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Patterns of primary care utilization before and after living kidney donation

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Abstract

Background—Annual visits with a primary care provider (PCP) are recommended for living kidney donors to monitor long-term health post-donation, yet adherence to this recommendation is unknown.

Methods—We surveyed 1170 living donors from our center from 1970–2012 to ascertain frequency of PCP visits pre- and post-donation. Interviews occurred median (IQR) 6.6 (3.8 – 11.0) years post-transplant. We used multivariate logistic regression to examine associations between donor characteristics and PCP visit frequency.

Results—Overall, only 18.6% had less-than-annual PCP follow-up post-donation. The strongest predictor of post-donation PCP visit frequency was pre-donation PCP visit frequency. Donors who had less-than-annual PCP visits before donation were substantially more likely to report less-than-annual PCP visits post-donation (OR = 9.814.4_{21.0}, p<0.001). Men were more likely to report less-than-annual PCP visits post-donation (adjusted OR = 1.21.6_{2.3}, p<0.01); this association was amplified in unmarried/non-cohabiting men (aOR = 2.43.9_{6.3}, p<0.001). Donors without college education were also more likely to report less-than-annual PCP visits post-donation (aOR = 1.31.8_{2.5}, p=0.001).

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AUTHORSHIP

All authors participated in study design/planning. J.L.A., B.J.B., S.A., S.E.H. participated in data collection/entry. X.L. participated in data management. J.L.A., X.L., A.B.M. participated in data analysis. J.L.A., A.B.M., M.L.H., J.E.L., T.P. participated in data interpretation. J.L.A., A.B.M., S.E.H., M.L.H., S.R.D., D.L.S., J.E.L., T.P. participated in preparation of the article. D.L.S. supervised the research.

DISCLOSURE

The authors declare no conflicts of interest.

Conflict of Interest Statement

The results presented in this paper have not been published previously in whole or part, except in abstract format.

Conclusions—The importance of annual PCP visits should be emphasized to all living donors, especially those with less education, men (particularly single men) and donors who did not see their PCP annually before donation.

Introduction

In the United States, approximately 6000 healthy individuals donate a kidney each year on behalf of a loved one, or even a stranger.¹ Live kidney donation (LKD) is a relatively safe surgical procedure and an ideal treatment modality for End Stage Renal Disease (ESRD) patients; LKD can also mitigate the shortage of deceased donor organs.^{2–7} In living donor transplantation, the ethical principle of beneficence favors the recipient by improving quality and duration of life, with donors accepting primarily psychological benefits in exchange for a procedure with low short-term risk.^{8,9} While live donor nephrectomy itself is relatively safe,¹ additional long-term risks to the donor include the development of ESRD,^{2,10} cardiovascular disease,^{10,11} gestational hypertension or preeclampsia,¹² difficulty obtaining health or life insurance,¹³ financial difficulties, psychological distress,⁸ and possibly all-cause mortality.¹⁰ The medical community is responsible for balancing the interests of the donor and recipient fairly, maximizing potential benefits to the recipient with minimizing potential risks for the donor. To that end, United Network for Organ Sharing (UNOS)/Organ Procurement and Transplantation Network (OPTN) policy provides standards for the medical evaluation and informed consent of live donor candidates to minimize negative outcomes following donation. Even though the importance of follow-up is broadly acknowledged in the transplant community, follow-up practices vary substantially by transplant center,¹⁴ and two year reporting of selected follow-up outcomes including kidney laboratory results, surgical complications, employment and insurance status was not implemented until February of 2013.¹⁵ The growing use of expanded criteria live donors, coupled with largely unknown long-term outcomes of LKD in light of new epidemiological evidence,^{16,17} has prompted calls to improve the long-term surveillance of live kidney donors.^{15,18,19}

Many transplant centers report difficulty meeting the 6-month, 1-year, and 2-year reporting requirements required by UNOS/OPTN, and few continue to routinely follow their live donors after the required two-year follow-up period. Using SRTR data, Schold et al. reported that centers achieved follow-up rates at 6 months, 1 year, and 2 years of 67%, 60%, and 50% for clinical and 51%, 40%, and 30% for laboratory data, but noted improvements in completion rates over time. Centers were more likely to have missing data during the required reporting years for live donors who were younger, African-American, lacked insurance, and had lower educational attainment.¹⁵ When surveyed, transplant centers cite donor inconvenience, costs, and lack of reimbursement to the transplant center for providing follow-up care as barriers to more complete follow-up.¹⁹ As such, the general recommendation is for all live kidney donors to see a primary care provider (PCP) annually for kidney specific laboratory tests and preventative health care. This recommendation provided to live donors is consistent with the recommended PCP visit frequency for the general population as well as the early-Chronic Kidney Disease (CKD) population.^{20–22} Annual follow-up for live kidney donors is critical because it facilitates health maintenance behaviors and allows for the early detection of renal function decline and subsequent clinical

management.^{23,24} For example, in the event of CKD, timely intervention is critical to slow its progression to ESRD and to prevent comorbidities including cardiovascular disease, diabetes, and hypertension.^{25,26}

The follow-up care patterns of live donors in the primary care setting are largely unknown. As such, our goals were to describe the frequency of PCP visits among live kidney donors before and after their kidney donation and to analyze independent associations between donor characteristics and PCP visit frequency before and after LKD.

