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# Roles of general practitioners in shared decision-making for patients with cancer: A qualitative study

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# Abstract

**Objective:** The shared decision-making (SDM) process for the treatment of pancreatic and oesophageal cancer primarily takes place with healthcare professionals (HCPs) in the hospital setting. This study aims to explore the perspectives of general practitioners (GPs) on their possible roles during this SDM process, their added value and their requirements for involvement in SDM.

**Methods:** Semi-structured interviews were conducted with 12 GPs about their views on SDM for patients with cancer. The interviews were analysed by two researchers using an inductive open coding approach.

**Results:** Five potential roles in SDM were described by the interviewed GPs, of which the role as 'coach' of the patient was mentioned by all. GPs see their main added value as their long-standing relationship with the patient. To be able to participate optimally in SDM, GPs indicated that they need to be kept up to date during the patient's care process and should receive enough medical information about treatment options and contextual information.

**Conclusion:** GPs see different potential roles for themselves when involved in SDM. Hospital HCPs that want to facilitate GP involvement should take the initiative, provide the GPs with enough and timely information and must be easy to consult.

#### KEYWORDS

general practitioner, oesophageal cancer, pancreatic cancer, primary care involvement, shared decision-making, treatment decision

# 1 | INTRODUCTION

Shared decision-making (SDM) is very important when choosing a treatment for oesophageal and pancreatic cancer. Even if a curative treatment option is possible (in 10%–25% of cases), the prognosis is poor. The overall 5-year survival rate for both patients with pancreatic cancer and advanced oesophageal cancer is less than 5% (Fest

et al., 2017; Lola Rahib et al., 2014; Short et al., 2017). Even when a potentially curative treatment option is available, this is not necessarily the obvious choice due to severe side effects, impact on quality of life and a limited chance of complete treatment success (cure). Patient preference is therefore a relevant factor, and encouraging patients to be involved in the decision-making process is important.

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Elwyn et al. (2012, 2017) describe how SDM can take place in clinical practice in a structured manner. They translated the principles of SDM into a model describing three steps ('talks') of SDM for each patient: (1) the team talk, during which the healthcare professional (HCP) makes patients aware that a choice exists, describes the choices and asks patients about their goals; (2) the option talk, during which the HCP discusses the treatment options and their corresponding harms and benefits with the patient using risk communication principles; and (3) the decision talk, during which the HCP helps the patient to make a preference-based decision. Throughout the process, the HCP offers support and ensures that patients do not feel abandoned when asked to participate in SDM. Elwyn's model does not elaborate on the variety of HCPs involved in the SDM process.

Potentially, the general practitioner (GP) could be valuable during this process. In the Netherlands, the GP is the first person of contact for non-emergency care and also serves as a gatekeeper for referral to hospital care (Berendsen et al., 2009). A large majority of people in the Netherlands are registered at a GP practice, with many people seeing the same GP for many years (van Weel et al., 2012). The GP could therefore play a useful role when patients have to make important decisions about treatment options with an impact on quality of life and prognosis. This has also been affirmed from the patient perspective: Recent research shows that patients appreciate and would like more GP involvement in cancer care and SDM (Halkett et al., 2015; Noteboom et al., 2021). It has been suggested that GPs should therefore play a role in the SDM process for patients with cancer in the form of a 'time-out consultation' (de Wit, 2017), which could take place between the option and decision talk. A time-out consultation is a personal consultation with the GP in which the values and wishes of the patient, as well as the proposed treatment options with their possible consequences, are discussed. Introducing such a conversation has shown promising results with regard to experienced comfort and support by patients and increased confidence regarding the treatment decision (Noteboom et al., 2020; Wieldraaijer et al., 2019).

Previous research has additionally shown that patients may not be aware of their own role in decision-making and feel that the GP should create awareness for this role (Brom et al., 2017; Noteboom et al., 2021). Therefore, we propose that GPs could also potentially play a role by explaining the concept of SDM at the very start of the care process, from the first referral of the patient to the hospital with abdominal complaints. This may help 'empower' patients: to become more aware of their role in being a part of any (diagnostic or treatment) decision, regardless of their eventual diagnosis. Patients might be better prepared when faced with SDM in case they are diagnosed with cancer.

