



## Patients' preferred and perceived roles in making decisions about adjuvant chemotherapy for non-small-cell lung cancer



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### ABSTRACT

**Background:** People with cancer have varying preferences for involvement in decision-making between active, collaborative and passive roles. We sought the preferred and perceived involvement in decision-making among patients considering adjuvant chemotherapy (ACT) after resection of early non-small cell lung cancer (NSCLC).

**Methods:** Patients considering ACT for NSCLC were asked to complete a self-administered questionnaire at baseline and 6 months. Preferred and perceived decision-making roles were assessed by the Control Preferences Scale (CPS). We examined differences between preferred and perceived roles, differences in preferred roles over time, determinants of preferences, and differences in treatment preferences between patients preferring active and less active roles.

**Results:** 98 patients completed the baseline questionnaire; 75 completed the 6 month questionnaire. Most patients were male (55%) with a median age of 64 years (range, 43–79 years). Preferred role in decision-making at baseline ( $n = 98$ ) was active in 27%, collaborative in 47%, and passive in 27%. Perceived decision-making roles matched the preferred role in 79% of patients. Individuals' role preferences often varied between baseline and 6 months, but there was no consistent direction to the change (25% changed preference to more active involvement, 22% to less active). Preferring a more active role was associated with university education (OR 2.9,  $p = 0.02$ ), deciding not to have ACT (OR 5.0,  $p < 0.01$ ), and worse health-related quality of life (HRQL) during ACT: physical well-being (OR 4.4,  $p = 0.05$ ), overall well-being (OR 5.5,  $p = 0.02$ ), sleep (OR 8.4,  $p < 0.01$ ) and shortness of breath (OR 7.6,  $p = 0.01$ ). Patients who preferred an active decision-making role judged larger survival benefits necessary to make ACT worthwhile than those preferring a passive role.

**Conclusion:** Most patients with resected NSCLC preferred and perceived a collaborative role in decision-making about ACT. Clinicians should elicit and consider patients' preferences for involvement in decision-making when discussing ACT for NSCLC.

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## 1. Introduction

People with cancer have widely varying preferences for involvement in decision-making between active, collaborative and passive roles. [1] Understanding these preferences is important in order

*Abbreviations:* NSCLC, non-small-cell lung cancer; ACT, adjuvant chemotherapy; CPS, control preferences scale; HRQL, health-related quality of life.

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to meet patients' decision-making expectations, navigate discussions about treatment recommendations, and to increase patient satisfaction with the decision-making process. [2–4] This is even more pertinent for preference-sensitive treatment decisions, such as the consideration of adjuvant chemotherapy (ACT) for resected non-small cell lung cancer (NSCLC).

ACT for resected stage II and IIIA NSCLC confers an 11% relative reduction in the hazard of death (95% CI 4%–18%,  $p = 0.005$ ) with an absolute benefit in overall survival at 5 years of 5% (from 44% to 49%) [5]. The poor prognosis of patients considering ACT for NSCLC makes this treatment decision scenario quite distinct from adjuvant (or curative) treatment decisions for other cancer types,

for example early breast or prostate cancers, where 5 year survival rates are significantly better (>90% and nearly 100% respectively). ACT for resected NSCLC can be considered a preference-sensitive treatment, as patients must trade-off its possible benefits against its potential harms and inconveniences. We have previously studied patients' treatment preferences for ACT in NSCLC and found that patients generally judge moderate survival benefits sufficient to make ACT worthwhile (for example an extra 9 months in survival times, or 5% in survival rate) [6]. A final treatment decision about ACT, however, should reflect a patient's preferences for the treatment and their preferred level of involvement in the decision-making process.

Preferred level of involvement in decision-making has been most studied in the setting of breast and prostate cancers, with most patients preferring a collaborative role [1]. Where preferred and perceived decision-making roles have been compared, patients with a discordance between their preferred and perceived roles generally preferred a more active role than was achieved [7]. Only two studies have described decision-making role preferences in patients with lung cancer, one in patients with lung cancer of unspecified stage [8] and one in patients with advanced disease [9]. The majority of patients preferred a passive role [8,9] and there was discordance between preferred and perceived role for a significant minority (29%) [8]. In keeping with studies in other cancer types [10–12], preferences for involvement generally changed to a more active role over time. [8,9]

The aims of this study were to determine the preferences for involvement in decision-making of patients with early stage NSCLC, their perceived experience of involvement, and predictors of preferences for decision-making role. We hypothesized that most patients with early stage NSCLC would prefer a collaborative role in decision-making at baseline; that preferences would change over time to a more active role; that preferred and perceived roles would be discordant with a more active role preferred than was experienced; and that younger age, female sex and higher educational attainment would be associated with preference for an active role.

