From predictions to practice: value of prediction models for personalised sarcoma care

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Chapter 4

Understanding how a personalised risk prediction tool (VALUE-PERSARC) supports informed treatment decisions of soft-tissue sarcomas patients in daily clinical practice – a mixed methods study

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Abstract

Introduction

Risk prediction models (RPM) can help soft-tissue sarcoma(STS) patients and clinicians make informed treatment decisions by providing them with estimates of (disease-free) survival for different treatment options. However, it is unknown how RPMs are used in the clinical encounter to support decision-making. This study aimed to understand how a PERsonalised SARcoma Care (PERSARC) RPM is used to support treatment decisions and which barriers and facilitators influence its use in daily clinical practice.

Methods

A convergent mixed-methods design is used to understand how PERSARC is integrated in the clinical encounter in three Dutch sarcoma centers. Data were collected using qualitative interviews with STS patients(n=15) and clinicians(n=8), quantitative surveys (n=50) and audiotaped consultations (n=30). Qualitative data were analyzed using thematic analysis and integrated with quantitative data through merging guided by the SEIPS model.

Results

PERSARC was generally used to support clinicians' proposed treatment plan and not to help patients weigh available treatment options. Use of PERSARC in decision-making was hampered by clinician's doubts about whether there were multiple viable treatment options, the accuracy of risk estimates, and time constraints. On the other hand, use of PERSARC facilitated clinicians to estimate and communicate the expected benefit of adjuvant therapy to patients.

Conclusion

PERSARC was not used to support informed treatment decision-making in STS patients. Integrating RPMs into clinical consultations requires acknowledgement of their benefits in facilitating clinicians' estimation of the expected benefit of adjuvant therapies and information provision to patients, while also considering concerns regarding RPM quality and treatment options' viability.

Introduction

Soft-tissue sarcomas (STS) are a rare and heterogeneous group of malignant neoplasms, with more than 100 histological subtypes [1]. They arise from mesenchymal cells and account for 1% of all adult malignancies [2]. STS may occur at every age and almost any anatomical site, but predominantly manifest in the extremities and trunk wall [3]. Treatment for aggressive and infiltrating (high-grade) extremity STS typically involves a combination of surgery and/or (neo)adjuvant radiotherapy. Each treatment modality has distinct advantages and risks. As none of the options are clearly superior from a medical perspective, a subjective trade-off needs to be made driven by patients' informed preferences.

Recent literature underscores the complexity of treatment decision-making for individual STS patients, especially the weighing of risks and benefits, and emphasizes the pivotal role of decision-support interventions to facilitate informed decision-making and reduce decisional conflict [4-6]. Therefore, our research group developed and validated a personalised risk prediction tool (Personalised Sarcoma Care: PERSARC) [7, 8]. This tool provides patients and clinicians insight into the personalised risks and benefits of each treatment option based on patient's age, tumour size, tumour depth and histology to support their decision-making process.

Risk Prediction Models (RPMs) like PERSARC seem well suited to effectively support decision-making during clinical encounters. Patients' goals and preferences for treatment vary widely, and RPMs provide individualised risks and benefits of treatment, which may help patients to weigh the treatment options and thereby engage them in the decision-making process [9, 10]. Providing patients with individualised information from RPMs can thus be a first step towards informed treatment decisions that are better aligned with patients' values and goals, thereby reducing decisional conflict, if RPMs are used as intended. However, most studies have focused on the development and validation of RPMs, but the extent to which and how RPMs are used in routine clinical practice remains largely unknown, which is crucial to interpret if and how their use impacts treatment decision-making [11, 12]. Therefore, the present study aims to understand how a personalised RPM (PERSARC) is used to support treatment decisions as well as to identify barriers and facilitators in clinical practice.

Methods

Study design

A convergent mixed-methods design was used to understand the use of PERSARC in the patient-clinician encounters and the factors influencing its use. Quantitative data assessed the extent to which PERSARC was used, while qualitative data added insights into why and

how PERSARC was or was not used. This study is embedded within the VALUE-PERSARC study, a pragmatic parallel cluster randomized trial that has been described elsewhere [13]. Briefly, the VALUE-PERSARC study evaluates the (cost-)effectiveness of PERSARC implementation in three intervention hospitals on knowledge and decisional conflict among STS patients relative to patients receiving care-as-usual in control hospitals. The VALUE-PERSARC study aims to include at least 120 patients aged ≥18 years with high-grade extremity STS treated between August 2021 and June 2024 in six tertiary referral centers. Clinicians in intervention hospitals use the VALUE-PERSARC app that incorporates the PERSARC RPM in patient-clinician encounters (Supplementary file 4), which could also be accessed by clinicians through a web browser. The present study, therefore, only includes patients and clinicians from the three intervention hospitals to evaluate the integration of PERSARC in clinical consultations. Figure 1 shows a description of the patient-clinician encounter where PERSARC is used to discuss treatment options.

The Medical Ethical Committee Leiden-Den Haag-Delft (METC-LDD) and five other participating Dutch sarcoma centers approved all study procedures (NL76563.058.21). The VALUE-PERSARC study was registered on 8 January 2021 in the Netherlands Trial Register (NL9160) and updated in ClincicalTrials.gov (NCT05741944).