Research into the involvement of GPs in SDM for patients with cancer has mostly focused on the wishes of patients (Brandenbarg et al., 2017; Halkett et al., 2015; Noteboom et al., 2021) and on measuring the effectiveness of 'time-out' consultations (Noteboom et al., 2020; Perfors et al., 2020; Wieldraaijer et al., 2019). One implementation pilot study also explored views of GPs but did not

report extensive qualitative results (Noteboom et al., 2020). Exploring the views of GPs with interviews could therefore be a useful addition to the body of knowledge on this topic. For example, it has not been studied which role(s) GPs see for themselves in decisionmaking for (pancreatic and oesophageal) cancer and whether they feel they are currently sufficiently equipped for these roles. The aim of this study is therefore twofold: (1) to explore how GPs see their roles during the SDM process of patients with pancreatic and oesophageal cancer and what they consider their added value in these roles and (2) to identify what GPs need from HCPs in secondary and tertiary hospitals to be able to take on these roles. The findings of this study can inform hospital HCPs on how to facilitate more GP involvement in SDM.

#### 2 **METHODS**

#### 2.1 Study design

A gualitative study was performed in which semi-structured in-depth interviews were held with GPs in the region Nijmegen-Eastern Netherlands.

#### 2.2 Setting

This study was conducted as part of the project 'Empower2Decide', which aims to improve SDM for patients with cancer and the collaboration of the HCPs involved in their care, in the region Niimegen-Eastern Netherlands. The initial focus of this project is on patients with pancreatic or oesophageal cancer. All of these patients who have any potential wish for hospital treatment are discussed in the Multidisciplinary Tumour Board of the Radboudumc, an academic tertiary hospital. The 'talks' of the SDM model by Elwyn et al. (2012, 2017) also primarily take place in this hospital. The talks differ slightly from how Elwyn et al. describe them: the team talk and option talk are combined into a single consultation due to the short time frame in which decisions need to be made. The decision talk is scheduled in a second appointment. One of the goals of this project is to improve SDM not just in the tertiary centre but during the whole patient journey and thus also involving GPs and the HCPs in connected secondary hospitals.

#### Sampling and recruitment 2.3

Participants in this study were GPs within the referral area of the Radboudumc. We included GPs who had seen a patient with pancreatic or oesophageal cancer in the past year in their practice, until data saturation was reached. This was done by first selecting relevant patients and then approaching their GPs. The surgery department selected 46 patients who had previously been discussed in the Multidisciplinary Tumour Board of the Radboudumc, starting with

those scheduled around 3 months back. Patients were selected who had been seen in a variety of secondary hospitals in the region, with the aim of achieving some spread in the location of the GP practices (purposeful sampling). The GPs of these patients were then sent an invitation letter by the surgery department of the Radboudumc, with the request to contact the researchers if they wanted to participate. After 1 month, a reminder was sent to GPs who had not responded to the invitation letter. Participating GPs were offered a gift voucher of 50 euros. The researchers remained unaware of the identity of the patients throughout the study.

#### 2.4 | Data collection

Individual in-depth interviews were conducted between March and June 2020 by LR and IA (Appendix A). Due to the COVID-19 pandemic, interviews were held by video calls [n = 7] or audio only [n = 5]. The interviews (25-60 min) were audio recorded and transcribed verbatim. IA and LR drafted a semi-structured interview guide inspired by a Dutch document on GPs and cancer care (Nederlands Huisartsen Genootschap, 2014), previous research on time-out consultations (Noteboom et al., 2020) and questions considered important by the Empower2Decide team (SM, MK, HS). All authors checked the draft and together settled on a final version of the interview guide. The main topics/questions are shown in Table 1. The first part of the interview contained questions about the GP's experiences regarding their patient with pancreatic or

#### TABLE 1 Content of interviews

Interview phase	Main questions/topics
1: Healthcare process of the recent patient with pancreatic or oesophageal cancer	• What did the healthcare process of your patient look like?
	<ul> <li>How were you involved as GP and how did you experience this?</li> </ul>
	<ul> <li>How did you experience the communication/collaboration with the local hospital(s)?</li> </ul>
2: Shared decision-making— open questions	<ul> <li>(How) were you involved in the SDM process of your patient regarding hospital treatment?</li> </ul>
	<ul> <li>How would you ideally like to be involved in the SDM process of patients with (pancreatic and oesophageal) cancer? In which situations, and why?</li> </ul>
	<ul> <li>What do you need from the hospital(s) in order to fulfil your desired roles in the SDM process?</li> </ul>
3. Shared decision-making— prompts on the ideas within the Empower2Decide project	<ul> <li>Opinion on implementing a standard 'time-out consultation'</li> </ul>
	• Opinion on the GP introducing the concept of SDM when referring patient to the hospital

oesophageal cancer and then explored the general views of the GP on their perceived role(s) regarding SDM for this group of patients and their requirements to fulfil this role. In the second part of the interview, the GPs were asked to comment on the specific ideas of the Empower2Decide project: implementation of a standard time-out consultation for patients with pancreatic or oesophageal cancer between the option and the decision talk and introduction of the concept of SDM to their patients at the time of the first referral to the hospital.

