

# Willingness of Patients with Breast Cancer in the Adjuvant and Metastatic Setting to Use Electronic Surveys (ePRO) Depends on Sociodemographic Factors, Health-related Quality of Life, Disease Status and Computer Skills

Die Bereitschaft zur Nutzung von technikbasierten Erhebungen (ePRO) bei Patientinnen mit Mammakarzinom in der adjuvanten und metastasierten Situation in Abhängigkeit von soziodemografischen Merkmalen, gesundheitsbezogener Lebensqualität, Erkrankungsstatus und Technikskills

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## Key words

- breast cancer
- metastatic setting
- patient-reported outcomes
- acceptance of technology-based surveys
- obstacles

## Schlüsselwörter

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- metastasierte Situation
- Patient-reported Outcomes
- Akzeptanz von technikbasierten Erhebungen
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## Abstract

**Introduction:** Because of the often unfavorable prognosis, particularly for patients with metastases, health-related quality of life is extremely important for breast cancer patients. In recent years, data on patient-relevant endpoints is being increasingly collected electronically; however, knowledge on the acceptance and practicability of, and barriers to, this form of data collection remains limited.

**Material and Methods:** A questionnaire was completed by 96 patients to determine to what extent existing computer skills, disease status, health-related quality of life and sociodemographic factors affect patients' potential willingness to use electronics methods of data collection (ePRO).

**Results:** 52 of 96 (55%) patients reported a priori that they could envisage using ePRO. Patients who a priori preferred a paper-based survey (pPRO) tended to be older (ePRO 53 years vs. pPRO 62 years;  $p=0.0014$ ) and typically had lower levels of education ( $p=0.0002$ ), were in poorer health ( $p=0.0327$ ) and had fewer computer skills ( $p=0.0003$ ).

**Conclusion:** Barriers to the prospective use of ePRO were identified in older patients and patients with a lower quality of life. Given the appropriate conditions with regard to age, education and current health status, opportunities to participate should be provided to encourage patients' willingness to take part and ensure the validity of survey results. Focusing on ease of use of ePRO applications and making applications more patient-oriented and straightforward appears to be the way forward.

## Zusammenfassung

**Einleitung:** Aufgrund der häufig ungünstigen Prognose insbesondere in der metastasierten Situation ist die gesundheitsbezogene Lebensqualität bei Brustkrebspatientinnen von großer Bedeutung. Seit einigen Jahren werden patientenrelevante Endpunkte zunehmend auch technikbasiert erhoben, der Wissensstand zu Akzeptanz, Praktikabilität und Hürden ist jedoch bislang begrenzt.

**Material und Methoden:** Anhand einer Fragebogenerhebung mit  $n=96$  Patientinnen wurde untersucht, inwiefern vorhandene Technikskills, der Erkrankungsstatus, die gesundheitsbezogene Lebensqualität und soziodemografische Faktoren die potenzielle Bereitschaft zur Nutzung technikbasierter Erhebungen (ePRO) beeinflussen.

**Ergebnisse:** Insgesamt gaben 52/96 (55%) der Patientinnen an, sich a priori eine Teilnahme an ePRO vorstellen zu können. Patientinnen, die a priori eine papierbasierte Befragung (pPRO) wünschten, waren älter (ePRO 53 Jahre vs. pPRO 62 Jahre  $p=0,0014$ ) und waren durch einen niedrigeren Bildungsstatus ( $p=0,0002$ ), einen schlechteren Gesundheitszustand ( $p=0,0327$ ) und geringere Technikskills ( $p=0,0003$ ) charakterisiert.

**Schlussfolgerung:** Bei Patientinnen mit höherem Alter und niedrigerer Lebensqualität konnten Hürden für eine prospektive ePRO-Teilnahme identifiziert werden. Bei entsprechenden Vorbedingungen das Alter, den Bildungsstatus und den aktuellen Gesundheitszustand betreffend, sollten Möglichkeiten der Unterstützung angeboten werden, um die Bereitschaft zur Teilnahme bzw. die Validität der Ergebnisse sicherzustellen. Sinnvoll erscheint weiterhin, die Handhabbarkeit von ePRO-Applikationen zu fokussieren und patientinnenorientiert erleichternd zu gestalten.