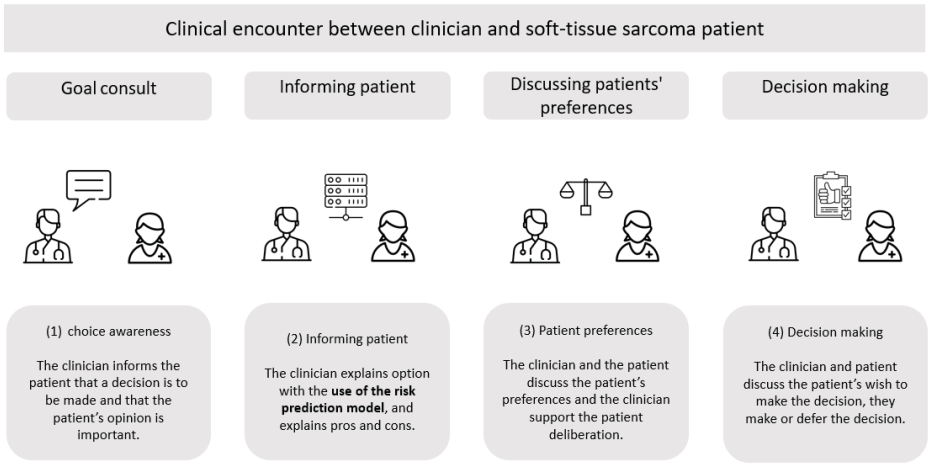

Figure 1. Components of clinical encounters between clinicians and soft-tissue sarcoma patients with the use of the PERSARC risk prediction tool.

Theoretical framework

We used the SEIPS 101 (System Engineering Initiative for Patients Safety) as the theoretical framework to understand the use of the PERSARC RPM in the patient-clinician encounters [14, 15]. SEIPS 101 is a simple practice-oriented model that explores interactions between

humans, the technology they use and the environment in which they work, and has been successfully applied across healthcare [16-20]. Both the qualitative and quantitative data were categorized according to the four elements of the SEIPS model to enable merging of insights derived from these data sources: 1) people (i.e., patients' and clinicians' attitudes towards and beliefs regarding the RPM), 2) environment (i.e., issues related to embedding the RPM in clinical workflows), 3) technology/tools (i.e., issues related to the software's usability or design of the app) and 4) tasks (i.e., actual use of the RPM in patient-clinician encounters).

Data collection

Quantitative data were collected to assess the extent to which PERSARC was used in clinical consultations, for which 3 data sources were used: audiotaped consultations, checklist filled in by clinicians and satisfaction surveys from both patients and clinicians (Table 1).

Audiotapes. The VALUEPERSARC app can be used to audio record patient consultations. Recording of the patient consultation is not mandatory, and is requested separately when patients register in the VALUE-PERSARC app. We used transcripts of the audiotaped consultations to 1) ascertain whether PERSARC was used by clinicians to support information provision about available treatment options (including their risks and benefits) and 2) evaluate the extent to which clinicians involved patients in the decision-making process. The coding scheme (Supplementary file 1) was developed by the VALUE-PERSARC research team, and was based on a 4-step model to make informed and value congruent medical decisions described by Stiggelbout and colleagues (i.e., creating choice awareness, information provision, discussing preferences, and decision-making)[21].

Checklist clinicians. After each consultation, clinicians were asked to complete a checklist to indicate whether they had used PERSARC during: a) the multidisciplinary tumour board meeting in which the patients was discussed, and b) the consultations with the patient. Clinicians received the checklist (Supplementary file 2) by email immediately after each patient consultation, with reminders sent after one week.

Satisfaction survey patients and clinicians. We evaluated satisfaction with the use of PERSARC using a self-developed questionnaire sent to all included patients and their clinicians, with reminders send after one week. The questionnaire consists of three short questions about the usefulness of PERSARC in a consultation, its helpfulness in the decision-making process and intentions for future use (Supplementary file 3).

Qualitative data were gathered to get a more in-depth understanding of patients' and clinicians' experiences with the integration of PERSARC in clinical practice and to identify

barriers and facilitators influencing its use in treatment decision-making processes, for which interviews were conducted with patients and clinicians and field notes were taken.

Interviews. Fifteen randomly selected STS patients and five clinicians treating STS patients (at least one per intervention hospital) were interviewed by two members of the research team (AK, LV) using a 16-item interview scheme. The interview scheme was developed by the research team (AK, LvB, EE) and guided by the SEIPS model [14] (Supplementary file 4).

Field notes. Field notes were made by the primary researcher (AK) during the observations of consultations. Additionally, throughout the study duration, notes were taken following contacts with clinicians (e.g., regarding patient inclusion) and patients (e.g., if assistance was needed with app installation or completion of study questionnaires). Field notes were used to contextualize quantitative and qualitative findings.

