Received: 10 January 2022 | Revised: 16 April 2022 | Accepted: 11 May 2022

DOI: 10.1111/ecc.13623

ORIGINAL ARTICLE

European Journal of Cancer Care WILEY

Health care professionals' perspectives on shared decision making supported by personalised-risk-for-recurrences-calculations regarding surveillance after breast cancer

Jet W. Ankersmid[1,2] | Constance H. C. Drossaert[3] | Luc J. A. Strobbe[4] | Melissa S. Battjes[1] | Cornelia F. van Uden-Kraan[2] | Sabine Siesling[1,5] | on behalf of the Santeon VBHC Breast Cancer Group

[1]Department of Health Technology and Services Research, Technical Medical Center, University of Twente, Enschede

[2]Santeon Hospital Group, Utrecht

[3]Department of Psychology, Health & Technology, University of Twente, Enschede, The Netherlands

[4]Department of Surgery, Canisius Wilhelmina Hospital, Nijmegen, The Netherlands

[5]Department of Research and Development, Netherlands Comprehensive Cancer Organisation, Utrecht, The Netherlands

Correspondence
Jet W. Ankersmid, MSc, Department of Health Technology and Services Research, Technical Medical Center, University of Twente, Enschede, The Netherlands.
Email: j.w.ankersmid@utwente.nl

Funding information
ZonMw, Grant/Award number: (project no. 516007001)

Abstract

Objective: Breast cancer patients for whom less intensive surveillance is sufficient can be identified based on the risk for locoregional recurrences (LRRs). This study explores health care professionals' (HCPs) perspectives on less intensive surveillance, preferences for shared decision-making (SDM) about surveillance and perspectives on the use of patients' estimated personal risk for LRRs in decision-making about surveillance.

Methods: We conducted semi-structured interviews with 21 HCPs providing follow-up care for breast cancer patients in seven Dutch teaching hospitals (Santeon hospitals).

Results: HCPs were predominantly positive about less intensive surveillance for women with a low risk for recurrences. They mentioned important prerequisites such as clearly defined surveillance schedules based on risk categories, information provision and communication support for patients and HCPs. Most HCPs supported SDM about surveillance and were positive about using patients' estimated personal risk for LRRs. HCPs specified prerequisites such as clear visualisation and explanation of risk information, attention for fear of cancer recurrence (FCR) and defined surveillance schedules for specific risk groups.

Conclusion: Mentioned prerequisites for less intensive surveillance need to be accounted for. Information needs and existing misconceptions need to be addressed. Outcome information regarding risks for LRRs and FCR can enrich the SDM process about surveillance.

KEYWORDS
breast cancer, follow-up, personalised, risk information, shared decision-making, surveillance

The research leading to this publication received funding from ZonMw (project no. 516007001).

1 | INTRODUCTION

The Dutch national guideline defines post-treatment surveillance after breast cancer as *'scheduled medical examinations to detect signs of potential recurrences or second primary tumours'* (NABON, 2012), which is part of the broader follow-up care after treatment. Post-treatment surveillance in the Netherlands is still one-size-fits all: annual imaging and physical examination for at least 5 years after treatment for all curatively treated patients, regardless of stage, age or treatment combination (NABON, 2012). A more personalised approach for surveillance after breast cancer should be considered as research has shown that risks for recurrences differ per patient (Witteveen et al., 2015); about half of the patients find recurrences themselves in between surveillance moments (Geurts et al., 2017); and studies have shown that more intensive surveillance is not more effective in improving health related quality of life, timeliness of recurrence detection and survival than less intensive surveillance (Høeg et al., 2019; Lafranconi et al., 2017; Moschetti et al., 2016). For some patients, the frequency stated in the current guideline may be appropriate, but for other patients, less intensive surveillance would be more effective due to a low risk for recurrences (Witteveen et al., 2020). Since every surveillance visit can be accompanied by stress, less visits could lower the burden for patients. Furthermore, less intensive surveillance can be more cost-effective for some patient groups (Draeger et al., 2020). However, little is known about the perspectives of health care professionals (HCPs) on less intensive surveillance after breast cancer in case of a low risk for recurrences.

The decision about the personalised post-treatment surveillance after breast cancer can therefore be seen as a decision for which no clear medical best option exists and for which shared decision-making (SDM) is specifically suitable (de Ligt et al., 2019). SDM can be defined as a process in which the patient and HCP decide together, based on the best available evidence and the patient's values and preferences (Elwyn et al., 2017; Stiggelbout et al., 2012, 2015). However, the scarce studies about SDM regarding post-treatment surveillance after curative breast cancer treatment suggest that SDM is rarely applied for this type of decisions and HCPs' perspectives remain unclear (Brandzel et al., 2017; Klaassen, Dirksen, Boersma, & Hoving, 2018).

The use of outcome information, such as the personal risk for recurrence of breast cancer, can enrich the process of SDM about surveillance. The INFLUENCE-nomogram is a validated prognostic model to calculate the 5-year risk for locoregional recurrences (LRRs) after breast cancer (Voelkel et al., 2019; Witteveen et al., 2015) and second primary breast tumours (Völkel et al., 2021), based upon characteristics such as TNM stage, receptor status and adjuvant treatment. Although the INFLUENCE-nomogram has been available for some years now its uptake in clinical practice is limited (Ankersmid et al., 2021) and little is known about how this nomogram can best be used in clinical practice and on how HCPs feel about using patients' estimated personal risk for LRRs as part of the SDM process on surveillance.

The aim of this study is to explore HCPs perspectives on less intensive surveillance for patients with low risk for recurrence, their attitudes (perceived benefits, barriers and prerequisites) about SDM regarding surveillance and their perspectives on the use of patients' estimated personal risk for LRRs in SDM about surveillance.

2 | MATERIALS AND METHODS

We conducted semi-structured interviews with 21 HCPs that provide breast cancer care in seven Dutch teaching hospitals, which together form the Santeon hospital group.