# 2.5 | Data analysis

The data were analysed in Atlas.ti 8.4.20 by thematic analysis, following an inductive open coding approach (Lester et al., 2020). The first three interviews were analysed separately by researchers IA and LR. The assigned codes were compared and discussed until consensus was reached on the codes for the first draft of the codebook. They also started axial coding in which codes were linked together and combined into subthemes. This process continued throughout the coding of the subsequent interviews, in which LR analysed the interviews first, adding new codes if needed, after which IA checked the coded interviews for agreement. Frequent meetings were held between IA and LR to discuss the codes and (sub)themes. When needed, coding of previously coded interviews was adapted in an iterative process. Together, they adapted the codebook throughout this process and created a first overview of the themes and subthemes. Finally, the findings were discussed with PW and RH, and the final themes and subthemes were decided upon.

#### 2.6 | Ethical statement

This type of study does not fall within the scope of the Dutch Medical Research Involving Human Subjects Act (WMO). We obtained an official exemption from the local Medical Ethics Committee CMO Arnhem-Nijmegen (file number 2020-6243). All study participants received written and oral information and signed an informed consent form.

## 3 | RESULTS

#### 3.1 | Characteristics PARTICIPANTS

Of the 46 approached GPs, 17 (37%) responded to the invitation letter. Three GPs declined participation, and two GPs intended to participate but eventually declined, due to lack of time and the inability to access patient files due to death of the patient. In total, 12 interviews were conducted. The last few interviews provided little new information; therefore, it was decided to not send out more invitations at this stage as data saturation was presumably reached. Participant characteristics are shown in Table 2.

	Participants ( $n = 12$ )
Gender	
Female (n)	8
Male (n)	4
Median age (range)	41.5 (34–65)
Median years of experience as GP (range)	11.75 (5-22)
Type of GP practice	
Solo practice (n)	1
Group practice (n)	8
Health centre (n)	3

#### 3.2 | Identified themes

The identified themes and subthemes on GPs' perspectives regarding SDM are shown in Table 3. We found four main themes: situations in which GPs add value to SDM, GP roles in SDM, added value of the GP to the SDM process and GP needs for conducting SDM.

#### 3.2.1 | Situations in which GPs add value to SDM

All interviewed GPs were interested in being involved in the SDM process of patients with pancreatic or oesophageal cancer by talking with the patient separately from the patient's SDM talks in the hospital. However, most GPs did not consider this necessary in all situations. GPs described two *situations in which GPs add value to SDM*. The first was when there is a *non-straightforward treatment* decision. GPs generally considered the treatment decision easy when a patient in relatively good health has a curative option. They indicated that they mainly see a role for themselves when the decision is more complex, for example, for frail patients with (physical or psychological) comorbidity, patients with complex home situations or patients who may have trouble overseeing their treatment options and consequences.

I have patients who are unable to oversee the different treatments, who engage with every option presented to them and they cannot process the information. So whether I want to be involved or not has to do with the ability of the patient. (GP 10)

Additionally, GPs mentioned they want to be involved when the *patient desires GP involvement*.

I told her ... if there are moments in which you need to decide something and you are struggling, or you want to discuss it, you can always [contact me]. You do not have to immediately say yes. (GP 6)

However, standard involvement of the GP in SDM, by means of planning a *time-out consultation* for each patient with pancreatic or oesophageal cancer (as suggested as a prompt in the interview guide), was not desired by a majority of interviewed GPs.

## 3.2.2 | GP roles in SDM

Five *roles for the GP* in their involvement in SDM were identified from the interviews. The role as a *coach* in making choices regarding treatment was mentioned during all interviews. The interviewed GPs indicated they would like to be a sounding board for their patient, in the consideration of which treatment fits best considering the patient's current situation and their personal priorities.