Table 1. Sources and data collection methods

	Quantitative			**Qualitative**	
	Audiotapes of consultation	***Checklist***	***Survey***	***Interviews***	***Field notes***
People					
Patients			Satisfaction with use of PERSARC	Perceived added value and usefulness PERSARC	Contextualize findings
Clinicians			Satisfaction with use of PERSARC	Perceived added value and usefulness PERSARC	
Environmental		Use PERSARC in MTB and consultation		Barriers and facilitators for embedding PERSARC in consultation	Contextualize findings
Tool/technology				Barriers and facilitators of app / software	Contextualize findings
Task-related	Use PERSARC in consultation, Patient involvement			Use PERSARC in consultation, Patient involvement	

**People Environment Tools Tasks (PETT) scan as derived from the SEIPS 101 model.*

Data analysis

Quantitative

The audio-recordings of patient-clinician encounters were transcribed verbatim and assessed by two reviewers (AK, LV) using the Observing Patient Involvement in Decision Making 5-item (OPTION-5) scale (score range, 0-100, with 0 indicating minimal behavior and 100 indicating maximal behavior) to code clinicians behavior to involve patients in decision-making [22]. Additionally, transcripts of recordings were independently reviewed to assess the extent to which PERSARC was used during the encounter. This included identifying the treatment options discussed (surgery, pre -or post operative radiotherapy), along with their benefits and risks using a predefined coding scheme (Supplementary file 1). Discrepancies were discussed until consensus was reached.

All quantitative data (i.e., the audiotapes, checklists by clinicians and surveys from patients and clinicians) were analyzed using descriptive statistics with IBM SPSS version 29.

Qualitative

Interviews with patients and clinicians were audio-recorded and transcribed verbatim. Transcripts of interviews were analysed by two researchers (AK, LV) independently using a combined approach of inductive and deductive thematic analysis [23]. Discrepancies in coding were resolved through consensus. Qualitative data analyses were performed using ATLAS.ti (v24) software.

Field notes were independently reviewed (AK, LV), and utterances were assigned to themes that emerged from the data. The researchers discussed the manner in which the data fitted in the themes to reach joint consensus.

Data integration

The results of the quantitative and qualitative analysis were integrated through merging. That is, the results were compared for each of the SEIPS model elements to assess how they confirmed, expanded or contradicted each other and to draw meta-interferences about how and why PERSARC was used in daily clinical practice to support treatment decisions [24, 25]. To merge the results, quantitative and qualitative themes were compared simultaneously in a back-and-forth process framed by the elements of SEIPS [26]. Joint display analysis was used to integrate the quantitative and qualitative data by constructing and reconstructing them to achieve a fuller understanding of both [27]. The final joint displays are presented in the results section and quotes from interviews and consultations will be provided for illustration.

Results

In total, data were collected from 50 patients and 8 clinicians in three tertiary sarcoma referral centers (Table 2). Median age of patients was 63 (IQR 51-72) years and 52% were male. Thirty audio-recorded clinical encounters (median duration: 17(SD 6 min)) were made. Thirty-eight clinicians completed the checklist on PERSARC use after the consultations as well as the clinicians survey. Fifteen patients and five clinicians were interviewed.

Table 2. Number of observed patients-, clinicians and clinical encounters using an individualised risk prediction tool (PERSARC)

	Quantitative				**Qualitative**	
	Audiotapes of consultation	***Checklist***	***Survey***		***Interviews***	
	+mean duration		*Clinician*	*Patients*	*Clinician*	*Patients*
Center 1	18 19(6)	20	20	26	3	5
Center 2	12 14(5)	15	15	19	1	8
Center 3	-	3	3	5	1	2
Total	30 16(6)	38	38	50	5	15

For each of the elements of the SEIPS model, we describe the results from the different data sources and how they were integrated.

Task-related

Observations from the audio-taped consultations showed that PERSARC was used in nearly all clinical encounters (27/30), and in most of these was used to mentioned more than one treatment option (26/30) (Table 3). However, the risks associated with treatment were not always graphically shown for more than one treatment option (12/30) or only one of the outcomes was discussed (i.e., the overall survival or local recurrence rates). The interviews expanded on these findings, showing how clinicians regularly implicitly steered towards a particular treatment option by emphasizing the side effects of the treatment option that they felt was not preferred (C: *“And, of course, as a doctor, I can be quite firm, saying: "Listen, I have this option and this one, but we're going with this". You can certainly steer as a doctor. It's just a matter of how you sell that car, or which cars you choose to showcase in your showroom, so to speak” (C1)).* Clinicians’ effort to involve patients in the clinical encounter, measured with the OPTION-5, achieved a median score of 15 (5-21) out of 100. Patients’ preferences were elicited in 4 out of 30 encounters. In most cases the treatment decision was unilaterally made by the clinician (21/30), and seldom in consultation with the patient (6/30). This contradicts the results from the interviews in which clinicians stated that they perceived patients were more engaged in the decision-making process when using PERSARC.