## Introduction

Despite recent advances in surgery, chemotherapy, and other forms of support, metastatic breast cancer remains a challenge for gynecologic oncology [1–3]. The mean life expectancy of these patients is 3 years and depends on tumor biology and the degree and site of metastasis, and the 5-year survival rate is 25 to 30% [4–11]. This means that the prognosis for these patients is significantly worse than that of patients in the adjuvant setting. The mean 5-year survival rate for all patients with breast cancer is currently around 80% [12–16]. For patients with metastases, palliative care may often be the only choice, with the remaining therapy options aiming to extend the patient's survival time while remaining largely free of tumor-related symptoms. This is why health-related quality of life should always be included in therapy planning [17–25]. In the medium or longer term, systemic chemotherapy may also reduce the health-related quality of life of patients receiving adjuvant treatment [26–28].

Measuring the health-related quality of life of patients with metastatic breast cancer is very relevant, and not merely for healthcare research. According to the German Act on the Reform of the Market for Medicinal Products (*Arzneimittel-Neuordnungsgesetz* [AMNOG]), the proof of the benefit of therapeutic interventions must be based on patient-relevant endpoints and should include various aspects which show “*how the patient feels, how he is able to perform functions and activities, and whether he survives*” (AMNOG 2010; § 35a SGB V and Code of Procedure of the Federal Joint Commission [*G-BA-Verfahrensordnung*], § 13) [29]. The measured variables used to assess the benefit (e.g. health-related quality of life) are referred to as patient-reported outcomes (PRO) and reflect the patient's subjective perception of her own state of health without evaluation by a third party [30, 31]. Particularly in oncology patients, the patient's subjective perception of her own state of health is considered an important indication of the efficacy of a specific therapy [32–34].

Paper-based surveys still predominate; electronic methods to collect PROs (e.g. with tablet PCs) have only begun to be used in recent years. But knowledge about the acceptance and practicability of this method of data collection remains limited [32, 35–42]. To date, there has been no study which has attempted to identify possible barriers to the use of electronic surveys which could arise from the side-effects of therapy or be due to aspects of the patient's biography. This lack result in a consistent bias in such surveys, as it is unclear whether insufficient computer skills, therapy-related barriers or other prerequisites necessary to complete an electronic survey might alter the response or even result in a refusal to participate in the survey, i.e., whether there are barriers which could influence the survey outcome. This study looked at whether previous experience of using a tablet or the internet (computer skills), disease status, patients' health-related quality of life and the sociodemographic variables “level of education” and “age” influenced the willingness of breast cancer patients with metastasis or receiving adjuvant treatment to use electronic surveys. The hypothesis was that older patients in a poorer state of health and a lower health-related quality of life faced greater barriers and required more support compared to younger patients in a better state of health, which is why particularly older and more ill patients may be less willing to complete ePRO questionnaires (e.g. using a tablet).

## Patients/Material and Methods

### Sample and study design

In summer 2015, 96 breast cancer patients with metastasis or receiving adjuvant therapy and treated consecutively at the University Gynecological Hospital in Tübingen completed a survey using a paper-based questionnaire. A total of 120 patients were asked to participate in the survey, resulting in a response rate of 80%. 65 patients (68%) had metastases and 31 patients (32%) were receiving adjuvant therapy. The data collected from the two patient groups were combined for statistical analysis. Patients completed the questionnaire during an outpatient visit to the hospital under the supervision of an attending physician. Patients were informed prior to completing the questionnaire about the aims of the study and that participation in the study was voluntary. The ethics committee gave its prior consent to the study (project number 196/2015B02). All female breast cancer patients aged more than 18 years who either had metastasis or were undergoing adjuvant treatment and who additionally had sufficient knowledge of German to answer the questionnaire were included in the study.