You actively question the patient about [the considerations]. What would it mean for you if you cannot do certain things anymore, or if you live half a year longer? That you question the patient in all kinds of ways, helping the thought process. (GP 1)

Most GPs also mentioned the role of *provider of information* to the patient. Whereas some GPs would like to go over the treatment options and their consequences with the patients, others indicated that they did not want to do this as they considered this the remit of specialists. They did not consider it the GP's job to repeat medical information about cancer treatments and would rather discuss the treatment decision in more general terms. As a third role, some GPs mentioned that they see themselves as a *supporter of the family*, both by helping the family consider the different treatment options and by caring for the well-being of the family members.

And to hear from the partner what it is like for them. You know, if someone chooses not to have surgery and there will certainly be a residual tumor, well that's some choice you make, that also has an impact on the partner. (GP 12)

The interviewed GPs also mentioned a role as a guide for the SDM process in the hospital. They can, for example, help a patient formulate their questions for the specialist. Furthermore, some GPs indicated that sometimes when they first refer a patient to the hospital, they make sure the patient knows they will have a choice regarding potential future treatment.

Only one GP actively mentioned informing patients about their role in future choices before being specifically prompted to reflect on this as part of the interview guide (see Table 1, Phase 3). In the context of our prompt, the interviewed GPs indicated they do not feel that introducing patients to the concept of SDM at *the time of referral* is always suitable, because no diagnosis has been set yet and it may unduly worry patients. They feel that it should always remain up to their own estimation whether the information should be provided at that given moment.

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TABLE 3 Identified themes and subthemes regarding the involvement of GPs in SDM for cancer treatment

Themes	Subthemes	Topics of the underlying codes
1. Situations in which GPs add value to SDM	Non-straightforward treatment decision	Related to medical or personal situation of the patient:
		Hard to treat or poor prognosis
		• Elderly patients or with significant comorbidity
		• Ability of the patient to understand treatment options
	Patient desires GP involvement	Perceived insufficient consultation time     at the specialist
		• Extra input desired from familiar HCP
2. GP roles in SDM	Coach	Sounding board for patient
		• 'Does the treatment suit the patient?'
	Provider of information	• Explain treatment options and consequences again
	Provider of support for the family	• Involve and support partner and children
	Guide for decision process in the hospital	• Encourage patient to take time to think
		Help patient create a list with questions for specialist
	Provider of support for the specialist	Provide information on specific characteristics of patient
		Mutual deliberation with expertise of both parties
3. Added value to the SDM process	Long-standing relationship between GP and patient	Knows patient, their family and (home)     situation
	Repeat information and take more time	<ul> <li>Repeating of treatment options has added benefit</li> </ul>
		Perception that GP can take more time than specialist
	Address option of doing nothing	• Perception that they are more likely to offer and stress the option of not starting a treatment
4. GP needs for involvement in SDM	Involvement throughout the patients care journey	<ul> <li>Important to be kept up to date—via letters, but also personal contact on key moments in the patients care</li> </ul>
		Low-threshold contact options with specialist
	Initiative to involve the GP	<ul> <li>Medical specialist can call the GP to invite them to become involved if necessary</li> </ul>
		• Medical specialist can inform patient that they are free to contact their GP
	Medical information from the hospital	• Treatment options with pros and cons and chance of adverse events
		• Report of multidisciplinary consultation
		• Too specific for the GP to discuss all information with the patient
	Contextual information from the hospital	<ul> <li>More in-depth information on (personal and medical) situation of patient and prognosis, with a phone call</li> </ul>
		How much has been communicated to patient?

#### TABLE 3 (Continued)

Themes	Subthemes	Topics of the underlying codes
	Considerations of specialist	• Which treatments are meaningful for the patient according to the specialist?
		• Motivations of the specialist to prefer a certain treatment
	Supporting tools	Discussion guide or checklist
		E-learning/training

That man last year who died of pancreatic cancer. He returned from holiday and was completely yellow. I'm not gonna tell that man, 'well, you remain in charge'. No. At that moment he just wanted to know, what's going on? (GP 9)

Lastly, most interviewed GPs saw a role for themselves as *provider of support for the specialist* during the decision-making process. GPs can provide information on the context of the patient and consider together with the specialist whether certain treatment options are sensible for the patient.