Table 3. Joint display of task-related factors influencing the use of PERSARC in consultation

	Quantitative results		**Qualitative results**	**Mixed method meta-inferences**
Use of PERSARC in treatment decision processes	Audiotapes of consultation Tasks clinician for informed decision-making using PERSARC (according to researchers)	*Consultations (N)*	Interviews ▼Clinician only discussed one treatment option or did not show OS/LR graphically or explained treatment side-effects.	▲*Expansion* Interviews revealed that clinicians choose *which* treatment options to discuss and *how* the option(s) are presented which expanded on the results of audiotaped consultation showing that PERSARC is only partly used as intended.
	Creating choice awareness	5/30	*Q: Do you also show the figures? Or do you only mention the OS/LR numbers?* *A: I mention the numbers. I haven't shown the figures because then I have to log in again and show everything separately. That would take too much time.."(C5)*	
	Use of RPM during clinical encounter	27/30*		
	No. Treatment options discussed with the use of RPM			
	• 1	1/30		
	• 2 or more	26/30		
	Type of treatment options discussed			
	noRT	29/30	▼Implicit steering towards a particular treatment option	
	• pre-operative RT	30/30		
	• post-operative RT	17/30	C: *"And, of course, as a doctor, I can be quite firm, saying: "Listen, I have this option and this one, but we're going with this". You can certainly steer as a doctor. It's just a matter of how you sell that car, or which cars you choose to showcase in your showroom, so to speak." (C1)*	
	Risks graphically shown with PERSARC no. of treatment options			
	• 1	14/30		
	• 2 or more	12/30		
	Explanation of input variables used in PERSARC	22/30		
Patient involvement	Benefits and harms of treatment options discussed		Interviews	▼*Contradiction* The low OPTION-5 scores accompanied by treatment decisions primarily made by clinicians are contradicted with the qualitative finding that clinicians perceived patients as more involved in decision-making process.
	• No	7/30		
	• Yes, implicitly	5/30		
	• Yes, explicitly	18/30		
	Clinician elucidated patient's preferences	4/30	▲ Clinicians perceived patients as more engaged in the decision-making process.	
	Treatment decision made by:			
	• Patient	3/30	*"I find that discussion important and it is supported by PERSARC. And I think it's good to discuss those numbers with the patient. Strangely enough, sometimes the patient makes a different decision than I would expect. But that's the beauty of it, at least you can indicate a number to some extent, and that leads to different conclusions from different people." (C5)*	
	• Patient and Clinician (Shared decision)	0/30		
	• Clinician	27/30		
	Treatment decision determined prior to consultation	15/30		
	Patient involvement (OPTION-5) mean+SD	17±14		

▼ *Barrier* ▲ *Facilitator* *In three cases, only one LR/OS estimate was mentioned and not visually shown, without further explanation, which was considered inappropriate use of PERSARC*

Environmental related

Clinicians stated in the interviews that they found it difficult to incorporate PERSARC into their consultations as that would mean presenting treatment options to patients that had not been discussed during the multidisciplinary tumour board (MTB) meeting. Moreover, the clinician checklists showed that during MTB meetings generally only the option deemed most suitable was discussed, even though multiple treatment options were mentioned during the majority of consultations with the use of PERSARC (Table 4). Another environmental barrier to PERSARC use was not having all tumour characteristics (e.g., tumour grade) needed by PERSARC to calculate prognostic estimates at the time of the patient-clinician encounter. This required the clinician to make an educated guess to be able to use PERSARC. Moreover, field notes from observed consultations and audio-taped consultation, showed that treatment decisions had already been made or initiated prior to the patient-clinician encounter, thus limiting the usefulness of PERSARC for treatment decision-making (Table 3). This was often due to time constraints, as patients had undergone extensive diagnostic procedures before being referred to a tertiary center for treatment, and therefore is an important barrier. Furthermore, both patients and clinicians expressed concerns in interviews about the time-consuming nature of filling in patient and tumour characteristics during consultations, which is in line with observations documented in field notes.

Patient-related factors

Nine patients (out of 50) reported in the satisfaction survey that PERSARC aided in clinical decision-making (Table 5). Qualitative results expand on this finding, as patients did not always feel that there was a choice in treatment. However, most patients also reported in the survey that they perceived PERSARC as embedded in the VALUE-PERSARC app as useful (48/50) and the majority (39/50) would use the app again. Reasons for patients to promote VALUE-PERSARC, mentioned in the interviews, were that it helped them in understanding the impact of different treatment options and provided insights into personalised prognostic estimates. The app was perceived as too complicated by some older (>65y) patients. For example, these patients experienced difficulties installing the app or completing the study questionnaires on their mobile phones, as observed by the primary researcher (AK).