2.1 | Participants and procedures

We recruited three HCPs per hospital to achieve data saturation (Weller et al., 2018). HCPs were selected based on their role in the follow-up care process. Through an earlier assessment in each of the Santeon hospitals (Ankersmid et al., 2021), the researchers had knowledge on which specialisms were specifically involved in surveillance for breast cancer patients. In each hospital, one or two HCPs of the involved specialisms were approached for an interview (in total 24 HCPs). Three HCPs were approached but did not reply to the invitation.

Interviews with the HCPs took place between August 2019 and February 2020. The interviews lasted about 45 min each and were performed by one researcher (JA), trained in conducting interviews. All participants were informed about the aims and procedures of the study before the interviews. All interviews were audio-recorded—with prior permission of participants—and transcribed verbatim. Field notes were made by JA during the interviews. Two of the interviews were conducted with two of the participants at the same time and one of the interviews took place by telephone due to pragmatic reasons. The rest of the interviews were performed at an individual basis and took place in one of the Santeon hospital locations. Data saturation was achieved, because in the last three interviews no new categories were identified.

This study was no subject to approval by an ethical committee. All participants were informed about the aims and procedures of the study before the interview and gave oral consent for audio-recording of the interview and processing and reporting of the data for scientific publication.

2.1.1 | Interview scheme

The interviews focused on a broad range of topics about preferences regarding post-treatment surveillance. For this study we focused on the following topics: (1) Perspectives on less intensive surveillance for women with low recurrence risks; (2) attitudes regarding SDM about surveillance; and (3) perspectives on the use of patients' estimated personal risk for LRRs in SDM about surveillance. An interview guide was used containing questions about each of these topics (see examples of the questions asked in Supporting Information S1). Questions

were mainly formulated open-ended and non-directive. Most topics started with an open-ended question followed by prompting questions to gain more specific information. Prompting questions were formulated two-directional, for example, by asking for both the advantages and disadvantages of less intensive post-treatment surveillance. 'Prerequisites' were defined as 'conditions that need to be achieved or actions that need to be taken prior to something else', for example, the implementation of less intensive surveillance or SDM about surveillance. HCPs were provided with a written version of the definitions (stated from the guideline) of follow-up, aftercare and post-treatment surveillance to be able to focus on post-treatment surveillance in the interviews.

2.2 | Data analysis

Data analysis was performed using Atlas.ti 9 for Windows. Transcripts were coded by two independent coders (JA & MB). Analysis was performed using the framework analysis method, which is a combination between inductive and deductive approaches (Gale et al., 2013). The topics mentioned above formed a base for the thematic framework. Within each main topic we searched, inductively for themes that emerged from the data. The coders discussed their individual findings several times and any differences in coding were solved based on consensus. Remaining inconsistencies in coding were discussed with a third coder (CD) until consensus was reached.

3 | RESULTS

3.1 | Characteristics of participants

In Table 1 the number of HCPs per specialism is displayed. In each of the seven hospitals, three HCPs were interviewed. Most participants were surgical oncologists ($N = 8$, 38%) and nurse practitioners (NPs) of the surgery department ($N = 7$, 33%). The majority of the respondents worked at the surgery department since surveillance after breast cancer is mostly coordinated by this department. Most respondents were female ($N = 18$, 85%) and the working experience in their specialism ranged from 1 to 20 years with a mean time of 8.5 years.

TABLE 1 Interviewed HCPs per specialism ($N = 21$)

Specialism	N	% of participants
Surgical oncologist	8	38.1%
Nurse practitioner surgery department	7	33.3%
Medical oncologist	2	9.5%
Nurse practitioner oncology department	1	4.8%
Breast cancer nurse	2	9.5%
General physician	1	4.8%

3.2 | Perspectives on less intensive surveillance for women with a low risk for recurrences

HCPs were predominantly positive about less intensive surveillance for women with a low risk for recurrences. All perceived benefits, barriers and prerequisites are displayed in Table 2. HCPs indicated several ***benefits for patients***, such as a lower burden of the surveillance (psychological as well as physical and practical) ($N = 19$), lower costs (deductible) ($N = 7$), and a higher confidence of patients in their body due to a low risk for recurrences and therefore not requiring more intensive surveillance ($N = 3$). Named ***benefits for hospitals and HCPs*** were lower burden of surveillance on outpatient clinics and radiology departments ($N = 9$) and effective use of resources ($N = 9$). As ***benefits for patients, hospitals and HCPs***, HCPs mentioned lower costs for hospitals and for society through lower health care insurance costs ($N = 16$) and a reduction of secondary findings and overdiagnosis ($N = 2$). The most mentioned ***perceived barriers for patients*** were possible later detection of recurrences and second primary tumours ($N = 16$) and increased fear and anxiety among patients who are not reassured ($N = 12$). Most named ***perceived barriers for care and HCPs*** were fewer opportunities to evaluate medical practice and care outcomes (including studies) ($N = 5$) and for monitoring of needs for aftercare among patients ($N = 4$). Most brought up ***prerequisites*** were clearly defined surveillance schedules based on risk categories ($N = 17$), information provision and communication support for patients and HCPs containing evidence on surveillance schedules based on risk categories ($N = 14$) and easy access to HCPs in case of worries ($N = 7$).

3.3 | Shared decision making about personalised post-treatment surveillance

Interviewed HCPs indicated that, currently, no SDM about post-treatment surveillance takes place. However, about 71% ($N = 15$) of the interviewed HCPs has a positive attitude towards SDM about post-treatment surveillance. Most mentioned ***reasons for SDM*** were patient empowerment ($N = 11$), patient centred care ($N = 6$) and increased patient satisfaction ($N = 5$). Most mentioned ***reasons against SDM*** were that it could lead to less or more intensive surveillance than deemed necessary by the HCP ($N = 6$); that it costs time ($N = 6$); and that some patients do not want or are not capable enough to participate in decision-making ($N = 6$).

