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Involving Patients and Their Families in Deciding to Use Next Generation Sequencing: Results from a Nationally Representative Survey of U.S. Oncologists

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Abstract

Objective: Next generation sequencing (NGS) may aid in tumor classification and treatment. Barriers to shared decision-making may influence use of NGS. We examined, from oncologists' perspectives, whether barriers to involving patients/families in decision-making were associated with NGS use.

Methods: Using data from the first national survey of medical oncologists' perspectives on precision medicine (N=1281), we approached our analyses in two phases. Bivariate analyses initially evaluated associations between barriers to involving patients/families in deciding to use

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NGS and provider- and organizational-level characteristics. Modified Poisson regressions then examined associations between patient/family barriers and NGS use.

Results: Approximately 59% of oncologists reported at least one barrier to involving patients/families in decision-making regarding NGS use. Those reporting patient/family barriers tended to have fewer genomic resources at their practices, to be in rural or suburban areas, and to have a higher proportion of Medicaid patients. However, these barriers were not associated with NGS use.

Conclusions: Oncologists encounter barriers to involving patients/families in NGS testing decisions. Organizational barriers may also potentially play a role in testing decisions.

Practice Implications: To foster patient-centered care, strategies to support patient involvement in genomic testing decisions are needed, particularly among practices in low-resource settings.

Keywords

genomic testing; barrier; provider communication; cancer

1. INTRODUCTION

A cornerstone of precision oncology includes the use of tumor genomics to guide cancer treatment decisions. Studies have shown that next generation sequencing (NGS) panels, genomic tests that allow for multiple genes to be assessed simultaneously, may aid in the identification of tumor mutations and other alterations as well as the selection of targeted treatment regimens based on tumor genomics [1]. Accordingly, the number of commercially-available NGS panels has substantially increased [2]. A recent national study found that three-quarters of oncologists use NGS tests, with one-third reporting using them often to guide treatment decisions [3]. However, there is a paucity of clinical guidelines regarding these panels, making it unclear what specific factors influence oncologists' use of these tests.

Patients' preferences for genomic testing may contribute to oncologists' decisions to use or not use NGS panels. Based on studies of shared decision-making in other cancer care contexts, patient-level factors such as uncertainty about the treatment decision [4], patient concerns about risks associated with treatment options [5], poor physician communication [6–8], and structural and time constraints in the clinical encounter [9] may play into oncologists' recommendation patterns. However, the extent that patient and family factors contribute to decision-making for multi-marker tumor panel testing is unknown. The objective of this brief report is to describe the barriers to involving patients and their families in the decision-making process for using NGS panels for cancer treatment management. We also examined the association between these barriers and oncologist- and practice-level characteristics and whether these barriers were associated with NGS use.

2. METHODS

We used data from the National Cancer Institute's *National Survey of Precision Medicine in Cancer Treatment*, a nationally representative survey of medical oncologists' perspectives on precision medicine [3]. The survey collected information on oncologists' demographics, practice characteristics, genomic testing resources, and use of multi-marker tumor panels. Of 3,378 eligible oncologists, 1,281 completed the survey (38% participation rate). Detailed information regarding the survey's data collection methods has been published elsewhere [10].

We examined oncologist-reported answers to the following question: "In the past 12 months, how important was each of the following factors in your decision to use multi-marker tumor panels to make treatment decisions for your cancer patients?" These factors (described in detail in Figure 1) were measured using a 4-point Likert-type scale; we created binary variables to reflect when patient/family factors were "sometimes" or "often," compared to "rarely" or "never," reported as barriers. We also examined use of NGS testing, a type of multi-marker tumor panel testing; oncologists who had used an NGS panel at least once in the past 12 months to guide treatment were considered NGS users.

All analyses were weighted. Survey weights were calculated based on oncologists' age, sex, and location and also adjusted for complex survey design by accounting for the probability of selection, noncontact, and noncooperation. We first evaluated bivariate associations between the patient/family barriers and the patient-mix, provider-level, and organizational-level characteristics among our full sample. As a sensitivity analysis, we also examined these associations among oncologists who (a) only reported NGS test use and (b) multi-marker tumor panel use, broadly, given that respondents may have been thinking about genomic tests other than NGS when answering these questions. Then, in bivariate and multivariate analyses, we used modified Poisson regressions to estimate prevalence ratios (PRs) and 95% confidence intervals (CI) to determine if patient/family barriers were associated with NGS use. Adjusted analyses included patient-mix, provider-level, and organizational-level characteristics. All analyses were conducted in STATA version 13.0 software (STATA Corp, College Station, TX).

3. RESULTS

About one-third of oncologists saw 100–199 cancer patients per month (Table 1). Most respondents practiced in a single specialty (44%) or multi-specialty (44%) group, and 42% saw patients at an academic medical center (Table 1). The majority specialized in both solid tumors and hematologic malignancies (58%), practiced in an urban location (54%), were affiliated with an academic institution (62%), and had some formal genomic training (56%).

3.1 Oncologist-reported barriers to testing

Overall, about 59% of oncologists reported barriers to involving their patients/families in the decision-making process for NGS use. *Lacking education materials to share with patients/families* was the most frequent barrier, with 34% citing it as sometimes or often a barrier (Figure 1). This was followed by *difficulty getting patients/families to understand treatment options* (29%), *difficulty getting patients/families to understand purpose of the test* (25%), and *insufficient time to discuss testing or treatment options* (24%). The least common reported barrier was *patient/family resistance to testing*, with 19% indicating this was sometimes or often a barrier.

