



Published in final edited form as:

*Int J Med Inform.* 2016 April ; 88: 52–57. doi:10.1016/j.ijmedinf.2016.01.005.

## Patient knowledge and Information-seeking about personalized cancer therapy

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### Abstract

**Background**—Understanding patients' knowledge and prior information-seeking regarding personalized cancer therapy (PCT) may inform future patient information systems, consent for molecular testing and PCT protocols. We evaluated breast cancer patients' knowledge and information-seeking behaviors regarding PCT.

**Methods**—Newly registered female breast cancer patients (n=100) at a comprehensive cancer center completed a self-administered questionnaire prior to their first clinic visit.

**Results**—Knowledge regarding cancer genetics and PCT was moderate (mean 8.7 +/- 3.8 questions correct out of 16). A minority of patients (27%) indicated that they had sought information regarding PCT. Higher education (p=0.009) and income levels (p=0.04) were associated with higher knowledge scores and with seeking PCT information (p=0.04). Knowledge was not associated with willingness to participate in PCT research.

**Conclusion**—Educational background and financial status impact patient knowledge as well as information-seeking behavior. For most patients, clinicians are likely to be patients' initial source of information about PCT. Understanding patients' knowledge deficits at presentation may help inform patient education efforts.

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**CONFLICTS OF INTEREST:** None

**AUTHORSHIP:** Conception and design: DR, RAY, SKP, YL, EVB, FM-B. Collection and assembly of data: DR, RAY, YL, EVB, FM-B. Data analysis and interpretation: RAY, DR, SRH, SKP, AMB-C, YL, EVB, FM-B. Manuscript writing: all authors. Final approval of manuscript: all authors.

## Keywords

Patient knowledge; Information-seeking behavior; Patient attitudes; Molecular testing; Personalized cancer therapy

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## BACKGROUND AND SIGNIFICANCE

Personalized cancer therapy (PCT) is an evolving field, in which patients are treated with drugs that target molecular alterations identified in their tumor. Several anti-cancer agents have recently been approved by the Food and Drug Administration only for patients with specific molecular subtypes (e.g., vemurafenib for melanoma with BRAFV600E mutations [1]). As an evolving treatment option, there are obstacles in the implementation of PCT [2]. The obstacles include tumor heterogeneity, costs of testing and morbidity of additional tissue sampling, uncertainty of effectiveness of therapies in early phase trials [2, 3]. However, there has been a growing interest in molecular profiling, especially genomic profiling and a growing number of biomarker-selected clinical trials (i.e. trials in which only patients with specific molecular markers can enroll) [3]. Even at large institutions with enterprise level molecular testing, enrollment on molecularly selected clinical trials have been lower than desired [4]. For PCT to advance, patients must participate in clinical trials and need to agree to make their data available for research. However, patients' knowledge about PCT, and their information-seeking behavior about PCT is largely unknown.

Patient knowledge may influence their choice of treatment [5] and willingness to participate in research [6, 7]. In breast cancer patients, studies have been done to develop education materials and decision aids to understand the disease process and treatment options [8–10]. However, in the context of PCT, there are limited tools, at least in part because we do not know what patients know and their expectations from PCT. Both providers and patients have expressed interest in PCT [11]. However, because PCT is constantly evolving, physicians and patients must keep up with changing knowledge.

General population interest and awareness about genetics has improved over time. However, individual understanding has been demonstrated to be either inaccurate or insufficient [12–14]. Studies have assessed patient knowledge about genetics [15–17], but we are not aware of any studies that have been conducted in the context of PCT.

The National Cancer Institute's Health Information National Trend Survey (HINTS), over the years, provides information about cancer information seeking in the general population [18]. From this baseline data, studies have explored subjects' attitudes and preferences in information seeking [19, 20]. Recently, direct-to-consumer genetic tests and genetic information has become available online [21]. However, concerns have been raised about the risk of misinformation and information quality [22, 23]. In the context of PCT, we do not know the patient's information seeking behavior. Thus, we wanted to assess the knowledge and information-seeking behavior of cancer patients in regards to PCT.

## OBJECTIVE

This study aimed to assess breast cancer patients' knowledge, and information seeking about PCT, and its association with privacy concerns about genomic information and patients' perception of PCT.