### Questionnaire

The survey consisted of three parts. The first part focused on the patients' socio-economic variables. The second part asked patients about their health-related quality of life and overall state of health. The survey questionnaires EORTC QLQ-C30 and EQ VAS (EQ-5D-5L) were used for this second part [43–46]; the questionnaires had already been previously approved for use in a parallel study (project number 234/2014B01). The third part consisted of an additional questionnaire consisting of validated “partial” questionnaires which had been developed to examine our study questions. In this third part of the survey patients were asked to provide information about their use of electronic technology at home, to evaluate their knowledge and understanding of computers and the internet and comment on their general attitude toward electronically-based surveys. EORTC QLQ-C30 is a disease-specific questionnaire, the use of which has already been validated in research. It consists of 5 subscales, various symptom scales, and individual items which aim to capture the patients' quality of life on a multidimensional level [43, 44]. The generic EQ-5D-5L questionnaire evaluates quality of life in five dimensions using a five-step scale and the EQ VAS scale, with the current state of health recorded as a number (0 = worst imaginable state of health, 100 = best imaginable state of health) [45, 46]. To evaluate quality of life, patients were surveyed using the EQ VAS scale which was combined with two questions from the EORTC QLQ-C30, and responses to questions about the patient's current health status and current quality of life were recorded using a seven-step Likert scale (from 1 = very poor to 7 = excellent). Calculations of mean values were done in accordance with the official EORTC guidelines which require a separate score to be calculated for each scale, with scores taking any value between 0 and 100 [47].

The additional questions on the patient's computer skills and needs based on their prior experience of digital media consisted of: the modules on the private use of technology from the KBF-BK questionnaire [48]; published, validated items of a survey on the acceptance and reliability of electronic psycho-oncologic screening [40]; and additional questions, developed by the authors, on the aspects “technical barriers” and “potential (technological) support structures which would take the patient's prior experience of technological research tools into account” [49, 50].

**Table 1** Sociodemographic characteristics of the patient cohort.

Sociodemographic variables	Total
Age	
▶ mean (median)	56.68 (54)
▶ standard deviation (range [min; max])	12.38 (60 [20; 85])
Highest level of education achieved	
▶ left school without any qualifications (= 1)	n = 1 (1%)
▶ qualified certificate of secondary education (= 2)	n = 31 (32%)
▶ general certificate of secondary education (= 3)	n = 28 (29%)
▶ entrance qualification for an advanced technical college (= 4)	n = 15 (16%)
▶ entrance qualification for university (= 5)	n = 13 (14%)
▶ not specified	n = 8 (8%)
Currently working	
▶ yes, full time	n = 11 (12%)
▶ yes, part time	n = 31 (32%)
▶ no	n = 43 (45%)
▶ not specified	n = 11 (11%)
Disease/therapy status	
▶ metastasis	n = 65 (68%)
▶ adjuvant	n = 31 (32%)

### Statistical analysis

A frequency analysis was done with MS Excel 2010 and IBM SPSS 21 to determine the descriptive characteristics of the collected data. Differences were identified using unpaired bilateral t-tests. A bilateral p-value of <0.05 was considered statistically significant in all analyses ( $\alpha = 0.05$ ). Pearson's correlation coefficient was calculated to show correlations between the variables "age", "level of education", "quality of life", "disease status" and "computer skills". All calculations were based on the assumption that data were normally distributed, and the Shapiro-Wilk test was used prior to the evaluation of data to verify the normal distribution of data.

## Results

### Sociodemographic variables

Table 1 shows the sociodemographic characteristics of the patient cohort. Mean age of the patients was 56.68 years (minimum: 20 years, maximum: 85 years). 30% of patients had higher educational qualifications (entrance qualification for an advanced technical college or for university), 42 patients (34%) were working despite disease (at least part time).

### Health-related quality of life and disease status

Table 2 shows patients' health-related quality of life and current state of health. The median value for the patient's health status on the EQ VAS scale was 64.67, with 60 as the most commonly reported value. The median state of health using the EORTC

**Table 2** Quality of life and state of health of the total patient cohort.

	EQ VAS scale (n = 96)	EORTC QLQ-C30 (current state of health) (n = 74)		EORTC QLQ-C30 (current quality of life) (n = 74)	
		Item value	Score value (in %)	Item value	Score value (in %)
Mean (median)	64.67 (70)	4.43 (4)	56.16 (50)	4.54 (5)	57.97 (66.67)
Standard deviation	18.15	1.32	23.56	1.31	23.50
Range (min; max)	90 (5; 95)	6 (1; 7)	99 (0;100)	6 (1;7)	99 (0;100)