3.2 Oncologist and practice characteristics and barriers

Availability of certain genomic testing services were associated with oncologists reporting lower testing barriers (Table 2). Specifically, genomic testing services associated with lower patient/family resistance to testing included on-site pathology, on-site genetic counselors, internal policies regarding genomic testing, and genomic/molecular tumor boards. On-site pathology was associated with less difficulty getting patients/families to understand the test's purpose and treatment options. Oncologists practicing in settings with internal genomic testing policies were less likely to report lacking education materials to share with patients/families.

Older age, practicing in rural and suburban areas, and treating a higher percentage of Medicaid patients were also associated with oncologists reporting barriers to involving patients/families in the decision-making process. Rural oncologists and those age 60 and older were more likely to report lacking genomic testing education materials and patient/family resistance to testing as barriers, compared to urban oncologists, and those age 30– 39, respectively. Suburban oncologists reported more patient/family resistance to testing compared to urban oncologists. Physicians seeing high percentages of Medicaid patients had difficulty getting patients/families to understand treatment options and lacked genomic testing education materials. Our sensitivity analyses (Appendix Tables 1 and 2) suggested that findings were similar for NGS users only and those using different types of multi-marker tumor panel tests.

3.3 Barriers and reported use of NGS tests

In bivariate and multivariate analyses adjusting for provider-level, organizational-level, and patient-mix covariates, oncologist-reported patient/family barriers were not predictive of using NGS in the past 12 months (Appendix Table 3). For example, lacking education materials to share with patients/families was not associated with whether oncologists used NGS in the past 12 months.

4. DISCUSSION

4.1 Discussion

Approximately 59% of oncologists reported barriers to involving patients/families in the decision-making process for NGS testing, suggesting a need for interventions to encourage involvement in genomic testing decisions. This would be particularly useful among oncologists in lower resourced settings, given that barriers were more likely to be reported among oncologists with fewer genomic testing resources at their practice settings, in rural or suburban areas, and in practices with a higher proportion of Medicaid patients.

Barriers to involving patients/families in the decision-making process for multi-marker tumor panel testing was not predictive of NGS use, suggesting that testing occurs despite the presence of these barriers. For oncologists who did not order NGS tests, provider- or organizational-level barriers may play a more predominant role than patient/family barriers. These findings align with studies demonstrating high acceptability of NGS panels among cancer patients to guide treatment selection [11]. The literature has shown that provider (e.g., comfort with interpreting results), organizational (e.g., access to clinical trials), and policy (e.g., costs, insurance coverage) barriers may be more salient for NGS use [12]. Future research examining these multilevel barriers may provide additional insights into implementing precision oncology.

Findings should be considered in light of some limitations. Oncologists engaged with precision oncology may have been more likely to respond to our survey; thus, we may be underrepresenting the extent of barriers to involving patients/families in testing decisions. Additionally, our participation rate was relatively low (38%). However, similar to previous analyses, we accounted for any nonresponse bias by including weights calculated using data from the survey's sample frame [3]. Third, we could not examine the relationship between barriers and the frequency of NGS testing. It is possible that oncologists who use NGS panels for a small portion of their patients may encounter more barriers than those who use NGS panels for a large portion of patients. Finally, we examined patient/family barriers in decision-making from the perspective of the oncologist, and not the patients' and families' perspectives, which would have provided additional insight on involving patients and families in treatment decision-making, particularly the use of NGS tests.

4.2 Conclusion and practice implications

This is the first nationally representative study to describe patient/family-level barriers to involving patients and families in the decision-making process for NGS. Additional strategies, such as the development and distribution of decision aids to guide genomic testing discussions between physicians and patients [13]and educational outreach among physicians to increase their knowledge of genetic testing and genetic testing guidelines [14], need to be implemented and evaluated to support the involvement of patients and their families in the decisions about genomic testing and to foster patient-centered care in this context. It will also be important for future studies to examine the multilevel barriers associated with uptake of NGS tests.

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Appendix

Appendix Table 1.

Bivariate associations between provider-level, organizational-level, and patient-mix characteristics associated with patient/family barriers to multi-marker tumor panel testing, among NGS users only (N=959)