In Table 3, the mentioned prerequisites for SDM about post-treatment surveillance are displayed. The most named ***prerequisites*** were having a framework for options and patient selection for decision-making ($N = 9$); information provision (well-framed) ($N = 8$); and having sufficient time ($N = 3$).

Table 4 shows which information is necessary for patients (according to HCPs) to participate in SDM. These ***information needs*** can be broadly divided into information on the options for (personalised) surveillance ($N = 11$); the nature and risks of the examinations (including radiation) ($N = 11$); the aim of surveillance ($N = 8$);

TABLE 2 Perceived benefits, barriers and prerequisites for less intensive surveillance for women at a low risk for recurrences

Perceived benefits				
Benefits for the patient				
Category	**Subcategory**		***N* (%)**	**Example quote**
Lower burden	Psychological	Less moments of stress and anxiety during imaging, physical examination and while waiting for results	*13 (62%)*	*'You have to go to hospital again. You have to wait for a result in the same room where you were once diagnosed. So it's also a psychological burden'.—P8*
		Less moments of feeling like a patient again	*13 (62%)*	*'In particular, let the patient be less of a patient'.—P14*
		Less moments of stress and anxiety in weeks/days before surveillance	*3 (14%)*	*'A lot of women say … I'm not concerned about it at all until I have my picture taken once a year. So I can imagine that that [less intensive surveillance] might also give a bit of peace of mind'.—P1*
	Physical	Radiation	*13 (62%)*	*'Less radiation for the patient'.—P10*
		Pain and discomfort mammography	*11 (52%)*	*'They do not have to undergo a mammogram, which is often painful. Especially in the operated breast'.—P5*
	Practical	Having to travel to hospital and spend time at hospital	*7 (33%)*	*'Sometimes coming to the hospital is also a burden'.—P13*
		Having to take time off during working hours	*2 (10%)*	*'They have to take a leave of absence for that'.—P3*
	Burden for caregivers		*1 (5%)*	*'Some patients think it's a waste of my time, or a waste of their own time, or that of their informal caregiver'.—P9*
Lower costs	Lower costs for patients (deductible)		*7 (33%)*	*'I do not know how expensive it is to have a consultation. But I can imagine that you do have to pay your deductible. And if you do not have such a high income, that's quite a burden'.—P5*
Confidence in body	Higher confidence of patients in their body due to low risk and not requiring more intensive surveillance		*3 (14%)*	*'Maybe they can also feel that their illness is not so bad, if they do not have to come back so often'.—P15*
Benefits for hospitals and HCPs				
Lower burden	Lower burden surveillance on outpatient clinics and radiology departments		*9 (43%)*	*'It's less burden on the hospital in terms of radiology slots and consultation slots'.—P16*
Efficient care	Effective use of resources and efficient healthcare		*9 (43%)*	*'Like this, you have more room for new patients and other counselling'.—P9*
Benefits for patients, hospitals and HCPs				
Lower costs	Lower costs for hospitals and for society through lower health care insurance costs		*16 (76%)*	*'That healthcare costs will be lower if you do not routinely perform mammograms for everybody each year'.—P19* *'Ultimately, the costs [of the hospital] are passed on to the patient'.—P20*
Reduction secondary findings and overdiagnosis	Reduction of secondary findings and over diagnosis		*2 (10%)*	*'Maybe less often secondary findings that you have to deal with. Things you did not need to know'.—P10*
Perceived barriers				
Barriers for patients				
Category			***N* (%)**	**Example quote**
(Possibly) later detection of recurrences and second primary tumours			*16 (76%)*	*'Early detection would be missing, so that you detect a local recurrence in the early stages and can easily treat it'.—P1*

TABLE 2 (Continued)

Perceived benefits		
Increased fear and anxiety among patients who are not reassured	*12 (57%)*	*'Yes, it can create tension in patients. Like, how do they know that cancer really has not come back if it's not looked at?'—P16*
Barriers for care and HCPs		
Fewer opportunities to evaluate medical practice and care outcomes	*5 (24%)*	*'You may have fewer pictures of the breast itself, so your image of the patient's breast is no longer annual'.—P9*
Fewer opportunities to monitor needs for aftercare among patients	*4 (19%)*	*'That moment when we see people is also linked to that mammogram. And that's where we do often detect anxiety, or relational tension, or intimacy issues that otherwise just do not come up'.—P9*
Higher demand for unstructured care moments in hospital or at GP	*3 (14%)*	*'Maybe people will come more often in between appointments'.—P13*
Fear of legal charges in case of recurrence	*2 (10%)*	*'If you do not properly inform patients in advance and you miss something, you can face legal charges as a clinician'.—P5*
Fear of letting patients go after treatment	*1 (5%)*	*'I think we [HCPs] also find it a little scary to do that [surveillance] right away every two years'.—P7*
Less income for hospitals due to less imaging and consultations	*1 (5%)*	*'The hospital also makes less money from it'.—P1*
Perceived prerequisites		
Category	***N (%)***	**Example quote**
Clearly defined surveillance schedules based on risk categories and scientific substantiation understandable for patients and HCPs	*17 (81%)*	*'You have favorable groups and unfavorable groups. You have to define those groups well and you have to be able to justify why you omit surveillance'.—P11*
Good information provision for patients and communication support for HCPs	*14 (67%)*	*'I think it starts with a good explanation … being able to tell a patient that someone has a low risk of recurrence. And that therefore you can indeed safely omit it [surveillance] then'.—P3*
Low threshold access to HCPs in case of worries or complaints	*7 (33%)*	*'That there is a place where a patient can always go when they have questions'.—P15*
Preparation and training of GPs	*3 (14%)*	*'GPs need to be properly trained, because they do need to know what to be aware of and what to look out for as well'.—P8*
Undiminished attention for aftercare for (late) effects of the breast cancer and treatment	*1 (5%)*	*'I also think about the late effects, we should not forget about those'.—P2*
Monitoring of the impact of less intensive surveillance on detection, type and stage of recurrences	*1 (5%)*	*'Monitor whether we see more frequent recurrences that are at a more advanced stage'.—P15*

alarm signals for recurrences ($N = 8$); the risk for LRRs and second primary tumours ($N = 7$); and information about disease and treatment characteristics ($N = 2$).