## METHODS

### Study population

Women diagnosed with breast cancer who were at least 18 years old and who registered as new patients at The University of Texas MD Anderson Cancer Center (MDACC), between October 2012 and January 2013. Participants were recruited during their first visit to MDACC; after registration, but prior to being seen by a clinician. Patients may have previously received care for breast cancer elsewhere. During registration, participants were asked to consent for tissue banking.

### Study questionnaires

Participants answered questions designed to assess knowledge about PCT, molecular testing and cancer genetics (Table 1). This was a cross-sectional survey with conventional sampling. These questions were part of a larger questionnaire and focused on demographics, definitions, expectations and knowledge about research [24, 25]. The knowledge questionnaire included 16 questions each of which could be answered "True", "False" or "Do not know" (Supplementary Document 1). The information-seeking questionnaire contained multiple-choice questions that assessed where participants looked for information and how they used the information that they found. Additional questions assessed attitudes regarding privacy of genomic information and research participation [24, 25]. We recorded participants' age, insurance, and clinical variables such as duration of illness, cancer stage, history of cancer therapy, history of genetic testing, and consent for tissue banking from the participants' medical records.

### Questionnaire development

Questions covering key concepts in PCT were developed by the study team based on literature review and expert knowledge [24, 25]. Prior to administration, the questionnaires were reviewed for content validity and underwent pilot testing. For pilot testing, we recruited patients from the study population. The patients were asked to complete the questionnaire and provide feedback on the questions. The pilot testing was stopped after at least two consecutive patients were able to complete the survey without encountering correctable problems. The pilot data is not included in the analysis. No changes to the questionnaire were made after pilot testing.

### Patient recruitment and data collection

Patients were first asked by the registration clerk whether they were willing to consider participation in a research study. Only those patients who agreed to consider participation were approached by study staff. Of 308 eligible patients, 123 agreed to consider participating in research; of these, 115 (93%) consented to participate. Following informed

consent, 100 participants completed the self-administered study questionnaire (32% response rate). We did not record reasons for refusal or contact the 15 participants with incomplete or non-returned surveys. Research staff were available to address any issues regarding completing the questionnaire. Additional data were obtained from patients' medical records [24, 25].

## Data Analysis

Knowledge scores were calculated as the number of correct answers to the 16 knowledge questions (Cronbach's alpha  $\alpha=0.88$ ). Mean and standard deviation were calculated for the knowledge scores and compared by demographic and clinical characteristics using a Kruskal-Wallis test (Table 1). A multiple linear regression model was conducted with knowledge scores as the outcome variable and demographic and clinical characteristics as predictor variables. Specific variables included were age, race, education, income, duration of illness, any cancer therapy, and genetic testing (Table 1).

Frequencies and percentages were calculated for whether participants had previously looked for information (yes/no) and compared by demographic and clinical characteristics using a Fisher's exact or chi-squared test. A multiple logistic regression model was constructed with the outcome variable being seeking information and predictors being demographic and clinical variables, similar to the linear regression model for knowledge scores (Table 1).

Knowledge score summary statistics were compared by information-seeking, privacy concerns about genomic information, and research participation using a Kruskal-Wallis test (Table 2). Knowledge regarding availability of therapies in clinical trials was compared by willingness to undergo molecular testing using a chi-squared test and logistic regression models. Knowledge of genetic privacy laws was also compared by willingness to undergo molecular testing using a chi-squared test and logistic regression models. Since this was an exploratory study, no corrections for multiple testing were made. The statistical significance threshold ( $\alpha$ ) was 0.05.

## RESULTS

Participants were predominantly white (71%), older (median age 56 years; range 26–84), and educated (79% with college degree or higher), and 63% had incomes over \$50,000/year. Most (71%) were diagnosed with breast cancer within the past year; 61% had early-stage disease and 55% had prior therapy for cancer (Table 1).

Participants correctly answered over half the knowledge questions (Mean=8.68/16, SD=3.8). Most participants correctly identified the definition of PCT (85%), molecular testing (62%) and molecular markers (76%). Many were aware of genetic privacy laws (75%) and of the existence of BRCA1/2 gene mutations implicated in hereditary breast and ovarian cancer (54%). However, 13% knew the difference between somatic and germline mutations and 15% understood that specific molecular characteristics of cancer cells have been identified. Most participants correctly identified the goals of PCT, such as reduced side effects (54%); 51% knew that not all participants will respond, and 61% knew that PCT can fail. However, 35% knew that a target for therapy may not be found in a particular patient's tumor. Most

knew about the use of molecular testing in research (75%), and that testing can identify risks for other cancers (76%). Slightly less than half of the participants knew that PCT was available in clinical trials (46%).