	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI
Provider-level characteristics										
Female (ref. male)	1.11	(0.87–1.42)	1.14	(0.92–1.41)	**1.29**	**(1.07–1.55)**	1.18	(0.93–1.51)	1.13	(0.85–1.51)
Age (ref. 30 to 39)										
40 to 49	0.96	(0.71–1.31)	1.06	(0.80–1.41)	0.89	(0.68–1.15)	0.96	(0.72–1.27)	1.30	(0.86–1.96)
50 to 59	0.90	(0.64–1.27)	0.99	(0.72–1.35)	1.09	(0.83–1.42)	**0.56**	**(0.38–0.82)**	1.38	(0.89–2.13)
60 and over	0.99	(0.71–1.37)	1.21	(0.90–1.62)	1.17	(0.91–1.52)	0.81	(0.58–1.13)	**1.66**	**(1.10–2.52)**
Years since graduation (ref. 10 to 19)										
20 to 34	0.94	(0.72–1.24)	1.06	(0.82–1.35)	1.04	(0.83–1.30)	**0.70**	**(0.53–0.92)**	1.03	(0.73–1.47)
35 or more	0.99	(0.80–1.31)	1.17	(0.91–1.51)	**1.26**	**(1.01–1.57)**	0.77	(0.58–1.02)	**1.53**	**(1.10–2.13)**
Primary specialty (ref. solid tumors)										
Hematologic malignancies	0.90	(0.48–1.69)	0.77	(0.42–1.43)	0.75	(0.43–1.31)	**0.39**	**(0.16–0.97)**	**0.20**	**(0.04–0.90)**
Solid tumors and hematologic malignancies	1.20	(0.94–1.53)	1.10	(0.89–1.36)	1.03	(0.85–1.24)	1.09	(0.86–1.39)	1.18	(0.89–1.57)
Primary practice affiliated with academic institution	0.79	(0.63–1.00)	0.85	(0.70–1.05)	0.99	(0.82–1.20)	0.86	(0.68–1.09)	**0.70**	**(0.53–0.92)**
Sees patients at academic center or medical school	0.80	(0.63–1.01)	**0.78**	**(0.63–0.96)**	0.90	(0.75–1.08)	0.82	(0.65–1.04)	**0.52**	**(0.38–0.70)**
Formal training on genomic testing	0.96	(0.77–1.21)	0.94	(0.77–1.15)	0.87	(0.73–1.04)	0.80	(0.63–1.00)	0.12	(0.64–1.11)
Organizational-level characteristics										
Primary practice (Ref: Solo practice)										
Single specialty practice	0.86	(0.52–1.42)	0.80	(0.52–1.24)	1.17	(0.72–1.91)	0.89	(0.53–1.47)	0.81	(0.47–1.37)
Multi-specialty practice	0.72	(0.43–1.19)	0.72	(0.46–1.11)	1.03	(0.63–1.69)	0.73	(0.43–1.22)	**0.46**	**(0.26–0.80)**

	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**
Other	0.68	(0.35–1.31)	0.74	(0.42–1.29)	0.79	(0.42–1.46)	0.44	(0.20–0.94)	**0.41**	**(0.18–0.93)**
Practice location (Ref: Urban)										
Suburban	1.00	(0.78–1.27)	0.97	(0.78–1.21)	0.97	(0.79–1.18)	0.77	(0.59–1.00)	**1.44**	**(1.07–1.94)**
Rural	1.01	(0.68–1.51)	1.11	(0.79–1.55)	**1.43**	**(1.11–1.84)**	0.98	(0.66–1.44)	**2.15**	**(1.47–3.14)**
Genomic services (Ref: No/Don’t Know)										
On-site pathology	**0.72**	**(0.57–0.91)**	**0.73**	**(0.60–0.90)**	**0.82**	**(0.68–0.99)**	0.88	(0.68–1.12)	**0.54**	**(0.42–0.71)**
Contract with off-site pathology lab	1.01	(0.74–1.40)	0.95	(0.72–1.26)	0.95	(0.74–1.21)	0.80	(0.60–1.08)	1.16	(0.78–1.74)
On-site genetic counselors	0.85	(0.67–1.08)	0.91	(0.74–1.13)	0.88	(0.73–1.06)	0.91	(0.71–1.16)	**0.57**	**(0.43–0.75)**
Internal policies regarding genomic testing	0.90	(0.71–1.12)	0.95	(0.78–1.16)	**0.81**	**(0.67–0.97)**	0.95	(0.75–1.20)	**0.75**	**(0.57–0.99)**
EMR alert for genomic testing	1.27	(0.97–1.66)	1.12	(0.87–1.43)	0.85	(0.66–1.10)	1.14	(0.85–1.51)	**1.42**	**(1.03–1.95)**
Genomic/ molecular tumor board	0.87	(0.68–1.10)	0.88	(0.71–1.09)	0.86	(0.71–1.04)	0.94	(0.74–1.20)	**0.56**	**(0.41–0.77)**
Patient-mix characteristics										
No. of unique patients with cancer/month (Ref: 1 to 49)										
50 to 99	1.16	(0.83–1.63)	1.38	(1.01–1.88)	**1.41**	**(1.07–1.85)**	**1.80**	**(1.24–2.62)**	1.23	(0.82–1.86)
100 to 199	1.25	(0.92–1.70)	1.35	(1.01–1.80)	1.18	(0.90–1.54)	**1.80**	**(1.27–2.57)**	1.39	(0.96–2.02)
200 or more	1.22	(0.84–1.76)	1.43	(0.94–2.00)	**1.76**	**(1.34–2.31)**	**1.76**	**(1.17–2.64)**	1.23	(0.78–1.94)
No. of unique patients with metastatic cancer/ month (Ref: 1 to 24)										
25 to 49	1.13	(0.80–1.58)	1.28	(0.94–1.76)	0.98	(0.75–1.29)	1.52	(1.05–2.18)	1.27	(0.86–1.89)
50 to 74	1.12	(0.79–1.60)	1.25	(0.90–1.73)	1.04	(0.79–1.36)	1.57	(1.08–2.27)	1.11	(0.72–1.70)
75 or more	1.19	(0.87–1.63)	**1.40**	**(1.05–1.88)**	1.10	(0.86–1.40)	1.49	(1.05–2.12)	1.14	(0.77–1.66)
% Medicaid	1.16	(1.00–1.34)	**1.16**	**(1.02–1.33)**	**1.13**	**(1.00–1.28)**	1.10	(0.95–1.29)	1.09	(0.91–1.30)

p-values that are significant (p<0.05) are bold

Appendix

Appendix Table 2.