**Table 3** Computer skills and willingness to complete electronic PRO questionnaires in the total patient cohort.

Computer skills	Total
<b>Computer skills (self-assessment by the patient)</b>	
Mean (standard deviation)	2.33 (0.75)
▶ beginner (= 1)	n = 10 (10%)
▶ basic (= 2)	n = 37 (39%)
▶ advanced (= 3)	n = 30 (31%)
▶ professional (= 4)	n = 4 (4%)
▶ not specified	n = 15 (16%)
<b>Computer use (years)</b>	
Mean (median)	16.73 (15)
Standard deviation (range [min; max])	8.25 (34 [2;36])
<b>Internet use (years)</b>	
Mean (median)	11.84 (10)
Standard deviation (range [min; max])	6.53 (24 [1;25])
<b>Use of tablets</b>	
Mean (standard deviation)	1.91 (1.02)
▶ not at all	n = 33 (34%)
▶ very little	n = 10 (10%)
▶ moderate	n = 19 (20%)
▶ a lot	n = 4 (4%)
▶ not specified	n = 30 (31%)
<b>Could you imagine completing an electronic questionnaire on your subjective perception of your own state of health?</b>	
▶ Yes	n = 52 (55%)
▶ No	n = 35 (37%)
▶ not specified	n = 8 (8%)
<b>Do you think that the introduction of electronic surveys will ...</b>	
▶ improve hospital care	n = 45 (47%)
▶ worsen hospital care	n = 11 (11%)
▶ not specified	n = 40 (42%)
<b>Compared to a paper-based questionnaire, an electronic questionnaire is ... less suitable (= 1), more suitable (= 5)</b>	
Mean (median)	3.34 (3)
Standard deviation	1.30
<b>Compared to a paper-based questionnaire, an electronic questionnaire is ... more tiring (= 1), less tiring (= 5)</b>	
Mean (median)	3.22 (3)
Standard deviation	1.21
<b>Compared to a paper-based questionnaire, an electronic questionnaire is ... more difficult (= 1), less difficult (= 5)</b>	
Mean (median)	3.06 (3)
Standard deviation	1.21

QLQ-C30 was 56, while the mean score for quality of life for the overall patient cohort was 58.

### Computer skills: previous experience of digital media

34 (35%) patients stated that they had advanced or professional computer skills while 47 (49%) patients reported having poor to moderate computer skills. Five patients reported that they did not use either a computer or the internet. When asked about

**Table 4** Subgroup analysis according to the preferred method of survey (ePRO versus pPRO).

	Electronic/tablet-based survey welcomed (n = 52)		Electronic/tablet-based survey not welcomed (n = 35)		Difference	95% CI	p-value ( $\alpha = 0.05$ )
	Mean	SD	Mean	SD			
Age	53.24	9.03	61.86	15.1	- 8.62	- 13.796; - 3.43	<b>0.0014</b>
State of health (EQ VAS)	69.06	17.35	60.41	18.13	8.65	0.73; 16.58	<b>0.0327</b>
State of health (EORTC QLQ-C30)	60.09	20.70	53.79	22.38	6.2998	- 5.14; 17.73	0.2747
Quality of life (EORTC QLQ-C30)	61.84	21.54	57.58	22.84	4.266	- 7.54; 16.08	0.4725
Level of education	3.44	1.05	2.6	0.88	0.84	0.41; 1.27	<b>0.0002</b>
▶ no qualifications	n = 0		n = 1 (3%)				
▶ qualified certificate of secondary education	n = 10 (19%)		n = 19 (54%)				
▶ general certificate of secondary education	n = 19 (37%)		n = 9 (26%)				
▶ entrance qualification for an advanced technical college	n = 10 (19%)		n = 5 (14%)				
▶ entrance qualification for university	n = 11 (21%)		n = 1 (3%)				
▶ not specified	n = 2 (4%)		n = 0				
Computer skills	2.56	0.66	1.94	0.7	0.61	0.29; 0.93	<b>0.0003</b>
▶ beginner	n = 1 (2%)		n = 7 (20%)				
▶ basic	n = 22 (42%)		n = 14 (40%)				
▶ advanced	n = 23 (44%)		n = 6 (17%)				
▶ professional	n = 4 (8%)		n = 0 (0%)				
▶ not specified	n = 2 (4%)		n = 8 (23%)				

their use of tablets, 33 patients (34%) used or had used tablets, 33 (34%) did not use them, and 30 (31%) did not specify their usage. **Table 3** shows the technology skills for the total patient cohort together with their disease-related use of computers.