## 2. Methods

### 2.1. Study design and setting

This study was part of a previously published multi-centre, observational cohort study of patients' preferences for ACT in NSCLC at 16 sites in Australia and New Zealand [6].

### 2.2. Participants

Patients were included if they had resected stage I to stage III NSCLC, were referred to a medical oncologist for consideration of adjuvant chemotherapy, and were willing and able to complete the study questionnaire. Information about ACT, including the provision of any supporting material, was given according to the local practices of each centre. Patients were excluded if they had evidence of metastatic disease or if they had received prior chemotherapy for NSCLC. All patients provided signed, written, informed consent. Ethics approval was obtained by the relevant ethics committees of each participating centre.

### 2.3. Study questionnaire

Participants completed a self-administered questionnaire at baseline and at 6 months, the latter being about 2 months after ACT was completed in those who had it. Patient characteristics at baseline were recorded on a study specific questionnaire. Aspects of health-related quality of life (HRQL) were assessed at baseline and at 6 months using the Patient Disease and Treatment Assessment

Form (Patient DATA Form) [13]. At baseline, patients were asked to record their expected HRQL during chemotherapy, and at 6 months were asked to record their experienced HRQL during chemotherapy. Tumour and treatment characteristics were obtained from medical records.

### 2.4. Assessment of preferred and actual decision-making role

Patients' preferences for involvement in decision-making were assessed using the validated and widely used Control Preferences Scale (CPS) [14,15]. This scale asks patients to select one of five statements that best describes their preferred role in decision-making. Response options, as outlined in Table 1, range from an active role ("I prefer to make the final selection about which treatment I will receive") to a passive role ("I prefer to leave all decisions regarding treatment to my doctor"). A patient's *perceived* role was obtained by asking them to select the response that best described the role they had been playing in dealing with their cancer diagnosis, and their *preferred* role by selecting the response that best described the role they preferred.

### 2.5. Statistical analysis

The 5 possible responses on the CPS were categorised into three decision-making roles: active (responses A and B), collaborative (response C), and passive (responses D and E) (Table 1). Proportions of patients within these categories were described for preferred and perceived roles at baseline, and for preferred role at 6 months.

The five possible responses on the CPS were assigned ordinal scores from 1 to 5 (1 = most active, 2 = active, 3 = collaborative, 4 = passive, 5 = most passive) to measure the change in preferred role over time, and the difference between preferred and perceived role. Differences between roles were then assigned a value (discrepancy score), with 0 indicating no difference and  $\pm 4$  indicating maximal change (from most passive or active to most active or passive). Differences in the preferred decision-making roles at baseline and at 6 months, and between patients' preferred and perceived roles, were then assessed using the Wilcoxon signed-rank and rank sum tests. Determinants of preferences were assessed using chi-squared tests of association and summarised by odds ratios. Wilcoxon rank-sum tests were used to assess differences in the survival benefits judged sufficient to make ACT worthwhile by patients preferring active and less active decision-making roles.

A sample size of 100 patients was sufficient to allow for description of the modal preferred and perceived decision-making roles with 95% confidence intervals of  $\pm 10$  percentage points.

## 3. Results

### 3.1. Patient characteristics

Patient, disease and treatment characteristics are summarised in Table 2. From 2010 to 2012, 98 patients with resected stage I to III NSCLC consented to the study and completed the baseline questionnaire and 75 (77%) patients completed the 6 month questionnaire. Patient characteristics were as expected for this study population. The majority were male (55%), with a median age of 64 years (range 43–79 years) and were previous smokers (82%). Patients most commonly had adenocarcinoma (63%), had undergone a lobectomy (85%), and almost half (46%) had stage II disease. 82 patients (84%) had ACT which was most commonly cisplatin and vinorelbine (74%). Reasons for not completing the 6 month questionnaire (available for  $n=9$ ) included study withdrawal ( $n=1$ ), cancer recurrence ( $n=5$ ), death ( $n=2$ ), and illness ( $n=1$ ). Patients who completed the 6 month questionnaire, compared with those