Bivariate associations between provider-level, organizational-level, and patient-mix characteristics associated with patient/family barriers to

	Difficulty getting patient/ family to understand purpose of the test		**Difficulty getting patient/ family to understand treatment options**		**Lack of education materials to share with patient/family**		**Insufficient time to discuss testing or treatment options with patient/family**		**Patient/family resistant to testing**	
	PR	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**
Provider-level characteristics										
Female (ref. male)	1.07	(0.85–1.36)	1.11	(0.90–1.37)	1.25	(1.04–1.50)	1.16	(0.92–1.47)	1.16	(0.88–1.53)
Age (ref. 30 to 39)										
40 to 49	0.97	(0.72–1.30)	1.06	(0.80–1.40)	0.92	(0.71–1.18)	0.98	(0.74–1.29)	1.34	(0.89–2.00)
50 to 59	0.96	(0.69–1.34)	1.02	(0.76–1.39)	1.14	(0.88–1.48)	**0.59**	**(0.41–0.85)**	1.39	(0.90–2.13)
60 and over	1.03	(0.75–1.42)	1.22	(0.92–1.63)	1.22	(0.95–1.57)	0.83	(0.60–1.14)	**1.71**	**(1.14–2.56)**
Years since graduation (ref. 10 to 19)										
20 to 34	0.98	(0.75–1.27)	1.10	(0.86–1.39)	1.05	(0.84–1.31)	**0.75**	**(0.58–0.98)**	1.10	(0.78–1.54)
35 or more	1.05	(0.81–1.38)	1.23	(0.96–1.56)	**1.30**	**(1.05–1.61)**	0.80	(0.61–1.06)	**1.56**	**(1.13–2.16)**
Primary specialty (ref. solid tumors)										
Hematologic malignancies	0.90	(0.48–1.71)	0.77	(0.42–1.43)	0.75	(0.43–1.30)	**0.39**	**(0.16–0.97)**	0.21	(0.05–0.93)
Solid tumors and hematologic Malignancies	1.24	(0.98–1.57)	1.11	(0.90–1.36)	1.02	(0.85–1.22)	1.10	(0.87–1.39)	1.26	(0.96–1.67)
Primary practice affiliated with academic institution	**0.79**	**(0.63–0.98)**	0.86	(0.70–1.04)	0.99	(0.83–1.19)	0.86	(0.69–1.07)	**0.70**	**(0.54–0.91)**
Sees patients at academic center or medical school	0.80	(0.64–1.01)	**0.80**	**(0.65–0.98)**	0.90	(0.75–1.08)	0.83	(0.66–1.04)	**0.51**	**(0.38–0.69)**
Formal training on genomic testing	0.97	(0.78–1.20)	0.95	(0.78–1.16)	0.88	(0.74–1.05)	0.80	(0.64–1.00)	0.90	(0.69–1.17)
Organizational-level characteristics										
Primary practice (Ref: Solo practice)										
Single specialty practice	0.80	(0.51–1.26)	0.88	(0.57–1.35)	1.08	(0.70–1.67)	0.92	(0.57–1.49)	0.98	(0.57–1.68)