Only a minority (27%) indicated that they had sought information regarding PCT. Among participants who sought information, the Internet was the most common and preferred source. Information about specific treatment options was more commonly-sought than information about doctors/hospitals, cancer genetics or clinical trials. Participants expressed concerns about information quality but required less than two hours to find information that they found information useful and easy to understand.

By univariate analysis, higher education ( $p=0.009$ ) and income ( $p=0.04$ ) were associated with higher knowledge scores and with seeking PCT information ( $p=0.04$ ). Participants who had previously undergone cancer therapy ( $p=0.03$ ) or genetic testing ( $p=0.02$ ) were more likely to seek information about PCT. In the multivariate model, income was significantly associated with knowledge scores. Participants in the highest income group had knowledge scores that were an average of 2.2 points higher than the lowest income group ( $p=0.038$ ). Participants that had prior cancer therapy were more likely to seek information about PCT (OR=4.28;  $p=0.04$ ) (Table 2). Other demographic and clinical variables including age, race, duration of illness, cancer stage were not significantly associated with knowledge or information-seeking behavior.

Participants who sought information had higher knowledge scores ( $p<0.001$ ). However, knowledge was not associated with privacy concerns about genomic information, willingness to participate in research, willingness to donate blood, to undergo tumor biopsies for research or to guide treatment (Table 2). Additionally, there was no correlation between knowledge about genetic privacy laws and willingness to share biological samples or genetic data for research.

## DISCUSSION

Breast cancer patients in our cohort had relatively low levels of knowledge about PCT, and few had sought information about PCT. Participants were able to answer most questions regarding definitions, some questions about what to expect from PCT and research on PCT, but relatively few questions about cancer genetics. Our findings are similar to other studies of patient knowledge regarding genomics [26, 27]. Interestingly, knowledge scores did not predict privacy concerns or willingness to participate in research [24, 26].

We assessed the key components postulated to be barriers to PCT: understanding tumor characteristics, therapy expectations, and research perceptions [2, 28, 29]. Few participants understood PCT-relevant tumor characteristics, many expected too much from PCT. If they expect good outcomes, patients are more likely to participate in cancer trials [30, 31]. In our study, many participants expected good outcomes from PCT. Future research is needed to determine if patients who are optimistic regarding PCT are more likely to participate in clinical trials of PCT.

Participants understood the importance of molecular testing for research. Half of our participants stated that they were willing to undergo new tissue biopsies for research [25]. Many participants knew that genomic testing can reveal additional information about risks for other illness and other cancers. This may inform organizational policies regarding return of incidental (i.e., unexpected but clinically-meaningful) research results.

We found no correlation between knowledge and willingness to participate in research. This is consistent with prior work that suggested other factors such as attitudes, perceptions about the therapy, research design that influence trial participation trials [32, 33]. Therefore, simply teaching patients facts about PCT is not likely to improve participation in clinical trials.

Clinical characteristics did not influence knowledge, suggesting that knowledge was not driven by their specific clinical needs but rather was associated with participants' level of education. This is a potential problem because, higher education is far from universal [34] and there are racial and socio-cultural disparities in educational attainment [35].

Previous studies showed that cancer patients have many information needs [36, 37], but only 27% of our participants sought PCT information. It is possible that biomarkers and genomics are complex topics that patients find difficult to understand. Further, information about cancer genetics may cause distress. Thus, patients may prefer to discuss these concepts with their clinician.[38] Although the Internet was the preferred and most common information source, online information about genetics may be problematic [39–41].

Genetic and genomic research involves ethical, legal and social issues. To address these issues, understanding patients' knowledge about PCT and addressing their concerns is essential. Our results may inform policy makers regarding patients' concerns, as well as how these concerns can be addressed by patient education, informed consent and organizational policies. Because only 27% of participants sought information about PCT prior to their first clinic visit, physicians may be their first source of PCT information. Good physician communication can encourage research participation [42, 43]. Although we found no correlation between knowledge and willingness to participate in research, better education by physicians may improve utilization of services and research participation [44]. Therefore, focus on physician knowledge and understating of PCT is still warranted; especially in primary care.