**Table 1**  
The Control preferences scale [15].

Response	Control preferences scale (CPS)	Decisional role
A	I prefer to make the final selection about which treatment I will receive	Active
B	I prefer to make the final selection of my treatment after seriously considering my doctor's opinion	Active
C	I prefer that my doctor and I share responsibility for deciding which treatment is best for me	Collaborative
D	I prefer that my doctor make the final decision about which treatment, but seriously consider my opinion	Passive
E	I prefer to leave all decisions regarding treatment to my doctor	Passive

**Table 2**  
Patients' demographic, disease, and treatment characteristics (n=98).

Characteristic		%
Gender	Male	55
	Female	45
Age (years)	Median	64
Marital status	Married/de facto	75
	Separated/divorced	13
	Single	3
	Widowed	9
Dependent person	Yes	32
	No	68
Dependent children	Yes	15
	No	85
Highest level of education	Less than high school	37
	High school or trade qualification	43
	University or college degree	20
Employment status	Retired or unemployed	56
	Employed	44
Friend or relative died from cancer	Yes	78
	No	22
Support available during ACT	All of the time	59
	Most of the time	27
	Some or none of the time	14
Tobacco use <sup>a</sup>	Never	13
	Previous	82
	Current	4
Stage	I	17
	II	46
	IIIA	33
	IIIB	4
Histology	Squamous cell	24
	Adenocarcinoma	63
	Large cell or other	13
Type of surgery	Pneumonectomy	14
	Lobectomy	85
	Wedge resection	1
Decided to have ACT	Yes	84
Type of ACT received	Cisplatin & vinorelbine	74
	Cisplatin & gemcitabine	5
	Carboplatin & gemcitabine	9
	Other	12
Cycles of ACT received	≤3	17
	4	71
	5	12
Recurrence of NSCLC during 1st 6 months (on study)	Yes	6

ACT: adjuvant chemotherapy; NSCLC: non-small-cell lung cancer.

<sup>a</sup> 1 patient had missing data on smoking status.

who did not, were more likely to be university educated (OR 3.74,  $p = 0.01$ ).

Anticipated and experienced HRQL scores are detailed in the published parent study [6]. Fatigue and nausea were anticipated to be the most troublesome aspects of HRQL (mean scores 5.2 and 5.0 respectively). Fatigue and altered sense of taste were experienced as the most troublesome aspects of HRQL (mean scores 6.2 and 5.6).

### 3.2. Preferred and perceived decision-making roles

At baseline, preferred decision-making roles ( $n = 98$ ) were active in 27%, collaborative in 47%, and passive in 27%. Perceived decision-making roles were active in 24%, collaborative in 48%, and passive in 28% (Fig. 1). Preferred and perceived decision-making roles at baseline were concordant in 79% of participants (Table 3). 9% per-

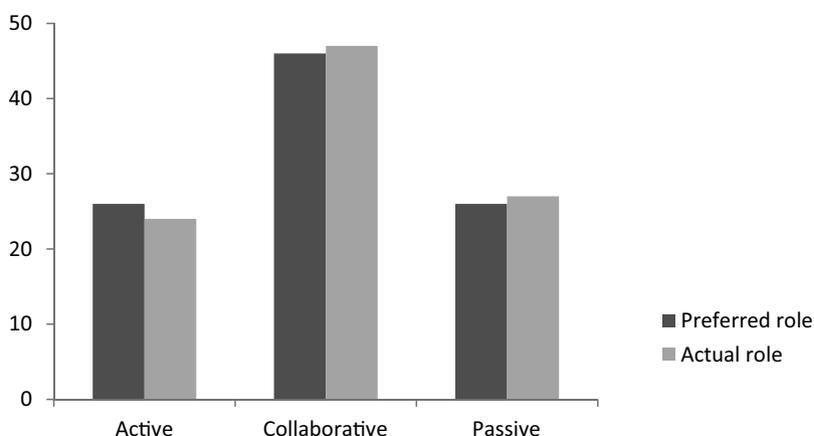


Fig. 1. Distribution of preferred and actual decision-making roles at baseline ( $n=98$ ).

**Table 3**  
Preferred versus perceived roles in decision-making about adjuvant chemotherapy (at baseline).

Perceived role at baseline	Preferred role at baseline					Total (%)
	Patient alone	Patient with doctor input	Shared decision	Doctor with patient input	Doctor alone	
Patient alone	0 <sup>a</sup>	0	1	0	0	1 (1)
Patient with doctor input	1	18 <sup>a</sup>	3	1	0	23 (23)
Shared decision	0	4	39 <sup>a</sup>	4	0	47 (48)
Doctor with patient input	1	2	2	8 <sup>a</sup>	0	13 (13)
Doctor alone	0	0	1	1	12 <sup>a</sup>	14 (14)
Total (%)	2 (2)	24 (24)	46 (47)	14 (14)	12 (12)	98 (100)

<sup>a</sup> Complete agreement between preferred and actual roles in 77 patients.