	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**
Multi-specialty practice	0.69	(0.44–1.09)	0.80	(0.52–1.24)	0.98	(0.63–1.53)	0.78	(0.48–1.27)	**0.54**	**(0.31–0.95)**
Other	0.64	(0.35–1.18)	0.81	(0.46–1.40)	0.73	(0.41–1.30)	**0.48**	**(0.23–0.99)**	**0.45**	**(0.19–1.03)**
Practice location (Ref: Urban)										
Suburban	0.99	(0.78–1.25)	0.95	(0.77–1.18)	0.96	(0.79–1.17)	**0.76**	**(0.59–0.98)**	**1.47**	**(1.10–1.96)**
Rural	1.03	(0.71–1.50)	1.03	(0.74–1.42)	**1.35**	**(1.06–1.74)**	0.93	(0.64–1.35)	**2.07**	**(1.44–2.99)**
Genomic services (Ref: No/Don't Know)										
On-site pathology	**0.72**	**(0.58–0.89)**	**0.75**	**(0.62–0.91)**	**0.82**	**(0.69–0.98)**	0.90	(0.71–1.14)	**0.53**	**(0.41–0.68)**
Contract with off-site pathology lab	1.08	(0.79–1.49)	1.02	(0.77–1.35)	0.98	(0.76–1.25)	0.85	(0.64–1.14)	1.26	(0.84–1.89)
On-site genetic counselors	0.82	(0.66–1.03)	0.91	(0.74–1.12)	0.87	(0.73–1.04)	0.89	(0.71–1.12)	**0.54**	**(0.42–0.70)**
Internal policies regarding genomic testing	0.88	(0.71–1.10)	0.93	(0.77–1.14)	**0.81**	**(0.68–0.96)**	0.94	(0.75–1.18)	**0.71**	**(0.54–0.92)**
EMR alert for genomic testing	1.26	(0.97–1.63)	1.09	(0.85–1.39)	0.90	(0.70–1.14)	1.11	(0.84–1.47)	**1.38**	**(1.01–1.87)**
Genomic/ molecular tumor board	0.89	(0.71–1.12)	0.91	(0.74–1.12)	0.88	(0.73–1.06)	0.97	(0.77–1.22)	**0.56**	**(0.41–0.76)**
Patient-mix characteristics										
No. of unique patients with cancer/month (Ref: 1 to 49)										
50 to 99	1.26	(0.91–1.74)	**1.46**	**(1.08–1.97)**	**1.41**	**(1.09–1.83)**	**1.82**	**(1.27–2.59)**	1.19	(0.90–1.99)
100 to 199	1.31	(0.98–1.77)	**1.39**	**(1.05–1.84)**	1.15	(0.89–1.49)	**1.74**	**(1.24–2.45)**	**1.44**	**(1.00–2.07)**
200 or more	1.27	(0.89–1.81)	**1.47**	**(1.07–2.03)**	**1.64**	**(1.26–2.14)**	**1.79**	**(1.22–2.62)**	1.31	(0.84–2.02)
No. of unique patients with metastatic cancer/ month (Ref: 1 to 24)										
25 to 49	1.19	(0.86–1.65)	1.33	(0.98–1.81)	0.99	(0.76–1.29)	**1.50**	**(1.06–2.13)**	1.32	(0.90–1.93)
50 to 74	1.21	(0.87–1.69)	1.33	(0.98–1.82)	1.06	(0.81–1.37)	**1.58**	**(1.11–2.25)**	1.22	(0.82–1.82)
75 or more	1.22	(0.90–1.66)	**1.41**	**(1.06–1.88)**	1.08	(0.85–1.37)	**1.48**	**(1.06–2.06)**	1.14	(0.78–1.65)

	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI
% Medicaid	1.13	(0.98–1.30)	**1.16**	**(1.01–1.32)**	**1.13**	**(1.00–1.27)**	1.12	(0.96–1.29)	1.09	(0.92–1.29)

p-values that are significant (p<0.05) are bold

Appendix

Appendix Table 3.

Associations between patient/family barriers and use of NGS

	uPR(95%CI)		aPR(95% CI)	
Difficulty getting patient/family to understand purpose of the test	1.01	(0.93– 1.09)	1.03	(0.93– 1.08)
Difficulty getting patient/family to understand treatment options	1.05	(0.97– 1.12)	1.05	(0.98– 1.13)
Lack of education materials to share with patient/family	1.03	(0.96– 1.01)	1.04	(0.97– 1.12)
Insufficient time to discuss testing or treatment options with patient/family	1.05	(0.97– 1.13)	1.02	(0.95– 1.11)
Patient/family resistant to testing	0.99	(0.91– 1.08)	0.99	(0.91– 1.08)

Adjusted analyses included provider-level, organizational-level, and patient-mix covariates.

NGS, next-generation sequencing; uPR, unadjusted prevalenceratios; aPR, adjusted prevalence ratios

REFERENCES

[1]. Tan O, Shrestha R, Cunich M, Schofield DJ, Application of next-generation sequencing to improve cancer management: A review of the clinical effectiveness and cost-effectiveness, Clin. Genet 93 (2018) 533– 544. doi:10.1111/cge.13199. [PubMed: 29265354]

[2]. Yohe S, Thyagarajan B, Review of Clinical Next-Generation Sequencing., Arch. Pathol. Lab. Med 141 (2017) 1544–1557. doi:10.5858/arpa.2016-0501-RA. [PubMed: 28782984]

[3]. Freedman AN, Klabunde CN, Wiant K, Enewold L, Gray SW, Filipski KK, Keating NL, Leonard DGB, Lively T, McNeel TS, Minasian L, Potosky AL, Rivera DR, Schilsky RL, Schrag D, Simonds NI, Sineshaw HM, Struewing JP, Willis G, de Moor JS, Use of Next-Generation Sequencing Tests to Guide Cancer Treatment: Results From a Nationally Representative Survey of Oncologists in the United States, JCO Precis. Oncol (2018) 1–13. doi:10.1200/PO.18.00169. [PubMed: 30949620]

[4]. Politi MC, Clark MA, Ombao H, Dizon D, Elwyn G, Communicating uncertainty can lead to less decision satisfaction: a necessary cost of involving patients in shared decision making?, Health Expect. 14 (2011) 84–91. doi:10.1111/j.1369-7625.2010.00626.x. [PubMed: 20860780]

[5]. Sheppard VB, Williams KP, Harrison TM, Jennings Y, Lucas W, Stephen J, Robinson D, Mandelblatt JS, Taylor KL, Development of decision-support intervention for Black women with breast cancer., Psychooncology. 19 (2010) 62–70. doi:10.1002/pon.1530. [PubMed: 19267384]

[6]. Hawley ST, Lantz PM, Janz NK, Salem B, Morrow M, Schwartz K, Liu L, Katz SJ, Factors associated with patient involvement in surgical treatment decision making for breast cancer, Patient Educ. Couns 65 (2007) 387–395. doi:10.1016/j.pec.2006.09.010. [PubMed: 17156967]