[The oncologist and I] consider together, do we have the same picture of this patient? Sometimes you can adjust the policy, when an oncologist wants to start palliative chemotherapy, that you can say, maybe for this patient we should consider if this is sensible. (GP 3)

## 3.2.3 | Added value to the SDM process

There are three main ways in which the interviewed GPs feel that they can *add value to the SDM process*. Most often mentioned was *the long-standing patient-doctor relationship* between the GP and the patient. The GP often knows the patient better than the specialist and may know the family and the patient's social situation. This contextual information can contribute to making the right treatment decision for the patient.

Then, the GP can provide an *additional moment for SDM* and can potentially take more time for this than the specialist. Especially when a patient has doubts, it can be helpful for them to have an additional consultation.

> I think it is good that the patient has two conversations [on treatment decisions]. One with the specialist, and one with the GP. Because the information still has to sink in, you have to chew on it, you have to start being able to imagine it. It is nice when the biggest emotions have disappeared. These are big decisions; those should be taken with care. (GP 1)

Lastly, some GPs felt that they were more likely than specialists to *address the option of not undergoing treatment* in the form of surgery, radiation or chemotherapy.

#### 3.2.4 | GP needs for conducting SDM

The interviewed GPs indicated they would like several kinds of support from the hospital when being a part of the SDM process for patients with cancer. Six subthemes were identified for this topic. First of all, GPs indicate that they need a certain level of basic *involvement throughout the patient's care journey* to stay up to date, which helps them when the need arises for them to be involved in SDM. It is important that this is facilitated by the hospital. Leaving it up to the patient to keep the GP updated when important changes take place may result in missed opportunities.

Often we are not kept up to date about what the plan is. The patient will think, the GP already knows because does not he hear this from the specialist? [...] So there may be false expectations with the patient and that can be difficult. Patients will blame us that we do not reach out. (GP 11)

A GP can be kept generally up to date via letter, but many GPs also mention that personal contact with the specialist (i.e. a telephone call) at key moments is also essential, for example, when a new diagnosis is set or when no more treatment options are possible for a patient. GPs also feel they should be able to easily consult the specialist if they have questions themselves.

Closely related to the first theme is the *initiative for involving the GP*. Some GPs would like the specialist to actively contact them when the specialist considers the involvement of the GP in SDM desirable. Several GPs also mentioned that they would like the specialist to suggest to the patient that they could contact their GP to discuss their treatment options.

Most interviewed GPs mentioned that when they are part of the SDM process, they need enough *medical information* to talk with the patient about their treatment options. The desired level of detail of this medical information differed for GPs, corresponding with to what extent they feel they should have a role as a provider of

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information. However, when treatment options are discussed, it is important that the GP has enough basic information to discuss the pros and cons.

I did discuss [the treatment options] with the patient but without good information, which would have made the conversation more valuable. If [patients] receive information about the options on paper, which I get explained to me with a phone call, that can be a sort of discussion guide. Because now she says 'I understood it like this', and I think, yes I guess so .... (GP 2)

Furthermore, GPs mentioned they would like to receive certain *contextual information*. They consider it important, for example, to know how much the patient knows. Has bad news already been communicated; have the options been explained? In addition, they would like to know how the patient appears to be dealing with everything that has happened. Preferably, contextual information is communicated via telephone.

In a letter is written formally what happened, and for background information that's good, but you want to know how was the patient in the hospital? Was it tense? Was it hard? In only one sentence, you can discuss this by telephone [with the specialist]. (GP 3)

Additionally, several GPs mentioned that they would like to know the *considerations of the specialist* and their opinion on the situation, also preferably via telephone. Which treatment options does the specialist still consider meaningful for this patient? If the specialist prefers one treatment option, why?

In this case, the patient wants everything, just to extend his life. But I cannot estimate to what extent the specialists agree with this, and if [the treatment] is still meaningful or just that the patient wants it. The considerations and reflections just would be nice to share. (GP 7)

Lastly, some of the GPs mentioned that *supporting tools* for SDM might be useful, such as a discussion guide or checklist for during the consultation itself, or more generally an e-learning module or training on how to hold SDM conversations about cancer treatment options.

# 4 | DISCUSSION

This study showed that GPs can take on several different roles in the SDM process of patients with pancreatic and oesophageal cancer, both with regard to supporting the patients and their family and with regard to supporting the specialist in their deliberations. GPs consider their main added value their long-standing relationship with the patient, meaning they are likely to know the patient and their context

better than the specialist. To be able to take a role in SDM, GPs consider it important that they are kept up to date during the patient's care process, with the specialist actively taking the initiative to involve the GP when this may be beneficial. Furthermore, GPs require enough information about the treatment options as well as contextual information.