Table 4. Joint display of environmental factor influencing the use of PERSARC in consultation

	Quantitative results		Qualitative results	Mixed methods meta-inferences
Use of PERSARC in MTB	<u>Checklist (use of PERSARC)</u> PERSARC discussed during MTB (according to clinician) • No • Yes, 1 options • Yes, 2 or more options	*Consultations (N)* 5/38 16/38 17/38	<u>Interviews</u> ▼Clinicians experienced difficulties to deviate from the treatment plan discussed during MTB *"You get a prescription from the MTB and you are going to discuss that with the patient (C4)"* <u>Field notes</u> Difficulties to embed the results of PERSARC in consultation. Sometimes treatment already started or the treatment decision was already made in MTB prior to patient-clinician encounter.	▲*Expansion* The quantitative findings, indicating that in almost half of the patients, only one option is discussed in MTB when using PERSARC, expand on clinicians' difficulties in deviating from this during consultation with the patient
Embedding in consultation	<u>Checklist (use of PERSARC)</u> PERSARC discussed with the patient during consultation (according to clinician) • No • Yes, 1 options • Yes, 2 or more options	*Consultations (N)* 1/38 4/38 33/38	▼Time constraints Interviews *"Yes, filling in the RPM consumes a lot more time. I: Is it a reason to not use it? C: Yes, certainly, that is a very solid reason not to do something (C4)"* *"Did you find it appropriate during consultation?" P: "In hindsight, yes. Initially, I thought it would be a very short conversation, we are in healthcare and people are busy. I have a long list of questions and we have to rush through it in 10 min, and it's a matter of life or death, so we are not going to waste our time on an app now (P13)"* <u>Field notes</u> Difficulties to use the app (log in), unavailability of variables needed to fill in PERSARC at the time of consultation.	▲*Expansion* Although the quantitative results show that more than two treatment options are often discussed, the qualitative results indicate that clinicians struggle to integrate the use of RPM into consultations due to time constraints and availability of variables.

▼ *Barrier* ▲ *Facilitator*

Clinician-related factors

Clinicians indicated in the survey that they perceived PERSARC to be useful during consultations with the patient (33/38). Interviews revealed that they did so because it enhances their understanding of individual patients' prognosis, making treatment decisions feel more tailor-made than if they had been informed by general statistics from the literature (Table 6). Simultaneously, all interviewed clinicians also expressed doubts about the retrospective data on which PERSARC is based (*"I: What is the reason that you don't use PERSARC outside the framework of this research? C: Well, I think it's because PERSARC is a predictive model that was ultimately developed based on retrospective data. That inherently makes it less informative (C4)"*. Two-thirds of the clinicians indicated in the survey that PERSARC was helpful in drafting the treatment plan. This is contradicted by the results of the interviews in which clinicians were uncertain whether patients truly had multiple viable treatment options, as they often considered one treatment option to be superior. Clinicians' doubts about the RPM were strengthened when its prognostic estimates were not in line with their perception of the superior treatment option.

Tool/technology related

Technology-related factors that hampered the use of PERSARC, mentioned by patients and clinicians during the interviews, included software problems leading to slow responses, the need to click through multiple pages, and system freezing. Additionally, some patients forgot their account password in the app. Both issues were frustrating as they consumed valuable time during patient-clinician encounters, leading to patients receiving insufficient information in a hurried manner as observed by the primary researcher (AK). Yet, interviews revealed that patients appreciated the access to comprehensive information within the app that could be shared with relatives and consulted at home.

Table 5. Joint display of patient-related factors influencing the use of PERSARC in consultation

	Quantitative results		Qualitative results	Mixed methods meta-inferences
Added value decision-making	Satisfaction survey patients	*Patients (N)*	Interviews	
	PERSARC assisted in making the treatment decision	9 /50	▼Patient did not feel there was a choice in treatment *"She [clinician] said it seems logical for you to do that [proposed treatment] and indeed that seemed very logical to me as well. So it was sort of if you don't do it [proposed treatment], then you have less of a chance [survival probabilities]. What do you want"(P12)*	▲*Expansion* The qualitative results expand on the quantitative finding that PERSARC did not help in making the treatment decision, because patients did not feel that there was a choice in treatment.
Usefulness of PERSARC	Satisfaction survey patients		Interviews	
	PERSARC as embedded in the VALUE-PERSARC app useful What was the added value of VALUE-PERSARC for you? *"Good/reliable source of information"* *"Provides insight into personal chances"* *"Could be shared with relatives"*	48/50	▲Patients prefer to have insight into prognostic estimates *"And what I really liked is that the results of the RPM showed me why we are doing this [the proposed treatment], and not the alternative [treatment]. So, why not first choose surgery or why not opt for radiation therapy instead?" (P13)*	▲ *Expansion* The qualitative results expand on the quantitative finding that the majority of patients found PERSARC useful, because it provided insight into prognostic estimates.
VALUE-PERSARC app	Satisfaction survey patients		Interviews	
	Prefers to use VALUE-PERSARC again What is the reason why you would not use VALUE-PERSARC again? *"I want the clinician to make the decision"*	39/50	▼Some (older) patients prefer to have the clinician make the treatment decision as they perceive the app as too complicated *"Yes, as a layperson, you naturally follow the advice of the experts, right? That's just what you do. We might be from a different generation. I think the generation after us might handle it [PERSARC] differently" (P10)* Field notes: The app was perceived as too complicated by some older (>65) e.g., these patients experienced difficulties to install or log into the app on their mobile phone	▲ *Expansion* The qualitative results expand on the quantitative finding that some (older) patients would not use the VALUE-PERSARC app again, as they perceived the app as too complicated.