**Table 4**  
Preferred roles in decision-making at baseline and 6 months.

Preferred role at baseline	Preferred role at 6 months					Total (%)
	Patient alone	Patient with doctor input	Shared decision	Doctor with patient input	Doctor alone	
Patient alone	0 <sup>a</sup>	1	0	0	0	1 (1)
Patient with doctor input	0	6 <sup>a</sup>	7	2	0	15 (21)
Shared decision	0	6	25 <sup>a</sup>	2	3	36 (50)
Doctor with patient input	0	1	5	4 <sup>a</sup>	1	11 (15)
Doctor alone	0	0	1	5	3	9 (13)
Total (%)	0 (0)	14 (19)	38 (53)	13 (18)	7 (97)	72 (100)

<sup>a</sup> Complete agreement between preferred role at baseline and at 6 months in 38 patients.

ceived having played a more active role than preferred, and 12% perceived having played a more passive role than was preferred (Table 5).

### 3.3. Preferred decision-making role over time

At 6 months ( $n=75$ ), the distribution of preferred decision-making roles reported ( $n=72$ ) was similar to baseline, being active in 19%, collaborative in 53%, and passive in 28%. Preferences were unchanged between baseline and 6 months in 53%. For the 47% of patients who changed their preference at 6 months, 25% changed preference to more active involvement, and 22% to a less active involvement (Table 4, Fig. 2).

### 3.4. Associations of preferring an active role in decision-making

Table 6 summarises the assessment of associations of preferring an active role. Preferring a more active role was associated with university education (OR 2.9,  $p=0.02$ ) and worse HRQL during chemotherapy: physical well-being (OR 4.4,  $p=0.05$ ), overall well-being (OR 5.5,  $p=0.02$ ), sleep (OR 8.4,  $p=0.00$ ) and shortness

of breath (OR 7.6,  $p=0.01$ ). Patients who decided to have ACT were less likely to prefer an active role (OR 0.20,  $p<0.01$ ).

Patients who preferred an active decision-making role judged larger survival benefits necessary to make ACT worthwhile than those preferring a collaborative or passive role. For example, patients preferring an active role required a median extra survival time of 1 year to make ACT worthwhile, compared with a median of 6 months in those preferring a collaborative or passive role (WRS,  $p=0.03$ ). Similarly, those who preferred an active role judged a median extra survival rate of 17.5% at 5 years necessary to make ACT worthwhile compared with a median extra 2.5% for those who preferred a collaborative or passive role (WRS,  $p<0.01$ ).

## 4. Discussion

The main findings of our study were that most patients with resected early stage NSCLC preferred a collaborative role in decision-making, nearly half changed their role preference over 6 months, and preferred roles were concordant with perceived roles for most patients. University education, worse HRQL during ACT, and deciding not to have ACT predicted preference for an active role. Patients who preferred an active role in decision-making judged

**Table 5**  
Discrepancy between preferred and perceived roles at baseline, and preferred roles over time.

Difference in preferred and perceived roles at baseline <sup>a</sup>	N	Discrepancy score <sup>c</sup>	N	Difference in preferred decisional roles from baseline to 6 months <sup>b</sup>
Played a more passive role than preferred	0	4	0	Changed preference to a more passive role
	1	+3	0	
	3	+2	5	
	8	+1	11	
Achieved desired role	77	0	38	No change in desired role
Played a more active role than preferred	7	-1	16	Changed preference to a more active role
	2	-2	2	
	0	-3	0	
	0	-4	0	

<sup>a</sup> No evidence of preference for more active role than was experienced ( $p=0.39$ , WSR).

<sup>b</sup> No evidence of change to a more active role ( $p=0.83$ , Wilcoxon Signed Rank Test).

<sup>c</sup> Discrepancy score calculated by subtracting preferred role from perceived role; or preferred role at baseline from preferred role at 6 months.