[7]. Alexander SC, Sullivan AM, Back AL, Tulsky JA, Goldman RE, Block SD, Stewart SK, Wilson-Genderson M, Lee SJ, Information giving and receiving in hematological malignancy

consultations., Psychooncology. 21 (2012) 297–306. doi:10.1002/pon.1891. [PubMed: 21294221]

[8]. Covvey JR, Kamal KM, Gorse EE, Mehta Z, Dhumal T, Heidari E, Rao D, Zacker C, Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature, Support. Care Cancer 27 (2019) 1613–1637. doi:10.1007/s00520-019-04675-7. [PubMed: 30737578]

[9]. Frerichs W, Hahlweg P, Müller E, Adis C, Scholl I, Shared Decision-Making in Oncology – Qualitative Analysis of Healthcare Providers' Views on Current Practice, PLoS One. 11 (2016) e0149789. doi:10.1371/journal.pone.0149789. [PubMed: 26967325]

[10]. Wiant K, Geisen E, Creel D, Willis G, Freedman A, de Moor J, Klabunde C, Risks and rewards of using prepaid vs. postpaid incentive checks on a survey of physicians., BMC Med. Res. Methodol 18 (2018) 104. doi:10.1186/s12874-018-0565-z. [PubMed: 30305049]

[11]. Liang R, Meiser B, Smith S, Kasparian NA, Lewis CR, Chin M, Long GV, Ward R, Menzies AM, Harris-Wai JN, Kaur R, Advanced cancer patients' attitudes towards, and experiences with, screening for somatic mutations in tumours: a qualitative study, Eur. J. Cancer Care (Engl) 26 (2017) e12600. doi:10.1111/ecc.12600.

[12]. Morash M, Mitchell H, Beltran H, Elemento O, Pathak J, The Role of Next-Generation Sequencing in Precision Medicine: A Review of Outcomes in Oncology., J. Pers. Med 8 (2018). doi:10.3390/jpm8030030.

[13]. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Decision aids for people facing health treatment or screening decisions, Cochrane Database Syst. Rev 2017 (2017). doi:10.1002/14651858.CD001431.pub5.

[14]. Blazer KR, MacDonald DJ, Culver JO, Huizenga CR, Morgan RJ, Uman GC, Weitzel JN, Personalized cancer genetics training for personalized medicine: Improving community-based healthcare through a genetically literate workforce, Genet. Med 13 (2011) 832–840. doi:10.1097/GIM.0b013e31821882b7. [PubMed: 21629123]

Highlights

- Oncologists faced barriers to involving patients/families in NGS testing decisions.
- Oncologists in low-resource settings were more likely to report barriers.
- Oncologist-reported patient/family barriers were not associated with NGS use.

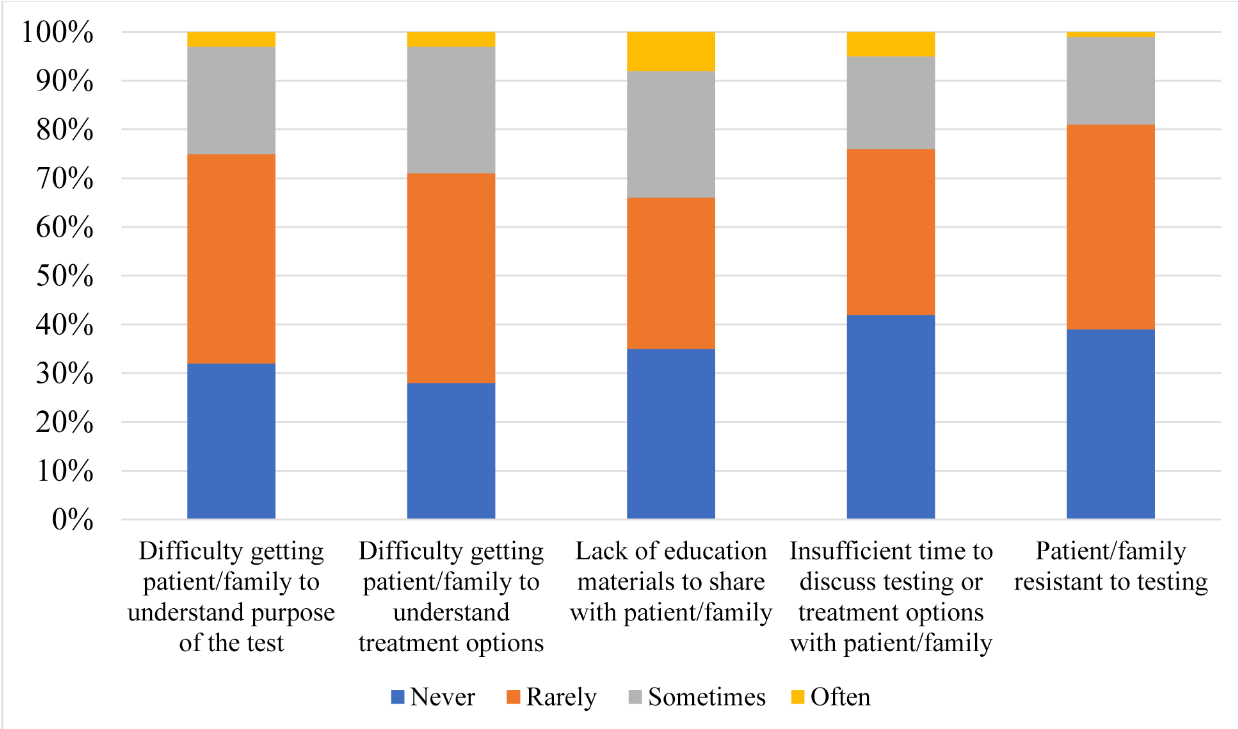

Figure 1. Oncologist-reported patient/family barriers to involving their cancer patients in the decision-making process for multi-marker tumor panels.