Several studies have been conducted in which the actual and/or desired role of GPs in cancer care or cancer-related SDM is described from the patient perspective (Anvik et al., 2006; Brandenbarg et al., 2017; Halkett et al., 2015; Lang et al., 2017; Lundstrom et al., 2011; Noteboom et al., 2020, 2021; Wallner et al., 2016). Similar roles for GPs compared to our study can be recognised in these studies, such as the role of coach in decision-making (Brandenbarg et al., 2017; Halkett et al., 2015; Noteboom et al., 2021), supporter of the family (Brandenbarg et al., 2017; Halkett et al., 2015; Lang et al., 2017) and provider of information (Lundstrom et al., 2011; Wallner et al., 2016), though the studies also show that GPs do not always take on these roles even when this is desired by patients. Noteboom et al. (2020) found that the discussion of cancer treatment decisions with the GP is often lacking. They suggest this may be because GPs do not recognise this need in patients or because GPs feel they do not have enough medical expertise (Anvik et al., 2006; Noteboom et al., 2021). Our study additionally suggests that not all GPs consider it their role to provide or repeat medical information about cancer treatments.

The value of easy contact and good coordination between GP and specialist as well as the need for GPs to be kept up to date by the specialist has been described before in the context of patients with cancer (Anvik et al., 2006; de Wit, 2017; Jiwa et al., 2013; Lang et al., 2017; Lundstrom et al., 2011). Previous studies also showed that cancer patients dislike it if the GP does not proactively contact them (Brandenbarg et al., 2017; Noteboom et al., 2020) and that satisfaction with GP involvement is higher if they do (Brandenbarg et al., 2017; Noteboom et al., 2021). In addition, a recent study showed that scheduling a timely time-out consultation does often not work out if left up to the patient (Perfors et al., 2020). This underlines the need expressed by GPs in this study that the specialist should take the initiative for involving the GP.

This study was focused specifically on SDM for patients with pancreatic and oesophageal cancer. In practice, GPs also reflected more generally on their involvement on SDM for cancer care and brought up examples of patients with different types of cancer. Therefore, the findings of this study are also potentially relevant for GP involvement in SDM for other types of cancer.

The results of this study can inform specialists how to facilitate more frequent SDM involvement by GPs. First, it seems important that a specialist (or other HCP in the hospital) takes the initiative for involving the GP (if this is in line with patient wishes) and also specifically informs the GP why they believe the GP could play an important role in SDM in this case. GPs mainly feel they have added value when decisions are not straightforward, but this may be the case for more patients with pancreatic and oesophageal cancer than GPs are aware of: Limited treatment success and severe side effects mean the decision to undergo potentially curative treatment is often not as straightforward as it may seem. Creating more awareness of this may therefore be the first step in involving GPs. Future research should study whether this approach is successful and whether and when the patients and GPs experience added benefit. Studying how this may differ for other types of cancer with choices that are potentially more straightforward may also be useful.

Furthermore, the field may benefit from developing general guidelines on how GPs should ideally be involved in SDM for cancer, rather than leaving this up to individual HCPs. This can provide clarity to all parties involved, including patients, regarding what they can expect of the GP's involvement.

# 4.1 | Strengths and limitations

The main strength of this study is the use of in-depth interviews to elicit GPs' views on their involvement in SDM. All GPs had recent experience with a patient diagnosed with pancreatic or oesophageal cancer, ensuring an opinion on the desirability of and needs for involvement in SDM for these patients. New GPs were included until data saturation was reached. However, the study also has several limitations. First, GPs from only one region in the Netherlands were included. Second, a limitation of the study is that it possibly mainly attracted GPs who have a positive outlook on involvement in SDM. This may have influenced the number of interviews needed for data saturation. GPs who are indifferent towards the subject are probably less likely to participate in an interview. Only one interviewed GP expressed a negative view on contributing to SDM for cancer patients beforehand. This in practice only concerned a negative view towards discussing medical details of treatments, while their views were otherwise similar to that of other GPs in this study. Third, whether there are GPs who do not wish to contribute to SDM for patients with cancer, and what this would mean for involving GPs in SDM, cannot be concluded from this study. Future (questionnaire-based) research with more participants in several regions could provide more insight into this.