Preferences for ***which HCP should guide SDM*** about surveillance and about ***when SDM should take place*** varied strongly between HCPs. However, most HCPs agreed that SDM should take place after the end of active treatment ($N = 12$) so that patients can have a better view on what the decision regarding surveillance entails and have more time to think about which considerations may play a role for them.

TABLE 3 Perceived prerequisites for shared decision-making about post-treatment surveillance after breast cancer

Category	*N* (%)	Example quote
Framework for options and patient selection for decision-making	*9 (43%)*	*'You do have to have a margin or a framework within which you can play around'.—P12*
Information provision (well-framed)	*8 (38%)*	*'You have to provide the patient with sufficient information to be able to participate in the conversation'.—P15*
Time	*3 (14%)*	*'I think … that it will not all work out in the time that's available. That it just takes more time'.—P21*
All steps of the shared decision-making process should be followed	*3 (14%)*	*'You have to tell the patient: There is something to choose, one choice is to do nothing and we are going to decide it together'.—P6*
Attention for motives that can play a role in decision-making, but that can be changed outside of surveillance schedule	*3 (14%)*	*'You have to have questioned the motives and considered together whether you can support them in any way. So if I were to offer pain relief or if I were to offer that the patient would get the results within an hour, instead of three days. Whether it would then be acceptable'.—P10*
Announcing to patient that there will be a decision to make about surveillance early in the care trajectory	*2 (10%)*	*'They need to know what to expect from an early stage'.—P6*
Capacity to participate in decision-making (patient)	*2 (10%)*	*'That means that the patient also has to be able to read and understand things to some extent'.—P6*
Agreements made in decision-making should be reported and clear for team	*2 (10%)*	*'You tell the patient: if there is something wrong, just call, and when the patient calls, the doctor's assistant tells them: go and see your GP, or do this or that'.—P9*
Trust	*1 (5%)*	*'You need trust'.—P2*
Clear starting point for surveillance	*1 (5%)*	*'If you can make a really good starting point, then that patient has the confidence'.—P3*
Patient should bring someone to the consultation	*1 (5%)*	*'Preferably, the patient should bring someone with them to the hospital'.—P6*

3.4 | Use of patients' estimated personal risk for locoregional recurrences in decision-making about personalised surveillance

Most HCPs ($N = 16$) were ***positive*** about the use of patients' estimated personal risk for LRRs (calculated with the INFLUENCE-nomogram) in decision-making about personalised surveillance. One HCP was in doubt because presenting the risk could cause anxiety for patients and for one HCP the preferences for the use of risk information were unclear. One HCP was against the use of risk information, because it might be too confronting for patients.

HCPs that were positive said that it is an important part of information provision and that it helps to make patients more aware of the relatively low risk and potential benefits of surveillance ($N = 9$): *'People frequently overestimate the risk. For that group, it is really good to make it transparent'.—P4*. Furthermore, they mentioned that providing risk information enables patients to participate in shared decision-making about surveillance ($N = 7$) and that it can reassure patients to know that their risk is low ($N = 6$). One HCP mentioned that it can help HCPs to be more aware of the risk for recurrences.

However, HCPs also saw some ***difficulties with the use of risk information***, such as uncertainty of predictions on an individual level which can make risk information feel unpersonal ($N = 8$); that a high risk can be burdensome or too confronting for patients ($N = 6$); doubts about which risks to present (e.g., only the risk for LRRs or also distant metastasis, DM) ($N = 3$); decisional regret in case of a recurrence in case of low risk ($N = 1$); and concerns about the time required for explanation and repetition of the risk information ($N = 1$).

The following aspects were mentioned most often as important ***prerequisites for the use of risk information***: Clear representation and explanation of risk information (with attention to framing and language) ($N = 9$); defined frameworks for risk groups and options for follow-up for these risk groups ($N = 7$); attention to other factors besides risk that play a role decision making (e.g., fear of recurrence and personality) ($N = 6$); and trustworthy risk information ($N = 4$).

TABLE 4 Information needs in shared decision-making about post-treatment surveillance after breast cancer