All factors reported in figure were oncologist reported responses to the question, “In the past 12 months, how important was each of the following factors in your decision to use multi-marker tumor panels to make treatment decisions for your cancer patients?”

Table 1.

Study sample characteristics (N=1281)

	Proportion (%)	n
Provider-level characteristics		
Sex		
Male	69	928
Female	31	353
Age		
30 to 39	21	271
40 to 49	30	391
50 to 59	24	304
60 and over	25	315
Years since graduation		
10 to 19	32	406
20 to 34	36	467
35 or more	32	408
Primary specialty[a]		
Solid tumors only	36	481
Hematologic malignancies only	6	77
Both solid tumors and hematologic malignancies	58	697
Primary practice affiliated with academic institution		
No	38	478
Yes	62	796
See patients at academic center or medical school		
No	58	732
Yes	42	549
Formal training on genomic testing		
No	44	567
Yes	56	713
Organizational-level characteristics		
Primary practice		
Solo practice	4	55
Single specialty group	44	544
Multi-specialty group	44	566
Other	8	110
Practice location		
Urban	54	694
Suburban	36	436
Rural	10	135

		Proportion (%)	n
On-site pathology			
	No/Don't know	30	376
	Yes	70	893
Contract with off-site pathology lab			
	No/Don't know	15	180
	Yes	85	1,095
On-site genetic counselors			
	No/Don't know	33	414
	Yes	67	859
Internal policies regarding genomic testing			
	No/Don't know	53	665
	Yes	47	609
EMR alert for genomic testing			
	No/Don't know	83	1,068
	Yes	17	212
Genomic/Molecular tumor board			
	No/Don't know	65	814
	Yes	35	460
Patient-mix characteristics			
No. of unique patients with cancer/month			
	1 to 49	27	361
	50 to 99	22	289
	100 to 199	34	430
	200 or more	16	194
No. of unique patients with metastatic cancer/month			
	1 to 24	27	353
	25 to 49	22	291
	50 to 74	22	266
	75 or more	29	356
% Medicaid			
	0 to <5%	23	266
	5 to <10%	32	390
	10% or more	45	508

Note. Not all categories equal 1,281 because of missing data. Means and proportions are weighted.

[a]Primary specialty was recoded to reflect the cancer types oncologists saw in their practice.

Table 2.

Bivariate associations between provider-level, organizational-level, and patient-mix characteristics associated with patient/family barriers to multi-marker tumor panel testing

	Barriers to involving cancer patients/families in decision-making for multi-marker tumor panels									
	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**
Provider-level characteristics										
Female (ref. male)	1.15	(0.93– 1.42)	1.17	(0.97– 1.41)	**1.31**	**(1.12– 1.55)**	1.14	(0.92– 1.42)	1.16	(0.91– 1.49)
Age (ref. 30 to 39)										
40 to 49	0.94	(0.71– 1.24)	1.02	(0.80– 1.32)	1.01	(0.80– 1.29)	1.05	(0.80– 1.37)	1.39	(0.96– 2.02)
50 to 59	0.95	(0.71– 1.27)	0.96	(0.73– 1.27)	1.16	(0.90– 1.48)	**0.71**	**(0.51– 1.98)**	1.44	(0.98– 2.12)
60 and over	0.99	(0.74– 1.31)	1.11	(0.86– 1.44)	**1.31**	**(1.04– 1.66)**	0.89	(0.66– 1.21)	**1.75**	**(1.22– 2.53)**
Years since graduation (ref. 10 to 19)										
20 to 34	0.89	(0.70– 1.13)	0.99	(0.79– 1.23)	1.06	(0.86– 1.30)	0.79	(0.62– 1.01)	1.17	(0.86– 1.60)
35 or more	1.01	(0.80– 1.29)	1.13	(0.90– 1.40)	**1.31**	**(1.08– 1.59)**	0.86	(0.67– 1.11)	**1.60**	**(1.19– 2.15)**
Primary specialty (ref. solid tumors)										
Hematologic malignancies	1.17	(0.75– 1.82)	1.01	(0.66– 1.53)	0.90	(0.62– 1.32)	0.61	(0.34– 1.12)	0.70	(0.35– 1.42)
Solid tumors and hematologic malignancies	1.23	(0.99– 1.52)	1.09	(0.90– 1.32)	1.02	(0.86– 1.21)	1.07	(0.86– 1.33)	**1.35**	**(1.04– 1.75)**
Primary practice affiliated with academic institution	0.84	(0.69– 1.02)	0.88	(0.73– 1.05)	0.97	(0.82– 1.14)	0.92	(0.75– 1.14)	**0.73**	**(0.57– 0.92)**
Sees patients at academic center or medical school	0.83	(0.68– 1.02)	**0.82**	**(0.68– 0.99)**	0.88	(0.75– 1.03)	0.85	(0.69– 1.05)	**0.55**	**(0.42– 0.71)**
Formal training on genomic testing	1.01	(0.83– 1.23)	0.96	(0.80– 1.15)	0.85	(0.73– 1.00)	0.84	(0.68– 1.02)	0.95	(0.75– 1.20)
Organizational-level characteristics										
Primary practice (Ref: Solo practice)										
Single specialty practice	0.77	(0.51– 1.17)	0.79	(0.54– 1.16)	0.95	(0.65– 1.38)	0.94	(0.59– 1.49)	0.81	(0.52– 1.27)
Multi-specialty practice	0.73	(0.48– 1.11)	0.77	(0.52– 1.14)	0.89	(0.61– 1.29)	0.80	(0.51– 1.28)	**0.47**	**(0.30– 0.76)**
Other	0.73	(0.44– 1.23)	0.88	(0.56– 1.40)	0.75	(0.47– 1.19)	0.67	(0.37– 1.20)	**0.50**	**(0.27– 0.93)**
Practice location (Ref: Urban)										