### Willingness to use electronic PRO questionnaires (ePRO)

Patients were asked whether they could potentially imagine participating in electronic PRO surveys, whether they were of the opinion that using electronic surveys to record PRO would improve or worsen hospital care, and whether compared to paper-based questionnaires electronic questionnaires were – in their view – more suitable or less suitable, more exhausting or less exhausting, and more difficult or less difficult to complete (**Table 3**). Overall, slightly more than half of all participants reported that they could imagine completing electronic surveys, while 37% stated that they did not wish to take part in such surveys. The question whether electronic surveys could have a positive impact on care was answered in the affirmative by 45 (47%) patients. No differences between electronic questionnaires and paper-based questionnaires were found with regard to suitability, how tiring it was to complete the survey, or the survey's degree of difficulty.

### Correlations between willingness to use technology and the variables “age”, “level of education”, “quality of life”, “health status” and “computer skills”

Patients were divided into one of two subgroups to identify possible relationships between patients' computer skills, disease status, health-related quality of life and the sociodemographic factors “level of education” and “age” and patients' willingness to use electronic surveys. **Table 4** shows the statistical differences between patients who rejected electronic surveys compared to those who were prepared to accept them. The patients in the subgroup who were prepared to record their subjective perception of their state of health using an electronic questionnaire

were on average almost 9 years younger and had a higher level of education (40% either had an entrance qualification for an advanced technical college or an entrance qualification for university). They also assessed the state of their health (69.06 vs. 60.41% and 60.09 vs. 53.79%, resp.), their quality of life (61.84 vs. 57.58%) and their computer skills (2.56 vs. 1.94) as higher compared to patients in the other subgroup. By comparison, patients who preferred a paper-based survey were older (mean age: 62 years), had on average a lower level of education, the state of their health was poorer and they had less previous experience with computers, the internet, or tablets. The differences between the two groups were statistically significant for the variables “age”, “level of education”, “state of health based on the EQ VAS scale” and “computer skills”.

### Willingness correlated with state of health

The total patient cohort was divided into two subgroups according to the patients' assessment of their own state of health evaluated using the EQ VAS scale. Subgroup 1 consisted of all patients who – on a scale from 0 to 100 – had reported their state of health as 60 or less; subgroup 2 consisted of patients in better health according to their own assessment. As shown in **Table 5**, the willingness to use electronic surveys was significantly lower for patients in poorer health: only 40% of the patients in this subgroup were willing to complete a survey on the subjective perception of their own state of health electronically, while 70% of patients in better health were willing to do so. There were no other significant differences between the two subgroups with respect to other surveyed items.

Correlation analysis showed a moderate statistical correlation between the variable “age” and the willingness to use electronic means to complete a survey ( $r = 0.321$ ,  $p = 0.002$ ) but showed no significant correlation for any of the other variables (**Table 6**).

**Table 5** Willingness to use electronic questionnaires: differences between subgroups.

	State of health $\leq 60$ (EQ VAS) (n = 40)		State of health $> 60$ (EQ VAS) (n = 50)		Difference	95% CI	p-value ( $\alpha = 0.05$ )
	Mean	SD	Mean	SD			
Age <sup>1</sup>	54.81	13.81	56.72	10.58	- 1.92	- 7.02; 3.19	0.4574
Compared to a paper-based questionnaire, an electronic questionnaire is ... less suitable (= 1), more suitable (= 5) <sup>1</sup>	3.26	1.32	3.35	1.25	- 0.05	- 0.7; 0.6	0.8830
Compared to a paper-based questionnaire, an electronic questionnaire is ... more tiring (= 1), less tiring (= 5) <sup>1</sup>	3.27	1.15	3.11	1.24	0.16	- 0.46; 0.78	0.6034
Compared to a paper-based questionnaire, an electronic questionnaire is ... more difficult (= 1), less difficult (= 5) <sup>1</sup>	3.35	1.16	2.94	1.14	0.40	- 0.19; 0.995	0.1809
Computer skills <sup>1</sup>	2.19	0.79	2.45	0.72	- 0.26	- 0.61; 0.08	0.1347
▶ beginner	n = 6 (15%)		n = 4 (8%)				
▶ basic	n = 14 (35%)		n = 20 (40%)				
▶ advanced	n = 10 (25%)		n = 19 (38%)				
▶ professional	n = 1 (3%)		n = 3 (6%)				
▶ not specified	n = 9 (23%)		n = 3 (6%)				
Willingness to use technology-based surveys <sup>2</sup>							<b>0.038</b>
▶ yes	n = 16 (40%)		n = 35 (70%)				
▶ no	n = 18 (45%)		n = 14 (28%)				
▶ not specified	n = 6 (15%)		n = 1 (2%)				
Do you think that the introduction of electronic surveys will ... <sup>2</sup>							0.9144
▶ improve hospital care	n = 18 (45%)		n = 25 (50%)				
▶ worsen hospital care	n = 4 (10%)		n = 6 (12%)				
▶ not specified	n = 18 (45%)		n = 19 (38%)				