Category	Subcategory	N (%)	Example quote
Information on the options for (personalised) surveillance (*N* = *11*, *52%*)	Advantages and disadvantages of personalised surveillance checks (frequency, duration)	*5 (24%)*	*'And then you have those kinds of discussions, like, do you really need to have that mammogram every year?'—P18*
	Recurrences are often found by women themselves in between regular surveillance moments/limited added value of surveillance in detecting recurrences	*4 (19%)*	*'And often when a recurrence is found, that patient feels it'.—P6*
	More intensive surveillance is not more effective	*3 (14%)*	*'You have to explain why it can be done once a year or less often'.—P8*
	Early detection is not the most important factor in prognosis when a recurrence occurs	*2 (10%)*	*'Whether you see metastases in your back now or two months from now, it does not matter for the prognosis'.—P2*
Information on the nature and risks of the examinations (including radiation) (*N* = *11*, *52%*)	Which examinations can be used in surveillance? (advantages/disadvantages)	*11 (52%)*	*'You have to explain why not every patient always gets a scan of the whole body, because many patients want that too'.—P7*
	Limited added value of physical examination in detecting recurrences	*2 (10%)*	*'I think people place an undue value on physical examination'.—P3*
Information on alarm signals for recurrences (*N* = *8*, *38%*)	Alarm signals for recurrences and designated contact person	*5 (24%)*	*'With these and these complaints, please contact …'—P8*
	What symptoms can occur, but are not alarm signals for recurrence?	*4 (19%)*	*'That you can give a kind of summary on paper to the patient. These treatments you have had, these could be side effects that you may still experience'.—P16*
	How to perform self-examination	*3 (14%)*	*'And an appendix with instructions on how to self-examine the breast'.—P4*
	It is ok to report your complaints to your health care professional	*2 (10%)*	*'That you can ring the bell in that time in between. That you do not have to wait for your exams'.—P10*
	It is ok to wait 1 week in case of complaints	*1 (5%)*	*'And it is important that people also learn to deal with their own complaints … and sometimes have to wait a few days'.—P7*
Information on the aim of surveillance (*N* = *8*, *38%*)	Surveillance is a momentary measurement	*5 (24%)*	*'Then they have had the result of the mammogram and they are all happy. But of course, it's just a snapshot in time'.—P3*
	Surveillance is not meant for active search for distant metastasis	*4 (19%)*	*'Also about why the rest of the body is not looked at*, i.e. *metastases'.—P1*
	Surveillance does not prevent from recurrences	*4 (19%)*	*'People prefer to have a full body scan every six months. Because they think that by doing so they can prevent [the cancer from coming back]'.—P8*
	Role of different health care professionals during surveillance	*3 (14%)*	*'Who the health professionals are*, i.e. *the contact details of the health professionals and the designated contact person'.—P4*
	Difference between aftercare and surveillance	*1 (5%)*	*'You also have to explain the difference in aftercare and surveillance, so that it is clear to patients'.—P4*
Information on the personal risk for locoregional recurrences and second primary tumours (*N* = *7*, *33%*)	Personal risk for recurrence	*4 (19%)*	*'What I try to tell patients is that the chances of a recurrence of breast cancer is very small'.—P5*
	After 5 years the risk for recurrences still exists	*2 (10%)*	*'Patients often think, oh, I'll stay under surveillance for five years and after those five years, well, then I'll be cured. Or then I cannot get cancer anymore'.—P10*

(Continues)

TABLE 4 (Continued)

Category	Subcategory	N (%)	Example quote
	Amputation of the breast does not mean cancer cannot recur locally	1 (5%)	*'Some think, if I get my breast removed, I will not get anything back at all'.—P2*
Information about disease and treatment characteristics (N = 2, 10%)	Information about disease and treatment characteristics	2 (10%)	*'To give an insight into the results of all diagnostic tests, of the procedures and treatments that have been carried out'.—P4*

HCPs indicated that risk information is currently mostly used by medical oncologists to decide about (neo-) adjuvant systemic therapy, but not yet for decisions about post treatment surveillance. Medical oncologists mostly used Predict (Wishart et al., 2012), a prediction tool, to estimate risk information. The three most mentioned ***best practices for the use of risk information in decision-making*** were filling in the prediction model in the presence of patients and explaining risk factors and parameters ($N = 8$); translating statistical data to the situation of the patients (concretizing) ($N = 5$); and explaining the uncertainty of prediction on an individual level ($N = 5$).

4 | DISCUSSION

This study examined HCPs perspectives on less intensive surveillance for women with a low risk for recurrences, attitudes towards shared decision-making about surveillance, and perspectives on the use of patients' estimated personal risk for LRRs in shared decision-making about surveillance.

Most HCPs do recognise the need for personalised surveillance and are open to less intensive surveillance for patients with a low risk for recurrences. Since surveillance also comes with individual costs such as increased burden and anxiety and societal costs, the benefit–cost ratio can be different for different risk groups. A simulation study by Draeger et al. (2020) has shown that a considerable reduction of clinical visits and associated costs could be achieved when applying a risk-based strategy for surveillance after breast cancer, for example, by using the INFLUENCE-nomogram for risk estimations (Draeger et al., 2020). This would lower the burden of surveillance for patients, health care institutions and HCPs.

In this study we identified important prerequisites for less intensive surveillance for patients with a low risk for recurrences. One of the important prerequisites that were mentioned was a low threshold for access to HCPs in case of worries or complaints. Another prerequisite was undiminished attention for aftercare for consequences of the breast cancer and treatment. In case of less intensive surveillance, aftercare should be organised in a more flexible manner (Davies & Batehup, 2011). A more patient-led, open access or GP-led approach for aftercare could be an example of flexible aftercare. Open access follow-up has shown to be a feasible alternative to routinised hospital-based follow-up in a study by Kirshbaum et al. (2017). Another alternative would be to implement regular monitoring of relevant patient reported outcomes (PROs) to monitor and address patients' needs when necessary (Riis et al., 2019). This approach is also being explored in colorectal- and ovarian cancer populations (Kargo et al., 2021; Kotronoulas et al., 2017).

Currently, no SDM takes place about post-treatment surveillance (Ankersmid et al., 2022). The majority of HCPs indicate to be open for SDM about this surveillance in clinical practice. Yet, we need to address information needs and existing misconceptions in order for patients and HCPs to participate in SDM. These results are in line with findings in other studies with patients, in which patients indicated that they do not feel informed enough to participate in (shared) decision-making about surveillance (Ankersmid et al., 2022; Brandzel et al., 2017). In the current study, we identified a range of topics that are important to address in the process of SDM according to HCPs, such as information on the aim and options for surveillance and the advantages and disadvantages of these options; and information on alarm signals and risk for recurrences.

One way to address these information needs in a structural manner is through a patient decision aid (PtDA). PtDAs are evidence-based tools designed to help patients make specific and deliberated choices among healthcare options (Stacey et al., 2017). Currently, there is one PtDA available for aftercare (Klaassen, Dirksen, Boersma, Hoving, Portz, et al., 2018). However, this PtDA does not explicitly separate aftercare from surveillance which makes it hard to personalise these two types of care during follow-up. Furthermore, it does not inform patients about their personal risk for recurrences. This information is essential for patients to put the added value of surveillance into context (Janz et al., 2017).