▼ *Barrier* ▲ *Facilitator*

Table 6. Joint display of clinicians-related factors influencing the use of PERSARC in consultation

	Quantitative results		Qualitative results	Mixed methods meta-inferences
Usefulness of PERSARC	Satisfaction survey clinician after each consultation PERSARC useful during the consultation with the patient Why did you find it useful? *"Provides insight into the value of adjuvant therapy"*	*Consultations (N)* 33/38	Interviews ▲PERSARC enhances clinicians' understanding of individual risk estimates *"It [PERSARC] helps to correctly weigh up the added value of adjuvant therapy" (C1)*	▲ *Expansion* Qualitative results expand on quantitative finding that clinicians' found PERSARC useful during consultation as it provides insights in the added value of adjuvant therapy.
			Interviews ▼Doubts about the accuracy of the risk estimates provided by the model *"Q: What is the reason that you don't use PERSARC outside the framework of this research? A: Well, I think it's because PERSARC is a predictive model that was ultimately developed based on retrospective data. That inherently makes it less informative. (C4)"*	▼ *Contradiction* Clinicians indicated PERSARC as useful in the majority of consultations, which is contradicted with the qualitative finding that they also expressed doubts about the accuracy of risk estimates.
Added value in decision-making	Satisfaction survey clinician after each consultation PERSARC of added value in drafting the treatment plan for the patient Why did you find it not useful? *"Treatment plan was already determined"* *"Based on retrospective data"*	*Consultations (N)* 25/38	Interviews ▼Doubts about viability multiple treatment options, i.e., clinician often thinks one option is superior *"Yes, and then there are simply good reasons to do so [treatment]. And then, well, it doesn't really matter much what that app thinks about it (C3)"*	▼ *Contradiction* Clinicians indicating PERSARC as helpful in drafting the treatment plan is contradicted with the qualitative finding that clinicians often consider their opinion superior.

▼ *Barrier* ▲ *Facilitator*

Discussion

PERSARC was not utilized to present all medically viable treatment options. Instead, it was frequently used to support the treatment plan developed during the MTB meeting that the clinician intended to propose to the patient. Barriers for using PERSARC to inform patients about treatment options include clinicians' doubts about whether patients truly have multiple viable treatment options and about the accuracy of the risk estimates from PERSARC, and time constraints. Conversely, facilitators for the use of the RPM include its efficacy in helping clinicians thoroughly assess the added value of adjuvant treatment and effectively communicate this information during clinical encounters, which is also perceived as beneficial by patients. Moreover, most patients would use the VALUE-PERSARC app again, as it gives them access to comprehensive information that can be shared with relatives and consulted at home.

The implementation of RPMs into clinical practice is known to be challenging [28], which is again found in the present study. Despite their potential to help clinicians and patients adequately weigh prognostic estimates with or without treatment, and thus support informed decision-making, these challenges persist. Our results indicate that clinicians experienced several difficulties when integrating PERSARC into clinical encounters.

Firstly, clinicians did not use the RPM to support patient-clinician decision-making as intended. Instead, they primarily used the prognostic estimates provided by PERSARC to guide patients towards the treatment option deemed superior by the MTB, rather than to inform patients and elicit their preferences. Clinicians' mention multiple treatment options in almost all clinical encounters, which gave them the feeling that patients had been engaged more. However, patients did not perceive having a choice, which is probably due to the implicit steering by clinicians towards their preferred treatment option. This steering seemed to stem from clinicians' concerns about the clinical equipoise of various treatment options for these STS patients. When prognostic estimates from the RPM did not align with clinicians' own assessments of treatment benefit, they questioned the data underlying the model. Overall, clinicians found it challenging to accept patient choices that differed from what they perceived as the best option and struggled to deviate from the MTB's recommendations, which often focused solely on the option with the greatest potential improvement in prognosis. These findings are consistent with previous studies showing that clinicians, despite using a decision aid, fail to first elicit patients' values and preferences to guide treatment decisions [12, 29, 30]. Furthermore, clinicians' longstanding commitment to doing what they perceive as best for their patients presents a significant barrier. To address this, a change in attitude is necessary. Although well-intentioned, this approach often overlooks the importance of patients' values, opinions, and preferences, which may differ from those of the clinicians [31]. This is particularly evident in their tendency to prioritize maximizing survival or reducing recurrence risk without fully considering the importance of quality of life for some patients.

Second, required time investment proved to be an important barrier for RPM use in the clinical encounter, which is consistent with previous studies on implementation of decision aids [32]. Given that filling in and explaining the RPM takes valuable time in the consultation, particularly when the app/software encountered technical problems, it led to a negative interaction between the patient and clinician. Patients received insufficient information and it was often done in a hurried manner, causing additional stress. The literature provides no conclusive evidence regarding the required length of consultation when using an RPM; some studies report prolonged sessions, while others do not, which might be explained by the complexity of the decision and the care setting [33, 34]. Nonetheless, despite the additional time required for filling in data for the RPM, its use may also contribute to more efficiency as the RPM proved valuable in explaining prognosis and consequences of treatment, which might take more time without the individualised data on risks and benefit. Further research should include possible logistical problems, such as the time to log in to the app or web browser and fill in the RPM, to determine its impact on the content and duration of the consultation.