Our study had several limitations. First, our participants were adult female breast cancer patients who were predominately white, well-educated, and had high annual incomes. These characteristics are similar to the breast cancer population at our center, but not the general population. Thus, our findings cannot be generalized across gender and other cancers. Our response rate (32%) should be interpreted in light of the two-stage recruitment process. Of 308 who were asked if they were willing to participate in a research project by the registration clerk, only 123 were approached by study staff (i.e., asked to consent for the study). It is possible that patients awaiting their first appointment at the institution were worried about their upcoming appointments, which may have affected their willingness to participate negatively. However, we cannot exclude the possibility that patients who agreed

to be approached by study staff were more educated and knowledgeable than the general population.

Additional work is needed to determine how knowledge changes with treatment and participation in research. This will help assess the effectiveness of informed consent and patient education materials. Qualitative studies are required to understand the relationship between knowledge and clinical and demographic characteristics.

## CONCLUSION

Patient knowledge about PCT is moderate. Knowledge score does not correlate with privacy concerns or attitudes toward research. Most participants did not seek information before their visit and thus, clinicians are likely to be patients' initial source of information about PCT. Understanding patients' knowledge and prior information-seeking regarding PCT may inform future patient education efforts.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

This research is supported in part by 1U01 CA180964, the Sheikh Khalifa Al Nahyan Ben Zayed Institute for Personalized Cancer Therapy; NCATS grant UL1 TR000371 (Center for Clinical and Translational Sciences); the Nellie B. Connally Breast Cancer Chair Fund, and the National Institutes of Health through MD Anderson Cancer Center Support Grant CA016672.

## REFERENCES

1. Chapman PB, Hauschild A, Robert C, Haanen JB, Ascierto P, Larkin J, Dummer R, Garbe C, Testori A, Maio M. Improved survival with vemurafenib in melanoma with BRAF V600E mutation. *N. Engl. J. Med.* 2011; 364:2507–2516. [PubMed: 21639808]
2. Meric-Bernstam F, Mills GB. Overcoming implementation challenges of personalized cancer therapy. *Nature Reviews Clinical Oncology.* 2012; 9:542–548.
3. Meric-Bernstam F, Johnson A, Holla V, Bailey AM, Brusco L, Chen K, Routbort M, Patel KP, Zeng J, Kopetz S, Davies MA, Piha-Paul SA, Hong DS, Eterovic AK, Tsimberidou AM, Broaddus R, Bernstam EV, Shaw KR, Mendelsohn J, Mills GB. A decision support framework for genomically informed investigational cancer therapy. *J. Natl. Cancer Inst.* 2015; 107
4. Meric-Bernstam F, Brusco L, Shaw K, Horombe C, Kopetz S, Davies MA, Routbort M, Piha-Paul SA, Janku F, Ueno N. Feasibility of Large-Scale Genomic Testing to Facilitate Enrollment Onto Genomically Matched Clinical Trials. *J. Clin. Oncol.* 2015 JCO. 2014.2060. 4165.
5. Lerman C NSSK, et al. Brca1 testing in families with hereditary breast-ovarian cancer: A prospective study of patient decision making and outcomes. *JAMA: the journal of the American Medical Association.* 1996; 275:1885–1892. [PubMed: 8648868]
6. McCarty CA, Nair A, Austin DM, Giampietro PF. Informed Consent and Subject Motivation to Participate in a Large, Population-Based Genomics Study: The Marshfield Clinic Personalized Medicine Research Project. *Public Health Genomics.* 2007; 10:2–9.
7. Mamo LA, Browe DK, Logan HC, Kim KK. Patient informed governance of distributed research networks: results and discussion from six patient focus groups, AMIA Annual Symposium Proceedings. *American Medical Informatics Association.* 2013:920.