The majority of HCPs were open for the use of information on the personal risk for recurrences in decision-making about post-treatment surveillance. This is in line with the developments in oncology as risk calculations are increasingly used to guide shared decision-making (Engelhardt et al., 2014, 2015). However, to our knowledge, no studies have examined the use of risk calculations in decision-making about surveillance before. HCPs indicate some important prerequisites. One point that HCPs were hesitant about was on whether or not risks for DM should also be provided next to the risk for LRRs. However, post-treatment surveillance is not primarily aimed at detection of DM as active surveillance for DM does not increase overall survival (NABON, 2012). It is therefore important to inform patients and HCPs clearly about the aim of surveillance and to emphasise the importance of self-examination and empower patients to be aware of their own body.

Other types of outcome information could further enrich the process of SDM about post-treatment surveillance, for example, information about the extent to which patients experience fear of recurrence

(FCR) and cancer worries after treatment. Research shows that many patients experience FCR after treatment and that the levels of FCR can fluctuate over time (Custers et al., 2020; Willems et al., 2016). Other studies among patients show that FCR could play an important role in experiences with and therefore preferences for surveillance (Brandzel et al., 2017). Providing patients with outcome information on FCR on a $N = 1$ or aggregated level can help to put into perspective the level of FCR of that individual patients experience and its' relation with her preferences for surveillance. Furthermore, discussing FCR more structurally can help in advising patients with high levels of FCR on managing their worries or referral to suitable (existing) interventions or supportive care.

4.1 | Strengths and limitations

To our knowledge this is the first study that examines HCP perspectives on less intensive surveillance for women with a low risk for recurrences, attitudes towards SDM about surveillance and perspectives on the use of patients' estimated personal risk for LRRs in decision-making about surveillance. A strength is that we have interviewed a relatively homogenous group of participants in terms of their specialism, as most of the participants were SOs or NPs of the surgery department. Another strength is that we have interviewed HCPs in Santeon teaching hospitals with dedicated breast centres. This study also has limitations. First, even though we made the separation between surveillance and aftercare, in current practice these concepts are intertwined. That's why sometimes it remained difficult to address surveillance as a separate topic. Second, although it is plausible that similar identified topics apply to other settings such as (types of) hospitals or countries, the results of the study may not be completely generalisable to breast centres in other countries. Finally, although this study provided insight into a range of topics that HCPs find important in SDM about personalised surveillance, it is important to perform more research using a more quantitative approach to get insight into the percentage of HCPs with a certain point of view and to explore possible causes for variation. A large-scale survey could be fit for this purpose.

4.2 | Implications for practice

Through this study, we learned about the perceived advantages and disadvantages about less intensive surveillance; we identified implications of and prerequisites for shared decision making about personalised post-treatment surveillance; and we explored HCPs perspectives on the use of information on patients' estimated personal risk for LRRs in SDM. Currently, we are using this knowledge in combination with the knowledge we have acquired on the informational needs of patients and HCPs to develop a tool and a multi-component implementation strategy to support the process of SDM about post-treatment surveillance.

4.3 | Conclusion

Prerequisites such as clearly defined surveillance schedules based on risk categories, good information provision and low threshold access to HCPs need to be fulfilled when implementing less intensive surveillance for patients with a low risk for recurrences. SDM about post-treatment surveillance is desired by HCPs. However, information needs and existing misconceptions need to be addressed to enable patients to participate in SDM. Outcome information regarding the personal risk and fear for recurrence can enrich the SDM process about surveillance.

ACKNOWLEDGEMENTS

We would like to thank the health care professionals that have participated in this research for their meaningful contributions. Open access funding enabled and organized by Projekt DEAL.

CONFLICT OF INTEREST

Jet W. Ankersmid, Constance H. C. Drossaert, Luc J. A. Strobbe, Melissa S. Battjes, Cornelia F. van Uden-Kraan and Sabine Siesling certify that they have no affiliations with or involvement in any organisation or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

AUTHOR CONTRIBUTIONS

Jet W. Ankersmid: conceptualisation, methodology, formal analysis, investigation, writing—original draft, writing—review & editing; **Constance H. C. Drossaert:** conceptualisation, methodology, formal analysis, writing—original draft, writing—review & editing; **Luc J. A. Strobbe:** conceptualisation, methodology, resources, writing—review & editing; **Melissa S. Battjes:** formal analysis; **Cornelia F. van Uden-Kraan:** supervision, writing—review & editing; **Sabine Siesling:** conceptualisation, methodology, supervision, writing—review & editing.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

STATEMENT ON PERSONAL DETAILS

We confirm that all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

ORCID

Jet W. Ankersmid https://orcid.org/0000-0002-4562-8147
Constance H. C. Drossaert https://orcid.org/0000-0002-7083-3169
Cornelia F. van Uden-Kraan https://orcid.org/0000-0002-3898-416X
Sabine Siesling https://orcid.org/0000-0002-0273-824X

REFERENCES

Ankersmid, J. W., Hoeve, J. C. v., Strobbe, L. J. A., Riet, Y. E. A. v., Uden-Kraan, C. F. v., Siesling, S., & Drossaert, C. H. C. (2021). Follow-up after breast cancer: Variations, best practices, and opportunities for improvement according to health care professionals. *European Journal of Cancer Care*, *30*(6), e13505. https://doi.org/10.1111/ECC.13505

Ankersmid, J. W., Drossaert, C. H. C., van Riet, Y. E. A., Strobbe, L. J. A., & Siesling, S. (2022). Needs and preferences of breast cancer survivors regarding outcome-based shared decision-making about personalised post-treatment surveillance. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-022-01178-z

Brandzel, S., Rosenberg, D. E., Johnson, D., Bush, M., Kerlikowske, K., Onega, T., Henderson, L., Nekhlyudov, L., DeMartini, W., & Wernli, K. J. (2017). Women's experiences and preferences regarding breast imaging after completing breast cancer treatment. *Patient Preference and Adherence*, *11*, 199–204. https://doi.org/10.2147/PPA.S122244