Strengths and limitations

Studies on the integration of RPMs into clinical consultations are rare; to our knowledge our study is the first trying to understand how and why RPM are used and to highlight barriers and facilitators for its use in daily clinical practice. A key strength is that we utilized multiple data sources, both qualitative and quantitative, including perspectives of both patients and clinicians, supported by audiotapes and observations of actual consultations over the duration of the study.

Some limitations should be noted. First, our study excluded patients that were (indicated to be) treated with chemotherapy. As a result, our findings do not address the potential role of chemotherapy in patient outcomes, an area that warrants further investigation in future studies. Additionally, the context of conducting this study alongside a clinical trial may have contributed to overestimating RPM utilization and its potential to support decision-making. Clinicians may have enrolled a selection of patients into the clinical trial rather than all patients they see in daily practice. Moreover, knowledge of being observed might have influenced clinicians to consciously or unconsciously modify their behavior (Hawthorne effect) during audiotaped or observed consultations [35]. Finally, after the study had started, a change in the sarcoma patient care pathway occurred due to COVID-19. Instead of two separate consultations for initial diagnosis and treatment, both consultations were merged into one diagnosis-treatment consultation, significantly impacting the available time for discussion of personalised risk generated by the RPM during the consultation. However, since this was not reversed after the COVID-19 pandemic, this has become the usual care setting for future patients, and thereby makes it likely that our results highlighting time constraints to use PERSARC still apply.

Implications

The potential success of using RPMs to support decision-making in the clinical encounter is dependent on several interacting elements, described by the SEIPS model. Continuous efforts are needed to improve technology- and environmental factors (i.e., design and usability of the RPM). Integrating the RPM into electronic health records (EHR) might overcome technology-related problems and time constraints, particularly since RPMs are often developed based on routinely collected data retrieved from EHR [28]. This will reduce the time needed for accessing an app or web browser and entering patient and tumour characteristics, thereby streamlining the process, and enhancing efficiency in the clinical encounter. In addition, opportunities to improve task-related factors rely on better and continuing training for clinicians on how to use RPMs and, moreover, how to incorporate them in accordance with the principles of patient-centered care [29]. It is also imperative that clinicians' attitudes and beliefs towards the RPM improve, partly by educating them about modelling and when necessary updating and extending the RPM. Finally, most patients in our study indicated that they found the RPM useful, and we think that given the shift towards using personalised outcome information to support medical decisions, in time clinicians and patients will become more accustomed to using RPM during clinical encounters.

Conclusion

Our findings show that PERSARC was generally used to support clinicians' proposed treatment plan and not to help patients weigh available treatment options. Still, both patients and clinicians perceived the use of the RPM during the clinical consultation as valuable in explaining prognosis and potential consequences of treatment. These results provide some guidance for improvements to fully realize the potential of RPMs to support clinical decision-making. To maximize RPMs effectiveness, it is imperative to promote multidisciplinary research that considers the various facets of the specific clinical context, implementation science and statistical modelling.

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Supplementary files

Supplementary file 1

Coding scheme VALUE-PERSARC
[translated from Dutch]

Length of consultation: … hours… min… seconds
Coded by:

1. Creating choice awareness
   1.1. Does the clinician explicitly state that a decision about treatment has to be made?
   ❑ No
   ❑ It remains implicit that a choice must be made, but can be inferred from the conversation
   ❑ Yes, for timing RT ❑ Yes, for surgery
   ❑ Other

2. Information provision
   2.1 Does the clinician use PERSARC?
   ❑ No
   ❑ Yes, on screen, via the web browser
   ❑ Yes, on the patient's phone
   ❑ Provides the numbers but does not show it (e.g. the following numbers came from the MTB)
   ❑ Other, namely

   2.2 Which treatment options were mentioned? (multiple options possible)
   ❑ No options were presented
   ❑ R0 + pre-op RT ❑ R0 + post-op RT ❑ R0
   ❑ R1-2 + pre-op RT ❑ R1-2 + post-op RT ❑ R1-2

2.2 Are benefits of the options mentioned?

❑ No

❑ Can be inferred from conversation, but not explicitly mentioned (record in table below)

❑ Yes (record in table below)

Treatment option	Benefits	Line number

2.3 Are risks of the options mentioned?

❑ No

❑ Can be inferred from conversation, but not explicitly mentioned (record in table below)

❑ Yes (record in table below)

Treatment option	Risks	Line number

2.5 Does the clinician explain on which input variables PERSARC is based?

❑ No

❑ Yes (mentioned at least on variable: age, tumour location, tumour size, tumour depth, histology, grade)

2.6 Which treatment options are discussed?

	R0		**R0 + pre-OK RT**		**R0 + post OK RT**	
		Framing		Framing		Framing
overall survival	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.
local recurrence	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.
distant metastasis	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.