8. Fagerlin A, Lakhani I, Lantz PM, Janz NK, Morrow M, Schwartz K, Deapen D, Salem B, Liu L, Katz SJ. An informed decision?: Breast cancer patients and their knowledge about treatment. *Patient Educ. Couns.* 2006; 64:303–312. [PubMed: 16860523]
9. Whelan T, Levine M, Willan A, Gafni A, Sanders K, Mirsky D, Chambers S, O'Brien MA, Reid S, Dubois S. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA.* 2004; 292:435–441. [PubMed: 15280341]
10. Waljee JF, Rogers MA, Alderman AK. Decision aids and breast cancer: do they influence choice for surgery and knowledge of treatment options? *J. Clin. Oncol.* 2007; 25:1067–1073. [PubMed: 17369570]
11. Gray SW, Hicks-Courant K, Lathan CS, Garraway L, Park ER, Weeks JC. Attitudes of Patients With Cancer About Personalized Medicine and Somatic Genetic Testing. *J. Oncol. Pract.* 2012
12. Andrykowski MA, Munn RK, Studts JL. Interest in learning of personal genetic risk for cancer: a general population survey. *Prev. Med.* 1996; 25:527–536. [PubMed: 8888320]
13. Lanie AD, Jayaratne TE, Sheldon JP, Kardia SL, Anderson ES, Feldbaum M, Petty EM. Exploring the public understanding of basic genetic concepts. *Journal of genetic counseling.* 2004; 13:305–320. [PubMed: 19736696]
14. Haga SB, Barry WT, Mills R, Ginsburg GS, Svetkey L, Sullivan J, Willard HF. Public knowledge of and attitudes toward genetics and genetic testing. *Genetic testing and molecular biomarkers.* 2013; 17:327–335. [PubMed: 23406207]
15. Green MJ, Biesecker BB, McInerney AM, Mauger D, Fost N. An interactive computer program can effectively educate patients about genetic testing for breast cancer susceptibility. *Am. J. Med. Genet.* 2001; 103:16–23. [PubMed: 11562929]
16. MacNew H, Rudolph R, Brower S, Beck A, Meister E. Assessing the knowledge and attitudes regarding genetic testing for breast cancer risk in our region of southeastern Georgia. *The breast journal.* 2010; 16:189–192. [PubMed: 20030654]
17. Ludman EJ, Curry SJ, Hoffman E, Taplin S. Women's knowledge and attitudes about genetic testing for breast cancer susceptibility. *Effective clinical practice: ECP.* 1998; 2:158–162. [PubMed: 10539540]
18. Cantor, D.; Covell, J.; Davis, T.; Park, I.; Rizzo, L. Bethesda, MD: National Cancer Institute; 2005. Health Information National Trends Survey 2005 (HINTS 2005): Final Report.
19. Hesse BW, Moser RP, Rutten LJJ, Kreps GL. The health information national trends survey: research from the baseline. *Journal of Health Communication.* 2006; 11:vii–xvi. [PubMed: 16641070]
20. Freimuth V. The Health Information National Trends Survey (HINTS): development, design, and dissemination. *Journal of Health Communication.* 2004; 9:483–484.
21. Gollust SE, Hull SC, Wilfond BS. Limitations of direct-to-consumer advertising for clinical genetic testing. *JAMA.* 2002; 288:1762–1767. [PubMed: 12365961]
22. Meric F, Bernstam EV, Mirza NQ, Hunt KK, Ames FC, Ross MI, Kuerer HM, Pollock RE, Musen MA, Singletary SE. Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. *BMJ.* 2002; 324:577–581. [PubMed: 11884322]
23. Lachance CR, Erby LA, Ford BM, Allen VC, Kaphingst KA. Informational content, literacy demands, and usability of websites offering health-related genetic tests directly to consumers. *Genet. Med.* 2010; 12:304–312. [PubMed: 20386454]
24. Rogith D, Yusuf RA, Hovick SR, Peterson SK, Burton-Chase AM, Li Y, Meric-Bernstam F, Bernstam EV. Attitudes regarding privacy of genomic information in personalized cancer therapy. *J. Am. Med. Inform. Assoc.* 2014 amiajnl-2013-002579.
25. Yusuf RA, Rogith D, Hovick SRA, Peterson SK, Burton-Chase AM, Fellman BM, Li Y, McKinney C, Bernstam EV, Meric-Bernstam F. Attitudes toward molecular testing for personalized cancer therapy. *Cancer.* 2015; 121:243–250. [PubMed: 25209923]
26. Richman AR, Tzeng JP, Carey LA, Retèl VP, Brewer NT. Knowledge of genomic testing among early-stage breast cancer patients. *Psycho-Oncology.* 2011; 20:28–35. [PubMed: 20200857]
27. Blanchette PS, Spreafico A, Miller FA, Chan K, Bytautas J, Kang S, Bedard PL, Eisen A, Potanina L, Holland J. Genomic testing in cancer: Patient knowledge, attitudes, and expectations. *Cancer.* 2014