Custers, J. A. E., Kwakkenbos, L., van der Graaf, W. T. A., Prins, J. B., Gielissen, M. F. M., & Thewes, B. (2020). Not as Stable as We Think: A Descriptive Study of 12 Monthly Assessments of Fear of Cancer Recurrence Among Curatively-Treated Breast Cancer Survivors 0–5 Years After Surgery. *Frontiers in Psychology*, *11*. https://doi.org/10.3389/fpsyg.2020.580979

Davies, N. J., & Batehup, L. (2011). Towards a personalised approach to aftercare: A review of cancer follow-up in the UK. *Journal of Cancer Survivorship*, *5*, 142–151. https://doi.org/10.1007/s11764-010-0165-3

de Ligt, K. M., van Egdom, L. S. E., Koppert, L. B., Siesling, S., & van Til, J. A. (2019). Opportunities for personalised follow-up care among patients with breast cancer: A scoping review to identify preference-sensitive decisions. *European Journal of Cancer Care*, *28*(3). https://doi.org/10.1111/ecc.13092

Draeger, T., Voelkel, V., Groothuis-Oudshoorn, C. G. M., Lavric, M., Veltman, J., Dassen, A., Boersma, L. J., Witteveen, A., Sonke, G. S., Koffijberg, H., & Siesling, S. (2020). Applying risk-based follow-up strategies on the Dutch breast Cancer population: Consequences for care and costs. *Value in Health*, *23*(9), 1149–1156. https://doi.org/10.1016/j.jval.2020.05.012

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., … van der Weijden, T. (2017). A three-talk model for shared decision making: Multistage consultation process. *BMJ (Online)*, *359*, 1–7. https://doi.org/10.1136/bmj.j4891

Engelhardt, E. G., Garvelink, M. M., De Haes, J. C. J. M., Van Der Hoeven, J. J. M., Smets, E. M. A., Pieterse, A. H., & Stiggelbout, A. M. (2014). Predicting and communicating the risk of recurrence and death in women with early-stage breast cancer: A systematic review of risk prediction models. *Journal of Clinical Oncology*, *32*, 238–250. https://doi.org/10.1200/JCO.2013.50.3417

Engelhardt, E. G., Pieterse, A. H., Van Duijn-Bakker, N., Kroep, J. R., De Haes, H. C. J. M., Smets, E. M. A., & Stiggelbout, A. M. (2015). Breast cancer specialists views on and use of risk prediction models in clinical practice: A mixed methods approach. *Acta Oncologica*, *54*, 361–367. https://doi.org/10.3109/0284186X.2014.964810

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 117. https://doi.org/10.1186/1471-2288-13-117

Geurts, Y. M., Witteveen, A., Bretveld, R., Poortmans, P. M., Sonke, G. S., Strobbe, L. J. A., & Siesling, S. (2017). Patterns and predictors of first and subsequent recurrence in women with early breast cancer. *Breast Cancer Research and Treatment*, *165*(3), 709–720. https://doi.org/10.1007/s10549-017-4340-3

Høeg, B. L., Bidstrup, P. E., Karlsen, R. V., Friberg, A. S., Albieri, V., Dalton, S. O., Saltbæk, L., Andersen, K. K., Horsboel, T. A., & Johansen, C. (2019). Follow-up strategies following completion of primary cancer treatment in adult cancer survivors. *Cochrane Database of Systematic Reviews*, *2019*(11). https://doi.org/10.1002/14651858.CD012425.pub2

Janz, N. K., Li, Y., Zikmund-Fisher, B. J., Jagsi, R., Kurian, A. W., An, L. C., McLeod, M., Lee, K. L., Katz, S. J., & Hawley, S. T. (2017). The impact of doctor–patient communication on patients perceptions of their risk of breast cancer recurrence. *Breast Cancer Research and Treatment*, *161*(3), 525–535. https://doi.org/10.1007/s10549-016-4076-5

Kargo, A. S., Jensen, P. T., Lindemann, K., Hjollund, N. H. I., Lund, B., Haee, M., Möller, S., Hansen, D. G., & Dahl Steffensen, K. (2021). The PROMova study comparing active and passive use of patient-reported outcome measures in ovarian cancer follow-up: Effect on patient-perceived involvement, satisfaction with care, and usefulness. *Acta Oncologica*, *60*(4), 434–443. https://doi.org/10.1080/0284186X.2021.1891281

Kirshbaum, M. N., Dent, J., Stephenson, J., Topping, A. E., Allinson, V., McCoy, M., & Brayford, S. (2017). Open access follow-up care for early breast cancer: A randomised controlled quality of life analysis. *European Journal of Cancer Care*, *26*(4), 1–9. https://doi.org/10.1111/ecc.12577

Klaassen, L. A., Dirksen, C. D., Boersma, L. J., Hoving, C., Portz, M. J. G., Mertens, P. M. G., Janssen-Engelen, I. L. E., Lenssen, A. M. M. R. N., Marais, M. B. ChB., Starren-Goessens, C. M. J., Kurris, F., Degenaar, A., & van Lierop, K. (2018). A novel patient decision aid for aftercare in breast cancer patients: A promising tool to reduce costs by individualizing aftercare. *The Breast*, *41*, 144–150. https://doi.org/10.1016/j.breast.2018.06.015

Klaassen, L., Dirksen, C., Boersma, L., & Hoving, C. (2018). Developing an aftercare decision aid; assessing health professionals and patients preferences. *European Journal of Cancer Care*, *27*(2), e12730. https://doi.org/10.1111/ecc.12730

Kotronoulas, G., Papadopoulou, C., MacNicol, L., Simpson, M., & Maguire, R. (2017). Feasibility and acceptability of the use of patient-reported outcome measures (PROMs) in the delivery of nurse-led supportive care to people with colorectal cancer. *European Journal of Oncology Nursing*, *29*, 115–124. https://doi.org/10.1016/j.ejon.2017.06.002

Lafranconi, A., Pylkkänen, L., Deandrea, S., Bramesfeld, A., Lerda, D., Neamțiu, L., Saz-Parkinson, Z., Posso, M., Rigau, D., Sola, I., Alonso-Coello, P., & Martinez-Zapata, M. J. (2017). Intensive follow-up for women with breast cancer: Review of clinical, economic and patients preference domains through evidence to decision framework. *Health and Quality of Life Outcomes*, *15*(1), 1–18. https://doi.org/10.1186/s12955-017-0779-5

Moschetti, I., Cinquini, M., Lambertini, M., Levaggi, A., & Liberati, A. (2016). Follow-up strategies for women treated for early breast cancer. *Cochrane Database of Systematic Reviews*, *2016*(5). https://doi.org/10.1002/14651858.CD001768.pub3

NABON. (2012). Breast cancer. *Dutch Guideline*, *version 2.0*.