## 4.2 | Conclusion

GPs see different potential roles for themselves when involved in SDM for patients with pancreatic and oesophageal cancer, which include both supporting the patient and the specialist in their deliberations. To be able to take a role in SDM, GPs consider it important that they are kept up to date during the patient's care process, with the hospital specialist actively taking the initiative to involve the GP when this may be beneficial. Furthermore, GPs require enough information about the treatment options as well as contextual information. In general, the field may benefit from developing guidelines in which the ideal involvement of the GP is described. Future research should study the added value of GP involvement in SDM from both the patient and the GP perspective.

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#### CONFLICT OF INTEREST

All authors declare they have no conflicts of interest.

#### AUTHOR CONTRIBUTIONS

All authors were involved in designing the study. IA, LR, PW and RH were involved in data analysis; MK, SM and HS aided in interpreting the findings. IA and LR wrote the manuscript. All authors critically revised the manuscript.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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#### REFERENCES

- Anvik, T., Holtedahl, K. A., & Mikalsen, H. (2006). "When patients have cancer, they stop seeing me"--The role of the general practitioner in early follow-up of patients with cancer--A qualitative study. BMC Family Practice, 7, 19. https://doi.org/10.1186/1471-2296-7-19
- Berendsen, A. J., Jong, G. M., Meyboom-de Jong, B., Dekker, J. H., & Schuling, J. (2009). Transition of care: Experiences and preferences of patients across the primary/secondary interface - A qualitative study. BMC Health Services Research, 9(1), 62. https://doi.org/10.1186/1472-6963-9-62
- Brandenbarg, D., Roorda, C., Stadlander, M., Bock, G. H., Berger, M. Y., & Berendsen, A. J. (2017). Patients' views on general practitioners' role during treatment and follow-up of colorectal cancer: A qualitative study. *Family Practice*, 34(2), 234–238. https://doi.org/10.1093/ fampra/cmw124
- Brom, L., De Snoo-Trimp, J. C., Onwuteaka-Philipsen, B. D., Widdershoven, G. A., Stiggelbout, A. M., & Pasman, H. R. (2017). Challenges in shared decision making in advanced cancer care: A qualitative longitudinal observational and interview study. *Health Expectations*, 20(1), 69–84. https://doi.org/10.1111/hex.12434
- de Wit, N. J. (2017). A "time out consultation" in primary care for elderly patients with cancer: Better treatment decisions by structural involvement of the general practitioner. *European Journal of Cancer Care* (England), 26(3), e12711. https://doi.org/10.1111/ecc.12711
- Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D., Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., ... van der Weijden, T. (2017). A

9 of 9

three-talk model for shared decision making: Multistage consultation process. *BMJ*, 359, j4891. https://doi.org/10.1136/bmj.j4891

- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6
- Fest, J., Ruiter, R., van Rooij, F. J., van der Geest, L. G., Lemmens, V. E., Ikram, M. A., van der Geest, L. G. M., Coebergh, J. W., Stricker, B. H., & van Eijck, C. H. J. (2017). Underestimation of pancreatic cancer in the national cancer registry - Reconsidering the incidence and survival rates. *European Journal of Cancer*, 72, 186–191. https://doi.org/ 10.1016/j.ejca.2016.11.026
- Halkett, G. K., Jiwa, M., & Lobb, E. A. (2015). Patients' perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis. *European Journal of Cancer Care (England)*, 24(5), 662–672. https://doi.org/10.1111/ecc.12224
- Jiwa, M., McManus, A., & Dadich, A. (2013). The impact of knowledge, attitudes and beliefs on the engagement of primary and communitybased healthcare professionals in cancer care: A literature review. *Current Medical Research and Opinion*, 29(11), 1475–1482. https://doi. org/10.1185/03007995.2013.838154
- Lang, V., Walter, S., Fessler, J., Koester, M. J., Ruetters, D., & Huebner, J. (2017). The role of the general practitioner in cancer care: A survey of the patients' perspective. *Journal of Cancer Research and Clinical Oncol*ogy, 143(5), 895–904. https://doi.org/10.1007/s00432-017-2343-4
- Lester, J. N., Cho, Y., & Lochmiller, C. R. (2020). Learning to do qualitative data analysis: A starting point. *Human Resource Development Review*, 19(1), 94–106. https://doi.org/10.1177/1534484320903890
- Lola Rahib, B. D. S., Aizenberg, R., Rosenzweig, A. B., Fleshman, J. M., & Correction, L. M. M. (2014). Projecting cancer incidence and deaths to 2030: The unexpected burden of thyroid, liver, and pancreas cancers in the United States. *Cancer Research*, 74(14), 4006. https://doi. org/10.1158/0008-5472.CAN-14-1642
- Lundstrom, L. H., Johnsen, A. T., Ross, L., Petersen, M. A., & Groenvold, M. (2011). Cross-sectorial cooperation and supportive care in general practice: Cancer patients' experiences. *Family Practice*, 28(5), 532–540. https://doi.org/10.1093/fampra/cmr011
- Nederlands Huisartsen Genootschap. (2014). NHG standpunt Oncologische zorg in de huisartsenpraktijk. https://www.nhg.org/themas/ publicaties/nhg-standpunt-oncologische-zorg-de-huisartsenpraktijk
- Noteboom, E. A., de Wit, N. J., Asseldonk, I., Janssen, M., Lam-Wong, W. Y., Linssen, R., Pepels, M. J. A. E., Schrama, N. A. W. P., Trompper, M. E. H., Veldhuizen, L. M., Wijtvliet, A. P., Zeldenrust, E. G. F., Hendrikx, A. M., van de Boomen, W. A., Elbersen, D. M., Jacobs, E. M. G., van der Wall, E., & Helsper, C. W. (2020). Off to a good start after a cancer diagnosis: Implementation of a time out consultation in primary care before cancer treatment decision. *Journal of Cancer Survivorship*, 14(1), 9–13. https://doi.org/ 10.1007/s11764-019-00814-5
- Noteboom, E. A., Perfors, I. A., May, A. M., Stegmann, M. E., Duijts, S. F., Visserman, E. A., Engelen, V., Richel, C., van der Wall, E., de Wit, N., & Helsper, C. W. (2021). GP involvement after a cancer diagnosis; patients' call to improve decision support. *BJGP Open*, 5(1), bjgpopen20X101124. https://doi.org/10.3399/bjgpopen20X101124
- Perfors, I. A. A., Noteboom, E. A., de Wit, N. J., van der Wall, E., Visserman, E. A., van Dalen, T., Verhagen, M. A. M. T., Witkamp, A. J.,

Koelemij, R., Flinterman, A. E., van Dorst, E. B. L., Pruissen-Peeters, K. A. B. M., Moons, L. M. G., Schramel, F. M. N. H., van Rens, M. T. M., Ernst, M. F., May, A. M., & Helsper, C. W. (2020). Effects of a time out consultation with the general practitioner on cancer treatment decision-making: A randomised controlled trial: Time out with the general practitioner and cancer treatment decision. *Psycho-Oncology*, 30(4), 571–580. https://doi.org/10.1002/pon.5604

- Short, M. W., Burgers, K. G., & Fry, V. T. (2017). Esophageal cancer. American Family Physician, 95(1), 22–28.
- van Weel, C., Schers, H., & Timmermans, A. (2012). Health care in the Netherlands. Journal of American Board of Family Medicine, 25(Suppl 1), S12–S17. https://doi.org/10.3122/jabfm.2012.02.110212
- Wallner, L. P., Abrahamse, P., Uppal, J. K., Friese, C. R., Hamilton, A. S., Ward, K. C., Katz, S. J., & Hawley, S. T. (2016). Involvement of primary care physicians in the decision making and care of patients with breast cancer. *Journal of Clinical Oncology*, 34(33), 3969–3975. https://doi. org/10.1200/JCO.2016.67.8896
- Wieldraaijer, T., Meij, M., Zwaard, S., Weert, H., & Wind, J. (2019). Introducing a time out consultation with the general practitioner between diagnosis and start of colorectal cancer treatment: Patient-reported outcomes. *European Journal of Cancer Care (England)*, 28(6), e13141. https://doi.org/10.1111/ecc.13141

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# APPENDIX A: INTERVIEWER CHARACTERISTICS AND DATA PROCESSING

Both interviewers were female, had no existing relationship with the participants and had no assumptions before the study started as this was a new topic to both researchers. IA has followed several interview trainings and qualitative data analysis courses and has been involved in several interviews studies previously. LR had followed a course on qualitative research (including interview training) before commencement of the study.

Data processing: All data collected during this study were stored on a secured server of the Radboudumc. Only IA and LR had access to the personal details of the participants. Transcription was conducted partly by LR and partly by a transcription service that is affiliated with Radboudumc and that ensures privacy. All transcripts were anonymised before being uploaded into Atlas.ti.