	Barriers to involving cancer patients/families in decision-making for multi-marker tumor panels									
	Difficulty getting patient/ family to understand purpose of the test		Difficulty getting patient/ family to understand treatment options		Lack of education materials to share with patient/family		Insufficient time to discuss testing or treatment options with patient/family		Patient/family resistant to testing	
	PR	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**	**PR**	**95%CI**
Suburban	1.02	(0.83– 1.27)	0.95	(0.78– 1.16)	0.98	(0.82– 1.17)	**0.78**	**(0.62– 0.99)**	**1.43**	**(1.11– 1.85)**
Rural	1.02	(0.72– 1.42)	1.07	(0.80– 1.43)	**1.27**	**(1.01– 1.61)**	0.88	(0.62– 1.25)	**1.83**	**(1.31– 2.56)**
Genomic services (Ref: No/Don’t Know)										
On-site pathology	**0.77**	**(0.63– 0.94)**	**0.81**	**(0.67– 0.97)**	0.85	(0.72– 1.01)	0.91	(0.73– 1.13)	**0.55**	**(0.44– 0.70)**
Contract with off-site pathology lab	1.13	(0.84– 1.52)	0.98	(0.76– 1.26)	0.90	(0.73– 1.12)	0.88	(0.67– 1.15)	1.13	(0.79– 1.59)
On-site genetic counselors	0.85	(0.69– 1.04)	0.90	(0.75– 1.09)	0.87	(0.74– 1.02)	0.93	(0.75– 1.15)	**0.60**	**(0.48– 0.76)**
Internal policies regarding genomic testing	0.88	(0.72– 1.07)	0.93	(0.78– 1.12)	**0.81**	**(0.69– 0.95)**	0.92	(0.75– 1.13)	**0.66**	**(0.52– 0.84)**
EMR alert for genomic testing	1.22	(0.96– 1.56)	1.09	(0.87– 1.37)	0.96	(0.77– 1.19)	1.08	(0.83– 1.41)	1.29	(0.97– 1.72)
Genomic/molecular tumor board	0.88	(0.71– 1.09)	0.91	(0.75– 1.10)	0.88	(0.75– 1.05)	0.99	(0.80– 1.22)	**0.59**	**(0.45– 0.78)**
Patient-mix characteristics										
No. of unique patients with cancer/ month (Ref: 1 to 49)										
50 to 99	1.12	(0.84– 1.49)	1.30	(1.00– 1.69)	**1.32**	**(1.05– 1.67)**	**1.74**	**(1.28– 2.36)**	1.03	(0.74– 1.44)
100 to 199	1.17	(0.91– 1.52)	1.27	(1.00– 1.62)	1.13	(0.90– 1.41)	**1.46**	**(1.08– 1.96)**	1.10	(0.82– 1.49)
200 or more	1.18	(0.86– 1.62)	1.26	(0.94– 1.69)	**1.50**	**(1.18– 1.91)**	**1.61**	**(1.14– 2.26)**	1.07	(0.73– 1.55)
No. of unique patients with metastatic cancer/month (Ref: 1 to 24)										
25 to 49	1.10	(0.83– 1.47)	1.26	(0.97– 1.65)	0.95	(0.75– 1.20)	1.27	(0.19– 1.57)	1.19	(0.87– 1.64)
50 to 74	1.10	(0.82– 1.47)	1.23	(0.93– 1.61)	1.03	(0.82– 1.30)	1.23	(0.20– 1.32)	**0.94**	**(0.66– 1.35)**
75 or more	1.15	(0.88– 1.50)	**1.32**	**(1.02– 1.69)**	1.08	(0.88– 1.34)	1.30	(0.19– 1.78)	**1.02**	**(0.74– 1.40)**
% Medicaid	1.12	(0.99– 1.28)	**1.18**	**(1.04– 1.33)**	**1.13**	**(1.02– 1.26)**	1.13	(0.99– 1.30)	1.09	(0.93– 1.27)

p-values that are significant ($p<0.05$) are bold.