28. Murphy J, Scott J, Kaufman D, Geller G, LeRoy L, Hudson K. Public Expectations for Return of Results from Large-Cohort Genetic Research. *The American Journal of Bioethics*. 2008; 8:36–43. [PubMed: 19061108]
29. Peppercorn JM, Smith TJ, Helft PR, DeBono DJ, Berry SR, Wollins DS, Hayes DM, Von Roenn JH, Schnipper LE. American Society of Clinical Oncology statement: Toward individualized care for patients with advanced cancer. *J. Clin. Oncol.* 2011; 29:755–760. [PubMed: 21263086]
30. Mills EJ, Seely D, Rachlis B, Griffith L, Wu P, Wilson K, Ellis P, Wright JR. Barriers to participation in clinical trials of cancer: a meta-analysis and systematic review of patient-reported factors. *The Lancet Oncology*. 2006; 7:141–148. [PubMed: 16455478]
31. Fetting JH, Siminoff LA, Piantadosi S, Abeloff MD, Damron DJ, Sarsfield AM. Effect of patients' expectations of benefit with standard breast cancer adjuvant chemotherapy on participation in a randomized clinical trial: a clinical vignette study. *J. Clin. Oncol.* 1990; 8:1476–1482. [PubMed: 2202790]
32. Manne S, Kashy D, Albrecht T, Wong Y-N, Flamm AL, Benson AB, Miller SM, Fleisher L, Buzaglo J, Roach N. Knowledge, Attitudes, and Self-efficacy as Predictors of Preparedness for Oncology Clinical Trials A Mediation Model. *Med. Decis. Making*. 2013 0272989X13511704.
33. Ellis PM, Butow PN, Tattersall MHN. Informing breast cancer patients about clinical trials: a randomized clinical trial of an educational booklet. *Ann. Oncol.* 2002; 13:1414–1423. [PubMed: 12196367]
34. Ryan, CL.; Sibens, J. Educational Attainment in the United States: 2009. Washington, DC: U.S. Census Bureau; 2012 Feb.
35. Farkas G. Racial disparities and discrimination in education: What do we know, how do we know it, and what do we need to know? *The Teachers College Record*. 2003; 105:1119–1146.
36. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere K, O'Neil J, Bilodeau B, Watson P, Mueller B. Information needs and decisional preferences in women with breast cancer. *JAMA*. 1997; 277:1485–1492. [PubMed: 9145723]
37. Harris K. The informational needs of patients with cancer and their families. *Cancer Pract.* 1998; 6:39–46. [PubMed: 9460325]
38. Jefford M, Tattersall MH. Informing and involving cancer patients in their own care. *The lancet oncology*. 2002; 3:629–637. [PubMed: 12372725]
39. E.S.o.H. Genetics. Statement of the ESHG on direct-to-consumer genetic testing for health-related purposes. *Eur. J. Hum. Genet.* 2010; 18:1271. [PubMed: 20736974]
40. Pagon RA, Pinsky L, Beahler CC. Online medical genetics resources: a US perspective. *BMJ: British Medical Journal*. 2001; 322:1035. [PubMed: 11325770]
41. Shepperd S, Farndon P, Grainge V, Oliver S, Parker M, Perera R, Bedford H, Elliman D, Kent A, Rose P. DISCERN-Genetics: quality criteria for information on genetic testing. *Eur. J. Hum. Genet.* 2006; 14:1179–1188. [PubMed: 16868557]
42. Albrecht TL, Blanchard C, Ruckdeschel JC, Coovert M, Strongbow R. Strategic Physician Communication and Oncology Clinical Trials. *J. Clin. Oncol.* 1999; 17:3324–3332. [PubMed: 10506636]
43. Paskett ED, Cooper MR, Stark N, Ricketts TC, Tropman S, Hatzell T, Aldrich T, Atkins J. Clinical trial enrollment of rural patients with cancer. *Cancer Pract.* 2002; 10:28–35. [PubMed: 11866706]
44. Kinney AY, Richards C, Vernon SW, Vogel VG. The effect of physician recommendation on enrollment in the Breast Cancer Chemoprevention Trial. *Prev. Med.* 1998; 27:713–719. [PubMed: 9808803]

### Highlights

- Female breast cancer patients completed a self-administered questionnaire.
- Cancer genetics and personalized cancer therapy knowledge was moderate.
- Only 27% of patients indicated that they had sought information regarding PCT.
- Education and income were associated with higher knowledge scores and information-seeking.
- Knowledge was not associated with willingness to participate in research.