<sup>1</sup> t-test; <sup>2</sup>  $\chi^2$  test**Table 6** Correlation analysis.

Variables	Correlation (Pearson)	Significance ( $\alpha = 0.05$ )
Age vs. willingness to participate in an electronic survey	<b>r = 0.321</b>	<b>p = 0.002</b>
Level of education vs. willingness to participate in an electronic survey	r = 0.097	p = 0.348
State of health (EQ VAS) vs. willingness to participate in an electronic survey	r = - 0.006	p = 0.954
State of health (EORTC QLQ-C30) vs. willingness to participate in an electronic survey	r = - 0.084	p = 0.487
LQ (EORTC QLQ-C30) vs. willingness to participate in an electronic survey	r = - 0.022	p = 0.857
Computer skills vs. willingness to participate in an electronic survey	r = 0.116	p = 0.263

## Discussion

In coming years, use of digital ePRO applications will become increasingly common in research and thus also in routine clinical practice. The data collected in this study show that, at present, it is primarily younger patients in better health who are spontaneously willing to participate in electronic surveys while the barriers to using electronic surveys are higher for older patients in a poorer state of health. Almost half of the patients clearly had no idea what was meant by the term “tablet”. This is in stark contrast to previous findings which had postulated that EPROs were very feasible but without explicitly looking at existing computer skills [39–42]. It could be that a need for support exists, but this has still to be substantiated (publication in progress). Possible approaches could include training patients to use the technology or support offered by study nurses or, in special cases, by members of the patient’s own family. The findings presented here expand the current understanding of this issue. Oncologic studies have shown that electronic PRO reports are well received by patients compared to paper-and-pencil versions *when the assign-*

*ment was randomized* [32,35–37,40]. However little attention has focused on the patients’ own preference for paper-based or electronically-based questionnaires or on the acceptance of electronic questionnaires if patients are free to choose between the two options. Schaeffeler et al. found that, while levels of reliability and acceptance were high among patients with breast cancer, the patients’ own preferences were not taken into consideration [40]. There were no previous studies of this type of patients with metastasis, and possible correlations between socio-economic status or state of health and the willingness to use ePRO were not much considered. This study offers some conclusions for clinical practice which could help to improve PRO surveys in breast cancer patients with metastasis or receiving adjuvant treatment. Thus, “age”, “level of education”, “state of health” and “computer skills” have all been identified as variables which affect patients’ willingness to use this form of survey. The results of the study emphasize the need to take a detailed (social) history of patients as this will allow those patients where the context and state of health indicate that there may be a barrier to using electronic surveys to be identified in advance [51] and allow their need for

support or preferences to be resolved early on. The findings also emphasize the necessity of focusing on the user-friendliness of e-based surveys and (after identifying the barriers) the importance of optimizing their ease of use. The findings also offer some hints to supervising researchers or physicians about the importance of taking individual needs and other influences into account, even within the setting of research studies. Further studies will be necessary to elucidate how to reach patients lacking a sufficient knowledge of German and with few or no computer skills.

### Conclusions for Practice

Currently, the majority of female patients with breast cancer would prefer ePRO surveys to be done as part of routine clinical examination. Higher age and metastases were identified as barriers to the prospective participation of patients in ePRO surveys. If certain conditions with regard to age, educational level and current state of health are present, support should be offered to ensure that patients are willing to participate as this will underpin the validity of the survey. It would be useful to focus on the ease of use of ePRO applications and design them to be more patient-oriented.

### Conflict of Interest

The authors declare no conflict of interest.

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