Riis, C. L., Bechmann, T., Jensen, P. T., Coulter, A., & Steffensen, K. D. (2019). Are patient-reported outcomes useful in post-treatment follow-up care for women with early breast cancer? A scoping review. *Patient Related Outcome Measures*, *10*, 117–127. https://doi.org/10.2147/prom.s195296

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, *4*(4). https://doi.org/10.1002/14651858.CD001431.pub5

Stiggelbout, A. M., van der Weijden, T., de Wit, M. P., Frosch, D., Légaré, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: Really putting patients at the Centre of healthcare. *BMJ (Online)*, *344*(7842), 1–6. https://doi.org/10.1136/bmj.e256

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. J. M. (2015). Shared decision making: Concepts, evidence, and practice. *Patient Education and Counseling*, *98*(10), 1172–1179. https://doi.org/10.1016/J.PEC.2015.06.022

Voelkel, V., Draeger, T., Groothuis-Oudshoorn, C. G. M., de Munck, L., Hueting, T., Gerken, M., Klinkhammer-Schalke, M., Lavric, M., & Siesling, S. (2019). Predicting the risk of locoregional recurrence after early breast cancer: An external validation of the Dutch INFLUENCE-nomogram with clinical cancer registry data from Germany. *Journal of Cancer Research and Clinical Oncology*, *145*(7), 1823–1833. https://doi.org/10.1007/s00432-019-02904-4

Völkel, V., Hueting, T. A., Draeger, T., van Maaren, M. C., de Munck, L., Strobbe, L. J. A., Sonke, G. S., Schmidt, M. K., van Hezewijk, M., Groothuis-Oudshoorn, C. G. M., & Siesling, S. (2021). Improved risk estimation of locoregional recurrence, secondary contralateral tumors and distant metastases in early breast cancer: The INFLUENCE 2.0 model. *Breast Cancer Research and Treatment*, *189*(3), 817–826. https://doi.org/10.1007/s10549-021-06335-z

Weller, S. C., Vickers, B., Bernard, H. R., Blackburn, A. M., Borgatti, S., Gravlee, C. C., & Johnson, J. C. (2018). Open-ended interview questions and saturation. *PLoS ONE*, *13*(6), e0198606. https://doi.org/10.1371/JOURNAL.PONE.0198606

Willems, R. A., Bolman, C. A. W., Mesters, I., Kanera, I. M., Beaulen, A. A. J. M., & Lechner, L. (2016). Cancer survivors in the first year after treatment: The prevalence and correlates of unmet needs in different domains. *Psycho-Oncology*, *25*(1), 51–57. https://doi.org/10.1002/pon.3870

Wishart, G. C., Bajdik, C. D., Dicks, E., Provenzano, E., Schmidt, M. K., Sherman, M., … Pharoah, P. D. (2012). PREDICT plus: Development and validation of a prognostic model for early breast cancer that includes HER2. *British Journal of Cancer*, *107*(5), 800–807. https://doi.org/10.1038/bjc.2012.338

Witteveen, A., Vliegen, I. M. H., Sonke, G. S., Klaase, J. M., IJzerman, M. J., & Siesling, S. (2015). Personalisation of breast cancer follow-up: A time-dependent prognostic nomogram for the estimation of annual risk of locoregional recurrence in early breast cancer patients. *Breast Cancer Research and Treatment*, *152*(3), 627–636. https://doi.org/10.1007/s10549-015-3490-4

Witteveen, A., de Munck, L., Groothuis-Oudshoorn, C. G. M., Sonke, G. S., Poortmans, P. M., Boersma, L. J., Smidt, M. L., Vliegen, I. M. H., IJzerman, M. J., & Siesling, S. (2020). Evaluating the age-based recommendations for long-term follow-up in breast Cancer. *The Oncologist*, *25*(9), e1330–e1338. https://doi.org/10.1634/THEONCOLOGIST.2019-0973

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Ankersmid, J. W., Drossaert, C. H. C., Strobbe, L. J. A., Battjes, M. S., van Uden-Kraan, C. F., Siesling, S., & on behalf of the Santeon VBHC Breast Cancer Group (2022). Health care professionals' perspectives on shared decision making supported by personalised-risk-for-recurrences-calculations regarding surveillance after breast cancer. *European Journal of Cancer Care*, *31*(5), e13623. https://doi.org/10.1111/ecc.13623

APPENDIX A

The Santeon VBHC Breast Cancer Group (collaborators) are Y.E.A. van Riet and J.M. Bode-Meulepas, Catharina Hospital, Eindhoven, The Netherlands; L.J.A. Strobbe, Canisius Wilhelmina Hospital, Nijmegen, The Netherlands; A.E. Dassen, Medisch Spectrum Twente, Enschede, The Netherlands; A.F.T. Olieman, Martini Hospital, Groningen, The Netherlands; H.H.G. Witjes, OLVG, Amsterdam, The Netherlands; A. Doeksen, St. Antonius Hospital, Utrecht, The Netherlands; C.M.E. Contant, Maasstad Hospital, Rotterdam, The Netherlands.