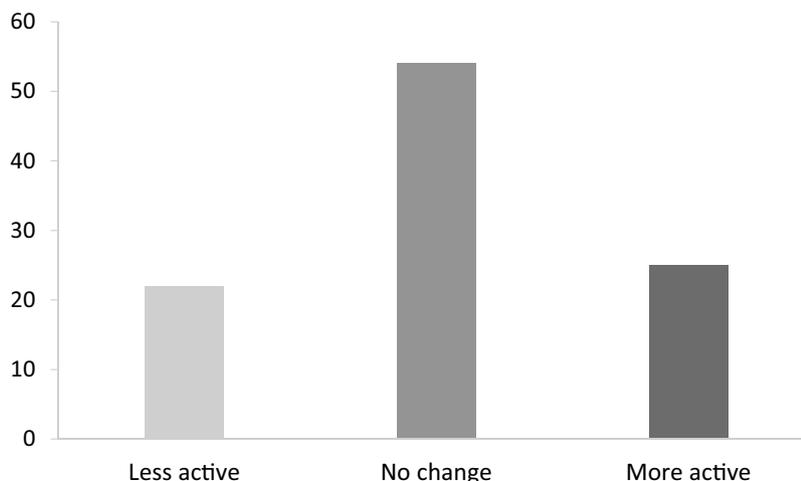
larger survival benefits necessary to make ACT worthwhile than those who preferred a more passive role.

#### 4.1. Distribution of role preferences

The distribution of role preferences in our study is consistent with other studies in cancer, with most patients preferring a collaborative role [1]. However, compared with two other studies in lung cancer, we found a much lower proportion (27%) of patients preferring a passive role. Pardon et al. [9] in their study of 128 patients with advanced lung cancer found 63% of patients preferred a passive role and, similarly, Davidson et al. [8] in their study of 22 patients with lung cancer of an unspecified stage found 57% of patients preferred a passive role. The lower proportion of patients preferring a passive role in our study may be due to differences in disease stage and treatment goals (palliative versus curative chemotherapy). An individual's preferred role in making decisions is not fixed and depends on the nature of the treatment decision in question and the degree to which the situation is perceived as life-threatening. Patients may desire less involvement at times of disease progression [10] or increased severity of disease, [16,17] yet opt for more involvement when decisions concern end of life care [9]. Hence, patients with advanced lung cancer may favour a passive role or paternalistic model, in contrast with those in our study who were considering adjuvant chemotherapy for potentially curable disease.

#### 4.2. Concordance between preferred and actual role played

The rate of concordance between preferred and perceived decision-making roles (79%) in our study was higher than that in other studies. A systematic review by Tariman et al. [7] included 22 studies reporting preferred and perceived decision-making roles, the majority in the setting of early stage breast and prostate cancer. All 22 studies showed a discordance between preferred and perceived roles with proportions of patients achieving their preferred role ranging from 42% [18] to 72%. [19] The higher proportion in our study may be explained by lung cancer clinicians being better able to elicit and negotiate their patient's decision-making preferences, differences in framing of the question between studies to discriminate perceived role from preferred role, or inherent differences in patients with lung cancer compared to other cancer types. Our study results may also reflect an evolving emphasis on patient preferences in decision-making over time. Regional differences in care should also be considered as was illustrated in an international study by Brown et al. [4] on decision-making preferences in patients with breast cancer. Patients in the Australian and New Zealand cohort, compared with the European cohort, had greater decisional satisfaction, and higher levels of shared decision-making skills demonstrated by their oncologists. Meeting patients' preferred decision-making role is desirable because it leads to improved decision-making outcomes such as reduced anxiety [2], increased patient satisfaction, and less decisional conflict [4,20].



**Fig. 2.** Preferred decision-making role at 6 months compared to baseline (%).

**Table 6**  
Association of preferring an active role with baseline characteristics and aspects of experienced self-rated HRQL.

Factor	OR*	p-value
Patient Characteristics		
Male	1.79	0.19
Age > 65 years	0.85	1.00
University education	2.94	0.02
Employed	1.40	0.38
Married/de facto	0.54	0.34
Dependent persons	1.20	0.36
Friend or relative died from cancer	0.95	0.67
Support available	0.48	0.16
Decided to have ACT	0.20	<0.01
Received ≤ 3 cycles ACT	0.49	0.77
Quality of Life Measures		
Appetite	1.21	0.39
Energy	3.60	0.05
Mood	1.03	0.70
Mobility	2.17	0.05
Physical well-being	4.38	0.02
Emotional well-being	2.64	0.16
Overall well-being	5.47	0.03
Fatigue	1.66	0.86
Nausea	1.39	0.73
Sleep	8.36	<0.01
Lack of appetite	1.20	0.98
Constipation	1.28	0.46
Hair loss	0.16	0.08
Altered taste	0.94	0.78
Vomiting	1.13	0.91
Shortness of breath	7.64	0.01
Sore mouth or throat	1.53	0.31

\* Odds ratio of preferring an active role (roles A and B); group comparison for each variable between those preferring a more active role (roles A and B) to those preferring a less active role (roles C, D and E) by Wilcoxon rank sum test.

