	The GP had a positive attitude towards the use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - Oncokompas^{2.0} makes patients more empowered - Patients will obtain insight into their symptoms and concerns - Oncokompas^{2.0} will relieve the workload of GPs - Increased insight for both GP and patients in case of vague symptoms and problems
	Reservations of the GP concerning the use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - Impersonal - Not suitable for all patients - Increase patients' awareness of problems
	Involvement of the GP during patient's use of Oncokompas ^{2.0}	<ul style="list-style-type: none"> - GPs as a consultant <ul style="list-style-type: none"> o Leave the initiative to the patient to discuss Oncokompas^{2.0} results o Estimate if a referral, suggested by Oncokompas^{2.0}, is appropriate - Intensive involvement of the GP <ul style="list-style-type: none"> o Receive a message if the patient has a serious symptom or concern, detected by Oncokompas^{2.0} o Discuss results of Oncokompas^{2.0} routinely with the patient

Appendix A. Oncokompas^{2.0}

The eHealth application Oncokompas^{2.0} is a personal and interactive application to support patients who have been treated for cancer. Oncokompas^{2.0} consists of three steps; “Measure”, “Learn” and “Act”.

In the “Measure” component patients can monitor their quality of life (QOL) with patient reported outcomes (PROs). The QOL domains used in Oncokompas^{2.0} include physical functioning in general but also specific physical symptoms and concerns after colon cancer, psychological functioning, social functioning, healthy lifestyle and existential issues. Patients decide which domain(s) they want to explore. A clickable demo and an animation video are available on the website www.oncokompas.nl. PROs on colon cancer were selected by a team of experts together with the project team of Oncokompas^{2.0} and based on the national guideline of colorectal cancer and literature.¹

Subsequently, patients receive automatically generated tailored feedback on data from their PROs in the “Learn” component, which are based on algorithms. These algorithms are based on existing Dutch guidelines and discussed by the expert team until consensus was reached. Feedback is shown using three colours, red (seriously elevated wellbeing risks), orange (elevated wellbeing risks) and green (no elevated wellbeing risks). Additional personalized information about the specific PROs will be provided. Furthermore self-support advice is shown in the “Learn” component, which is tailored to the individual outcomes of the patients.

Afterwards, personalized supportive care options (care professionals and self-management options) are provided in the “Act” component, which are based on individual PROs and patients’ preferences. When patients receive a red score (seriously elevated wellbeing risks) in the “Learn” component, the advice in the “Act” component includes to consult their GP or medical specialist.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Laura Duineveld (page 4)
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	PhD student, MD (not mentioned in the manuscript)
3.	Occupation	What was their occupation at the time of the study?	PhD student and GP trainee (In the correspondence, page 1, the 'Department of Primary Care' is mentioned and 'researcher' is mentioned, page 4)
4.	Gender	Was the researcher male or female?	Female (not mentioned in the method section)
5.	Experience and training	What experience or training did the researcher have?	Previous observational study and course 'Qualitative research' (Academic Medical Centre, Amsterdam) (Page 4)
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	The interviewer knew 50% of the participants by face and never met the other 50% of the participants prior to the study (not mentioned in the manuscript)
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	The interviewer sent an e-mail before the interview took place this reasons for doing the interview study (page 4)
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	The interviewer introduced herself by telling that she was a PhD student of the Department of Primary Care and a GP trainee. (not mentioned in the manuscript)
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (page 5)
Participant selection			
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Purposive (page 4)
11.	Method of approach	How were participants	Initial contact via e-mail (page

		approached? <i>e.g. face-to-face, telephone, mail, email</i>	4)
12.	Sample size	How many participants were in the study?	20 (page 4)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	0 (page 4)
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	at the researcher's workplace in the Academic Medical Centre (n=9), at the participant's clinic (n=7) or at the participant's home (n=4) (page 4)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No (page 4)
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	10 men and 10 women, with 3 to 34 years of experience as a GP (page 4 and 16)
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	A pre-defined topic list was used during the interviews. Questions and topics were based on literature and expertise of the research team. After the first two interviews, the topic list was refined and sharpened but no major changes in the questions were made. (page 4 and 17)
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No (not explained in method section)
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording (page 4)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, during and after the interviews (page 4)
21.	Duration	What was the duration of the interviews or focus group?	between 39 and 66 minutes (page 4)
22.	Data saturation	Was data saturation discussed?	Yes (page 4)
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No (not explained in method section)
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Two coders coded the first 10 interviews. Subsequently, one coder coded the remaining 10 interviews according to the prior refined framework. (page 5)
25.	Description of the coding tree	Did authors provide a description	Yes (page 18 and 19)

		of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data (page 5)
27.	Software	What software, if applicable, was used to manage the data?	MaxQDA version 11 (page 5)
28.	Participant checking	Did participants provide feedback on the findings?	No (not explained in the method section)
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>	Yes. Each quotation was identified. (page 5-10)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes (page 5-10)
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes (page 5-10 and 18-19)
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes (page 5-10 and 18-19)