### Summary Table

What was already known	What this study added to knowledge
Patient knowledge may influence their choice of treatment and willingness to participate in research.	Knowledge did not predict privacy concerns or willingness to participate in research.
Cancer patient's have been studied.	We assessed patient knowledge of genetics in the context of PCT and molecular testing
Patient knowledge on genetics is inaccurate or insufficient.	We qualified knowledge on genetics in terms of general knowledge, definitions, therapy, research perceptions and cancer biology.
Cancer patients, in general, have many information needs and they seek information online.	Physicians may be their first source of PCT information.

**Table 1**

## Determinants of Knowledge and Information-seeking

Variable	Category	N	Knowledge Score Mean	Sought Information about PCT (N)
Age	18–50yr	32	8	12 (37%)
	>50yr	68	9	15 (22%)
Race	Non-white	28	7	6 (21%)
	White	70	9	21 (30%)
Education <sup>a,c</sup>	High School or less	21	7	4 (19%)
	College degree	55	9	11 (20%)
	Graduate and higher	23	10	11 (48%)
Income Group <sup>b,c,d</sup>	<\$50000	32	8	6 (19%)
	\$50000–\$99999	26	9	4 (15%)
	\$100000 and above	28	10	12 (43%)
Insurance Type	Self-Pay	2	12	0 (0%)
	Medicare & Medicaid	32	8	6 (19%)
	Other Insurance	66	9	21 (32%)
Marital Status	Single / Widowed	25	9	3 (12%)
	Married / Partnered	75	9	24 (32%)
Have Children	Yes	80	9	25 (31%)
	No	20	8	2 (10%)
Family History of Cancer	Yes	57	9	16 (28%)
	No	40	9	10 (25%)
Duration of illness	0–1 yr	71	8	18 (25%)
	> 1 yr	29	10	9 (31%)
Stage of Cancer	Early (Stages 0, I and II)	60	9	14 (23%)
	Advanced (Stages III and IV)	39	9	13 (33%)
Cancer Therapy <sup>c, e</sup>	Yes	55	9	20 (36%)
	No	45	8	7 (15%)
History of Genetic Testing <sup>c</sup>	Yes	15	10	8 (53%)
	No	85	9	19 (23%)

<sup>a</sup> - Significant association with knowledge score - univariate analysis (p<0.01)

<sup>b</sup> - Significant association with knowledge score - univariate analysis (p<0.05)

<sup>c</sup> - Significant association with information seeking - univariate analysis (p<0.05)

<sup>d</sup> - Significant association with knowledge score (p<0.05) - multivariate analysis

<sup>e</sup> - Significant association with information seeking (p<0.05) – multivariate analysis

Relationship between patient knowledge scores and their information-seeking behavior, privacy concerns and research participation attitudes.

**Table 2**

	N	Knowledge Score		p-value
		Mean	SD	
Information-seeking about PCT	No	7.89	3.92	<b>0.0002*</b>
	Yes	10.96	2.14	
Privacy concerns <sup>a</sup>	Less concerned	8.6	3.9	0.068
	More concerned	13	3.3	
Willing to undergo molecular testing to guide own therapy <sup>b</sup>	Disagree	7.8	4.0	0.235
	Agree	77	3.5	
Willing to give blood sample to guide own therapy <sup>b</sup>	Disagree	8.4	3.5	0.610
	Agree	84	3.6	
Willing to undergo needle biopsy of tumor to guide own therapy <sup>b</sup>	Disagree	8.5	3.8	0.641
	Agree	71	3.6	
Willing to undergo molecular testing for research <sup>b</sup>	Disagree	8.61	3.8	0.396
	Agree	55	3.5	
Willing to give blood sample for research <sup>b</sup>	Disagree	8.26	3.8	0.247
	Agree	61	3.5	
Willing to undergo needle biopsy of tumor for research <sup>b</sup>	Disagree	8.86	3.6	0.811
	Agree	42	3.7	

\* p < 0.05

<sup>a</sup> - Summary of privacy concerns from privacy questionnaire [24]

<sup>b</sup> - Questions from research perception questionnaire [25]

Note: Table 2 includes only patients with responses to the questions and who completed the knowledge questionnaire.