#### 4.3. Preferences over time

In our study, nearly half of the patients changed their role preference over time, with near equal proportions changing to either a more active role (25%), or a more passive role (22%). This is largely consistent with three prior studies that have prospectively evaluated changes in decision-making preferences over time. Butow et al. compared the decision-making preferences of cancer patients immediately before and after their first consultation with a medical oncologist, and again 6 months later [10]. Preferences shifted at 6 months with 46% of patients wanting a more active role and 23% wanting a more passive role. Vogel et al. studied the decision-making preferences of patients with breast cancer at baseline, 3 months and 6 months and found that nearly half of all patients changed their preferences at least once during their treatment [12]. Hack et al. studied the preferred and perceived decision-making role of 285 women with breast cancer at baseline and 3 years [11]. Over half of all women changed their preferred decision-making role at 3 years, with patients 3.5 times more likely to move toward wanting more active than passive involvement. Whilst our study showed nearly half of all patients changed their role preference over time, there was no evidence that a change to a more active role was favoured.

#### 4.4. Predictors of preferred role in decision-making

Evidence for associations of patient factors with preferred role in decision-making is inconsistent [1]. Our finding that university education predicts an active role preference is consistent with some prior studies, [18,19,21–24] mainly in early breast cancer, but not others [20,25–29], mainly in prostate or mixed cancers. The few studies that have assessed associations between HRQL and preferred role in decision-making varied in their patient populations,

and the roles tested for association (e.g. concordance, discordance, perceived or preferred roles) [2,11,30]. One study, of patients with early breast cancer, showed that an active actual role, but not preferred role, or role congruence, was associated with better HRQL at 3 years [11]. Our study found different results but is difficult to compare directly to Hack et al. given the different cancer types, patient populations and time of assessment of HRQL (at 6 months v 3 years).

To our knowledge, no prior study has sought to determine a relationship between preferred role in decision-making and treatment preference for ACT. We found that patients who preferred an active decision-making role judged larger survival benefits necessary to make ACT worthwhile than those preferring a collaborative or passive role. Perhaps patients who prefer to be more involved in decisions about chemotherapy are more likely to seek information regarding the possible harms and inconveniences, and thus require greater survival benefits from chemotherapy to make it worthwhile. This is also consistent with our finding that deciding not to have ACT was associated with a preference for an active role.

#### 4.5. Strengths and limitations

This is the first study to report patients' preferences for involvement in decision-making about ACT for NSCLC. Other strengths include the prospective, multicentre design that allowed for wide sampling of patients seeing different medical oncologists across Australia and New Zealand to minimise the influence of any one oncologists' communication style on the results.

Limitations include the likely exclusion of the culturally and linguistically diverse (CALD) population, due to the requirement for English language skills, which comprises a significant proportion of patients with NSCLC in some geographical areas. Ethnicity has been shown to influence decision-making preferences in some [31,32], but not all [22,25] studies. Our study population (median age 64 years) is younger than that of all patients with lung cancer (median age 70 years). Given age is a predictor of a preference for a passive decision-making role, [8,11,19,22,24] the preference for an active role in this population may be overestimated by our study. Conclusions regarding predictors of role preference may be limited by inadequate power to detect these associations, and regarding preferences over time by the fewer numbers of completing the 6 month questionnaire.

#### 4.6. Clinical and research implications

The clinical implications of our results are that oncologists should determine and consider each of their patient's decision-making preferences during the decision-making process. A patient's preferred decision-making role can change over time, and so patients' preferences should be elicited with each clinical encounter involving a treatment decision. This will increase the likelihood of meeting patients' preferences and expectations, improving decisional satisfaction, and ultimately helping patients make the best decision. Future research should focus on including more patients who decline ACT or who are not referred for consideration of ACT.

## 5. Conclusion

Patients with resected early stage NSCLC considering ACT varied in their preferred role in decision-making, with most patients preferring a collaborative role. The distribution of role preferences was stable over time, though nearly half of the individuals changed their preference to either a more or less active role. For the vast majority, role preferences were concordant with their perceived role in decision-making at baseline. Clinicians should elicit and

consider patients' preferences for involvement in decision-making when discussing ACT for NSCLC.

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