	R1-2		**R1-2 + pre-OK RT**		**R1-2 + post OK RT**	
		Framing		Framing		Framing
overall survival	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.
local recurrence	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.
distant metastasis	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.	%	❑ Neg. ❑ Pos.

3. Patients preferences

3.1 Does the clinician elicit patient preferences?

❑ Yes

❑ No

4. Decision Making

4.1 Has a decision been made regarding the treatment during the consultation?

❑ No

❑ Yes, about the surgery

❑ Yes, about neo-adjuvant RT

❑ Decision seems to be predetermined prior to the consultation (e.g., in the MDT)

❑ Yes, before the surgery θ Yes, before RT

4.2 Who makes the final decision?

❑ Patient

❑ Patient and clinician (Shared decision)

❑ Clinician

Supplementary file 2

Checklist orthopaedic/oncological surgeon

To be filled in by orthopaedic/oncological surgeon:

1. In which hospital is the patient being treated? …..

2. What was the date of the consultation: …

3. Did you use the PERSARC RPM during the multidisciplinary tumour board meeting?

❑ No

❑ Yes, specifically for: ❑ 1 treatment option ❑ 2 or more treatment options

4. Did you discuss the outcomes of the PERSARC RPM with the patient during consultation?

❑ No

❑ Yes, specifically for: ❑ 1 treatment option ❑ 2 or more treatment options

5. To what extent do you feel the patient understood the risk information?

Did not understand								Completely understood	
1	2	3	4	5	6	7	8	9	10

Supplementary file 3

Satisfaction survey orthopaedic/oncological surgeon
[translated from Dutch]

Did you find the PERSARC RPM useful during the multidisciplinary tumour board meeting?

- ❑ Yes
- ❑ No
- ❑ Partly
- ❑ Why did you find it useful/not useful?

Did you find the PERSARC RPM useful during the consultation with the patient?

- ❑ Yes
- ❑ No
- ❑ Partly
- ❑ Why did you find it useful/not useful?

Did the PERSARC RPM help in drafting the treatment plan for the patient?

- ❑ Yes
- ❑ No
- ❑ Partly
- ❑ Why did you find it useful/not useful?

Satisfaction survey patient
[translated from Dutch]

Did you find the PERSARC app useful?

- ❑ Yes
- ❑ No
- ❑ Partly

Did the PERSARC app help in making the treatment decision?

- ❑ Yes
- ❑ No
- ❑ Partly
- ❑ 2x no → question 4

What was the added value of the PERSARC app for you?

- ❑ Good/reliable source of information
- ❑ Provides insight into personal chances
- ❑ I was more involved in the decision-making process of my treatment
- ❑ It helped to visualize the consequences of different treatment options.
- ❑ Other, namely…."

What is the reason why you would not (again) use the PERSARC app in the future?

- ❑ I want the doctor to make the decision.
- ❑ I did not have enough time to process the information from the app.
- ❑ I did not understand well what I should do with the information from the app.
- ❑ I found it too confronting to see my future perspective.
- ❑ Other, namely…."

Supplementary file 4

Interview scheme clinician
[translated from Dutch]

1. Background Characteristics (Oncologist/Orthopaedic/...)
   1.1 Approximately how many new patients with sarcomas in the limbs do you see per month?

PERSARC Usage
   2.1 At what moments did you use the PERSARC app (MDT meetings, consultations...)?
   2.2 Did you use the app in the MDT meeting? If yes, how?
   2.3 Did you use the app in consultations? If yes, how?
   2.4 How did you experience the use of the PERSARC app?
   2.5 Did the consultation with the patient appear differently due to the use of the app compared to before using the app?
   2.6 Do you feel that the use of the app has changed the way you look at treatment decisions, and if so, how?
   2.7 Has the patient's input remained the same or changed with the use of the app? How?
   2.8 What is your opinion on the use of the app?

Barriers and facilitators
   2.9 What helped you to use the app in the MDT meeting?
   2.10 What helped you to use the app in the conversation with the patient?
   2.11 What did you find challenging about using the app?
   2.12 What prevented you from using the app in the MDT meeting?
   2.13 What prevented you from using the app in the conversation with the patient?
   2.14 Do you want to continue using the PERSARC app?
   2.15 What can we do to improve the app? What do you feel is missing in the app?

Interview scheme patient
[translated from Dutch]

1. Background patient

Use of PERSARC

2.1 Are you familiar with the PERSARC app?
2.2 Can you tell us on what basis you made your treatment choice?
2.3 Did your doctor fill out the app together with you?
2.4 Did you record the consultation, and if so, did you listen to it again?
2.5 How did the doctor use the app in the conversation with you?
2.6 Did you consult the app at a later time, and if so, for what purpose, and how often?
2.7 Did you share the information from the app with anyone? If yes, with whom and for what purpose?

Barriers and facilitators

2.8 What did you like about the app?
2.9 What did you dislike about the app?
2.10 What helped/encouraged you to use the app?
2.11 What prevented you from using the app or consulting it more often?
2.12 What can we do to improve the app? What do you feel is missing in the app?
2.13 Would you recommend someone else to use the app?