Materials and Methods

Our study population consisted of 1170 US-based adults (18 years of age or older at time of donation) who underwent live donor nephrectomy at The Johns Hopkins Hospital from 1970 through 2012. As previously reported, donors were contacted via telephone at least two years after their date of donation.¹³ Participants completed a mail or telephone survey, depending on their preference. Death was ascertained through a combination of medical record review, information from the donor's family, Social Security Death Master File linkage, and Accurant person searches. Participants with missing values for any analyzed variables (4.9%, N=57) were excluded from the analysis. This study was approved by The Johns Hopkins Institutional Review Board (IRB), study number NA_00044282. The clinical and research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the 'Declaration of Istanbul on Organ Trafficking and Transplant Tourism'.

Participants were asked to report basic demographics including marital status, highest level of education completed, and smoking history; age, gender, and race were ascertained directly from the medical record. Participants were asked, separately, "[Before/Since] your kidney donation, about how many times did you see a primary care doctor for a regular check-up? (Your primary care doctor is your family doctor or gynecologist, if applicable)". Accepted responses were "not at all", "less-than-annually", "annually", and "more-than-annually".

We examined associations between donor characteristics (age at time of donation, age at survey completion, gender, race, education, marital status, time to follow-up, and smoking history) and PCP visit frequency before and after donation using chi-square and multivariate logistic regression. For analytical purposes, donors were classified as "non-partnered" (single or divorced) or "partnered" (married or cohabiting). We also dichotomized PCP visit frequency into "at-least-annually" (participant answered either "annually" or "more-than-annually") or "less-than-annually" (participant answered either "less-than-annually" or "not at all").

We hypothesized that PCP visit frequency pre-donation would be a strong predictor of PCP visit frequency post-donation, and might mediate associations between demographic variables (such as age and race) and post-donation frequency.²⁷ For example, if men were less likely than women in general to visit PCPs, we would observe this pattern in both pre-donation and post-donation PCP visit frequency. In this case, a model adjusting for pre-

donation visit frequency would show no association between gender and post-donation frequency. However, in this case pre-donation PCP visit frequency would not be a confounder of the relationship between gender and post-donation frequency; rather, it would be part of the mechanism through which gender *affected* post-donation frequency. To address the question of mediation, we constructed two models of visit frequency post-donation: one including PCP visit frequency pre-donation as a covariate, and one including demographic covariates but excluding PCP visit frequency pre-donation. This allowed us to assess whether visit frequency pre-donation mediated associations between demographic factors and visit frequency post-donation. Additionally, we performed multivariate logistic regression to explore associations of donor characteristics with PCP visit frequency post-donation, testing for potential effect modification between donor gender and partnership.

All analyses were performed using STATA 13.1/SE for Linux (College Station, Texas). 95% confidence intervals are reported as per the method of Louis and Zeger.²⁸

Results

Study Population

Among 1170 study participants, median age (IQR) at donation was 45 (36 – 53) years, 438 (37.4%) were male, 160 (13.7%) were African-American, 420 (35.9%) had less than college education, 339 (29.0%) were single or divorced, and 477 (40.8%) were current or former smokers. Median (IQR) time from donation to interview was 6.6 (3.8–11.0) years. Median age at follow-up was 53 (44 – 61) years (Table 1). The participation rate was 76% across four decades of kidney donation at our institution (Figure 1).

Pre-donation PCP Visits

Among all participants, 283 of 1170 donors (24.2%) reported seeing a PCP less-than-annually before kidney donation (Table 2). Among these, 70 donors reported never seeing a PCP pre-donation (24.7% of donors who saw a PCP less-than-annually, 6.0% of all donors). The remaining 75.3% (18.2% of all donors) reported at least one PCP visit before donation. Men had threefold higher odds of having less-than-annual pre-donation visits than women (adjusted OR = $2.53_{3.4,4}$, $p<0.001$). Among men, non-partnered men (single or divorced) had higher odds of less-than-annual pre-donation PCP visits (aOR = $1.01_{7.2,6}$, $p=0.02$) than men who were married or cohabiting (partnered). Among partnered donors, men had higher odds than women of less-than-annual pre-donation PCP visits (aOR = $2.33_{2.4,5}$, $p<0.001$). This association was strongest comparing non-partnered men to partnered women (aOR = $3.45_{3.8,5}$, interaction $p<0.001$) (Table 3A). For women, partnered status was not associated with pre-donation PCP visit frequency ($p=0.1$). In other words, non-partnership was associated with less-than-annual pre-donation visits for men, but not for women. Donors who were 50 years or older at the time of donation (aOR = $0.50_{0.60,9}$, $p=0.01$) or African-American (aOR = $0.20_{0.30,5}$, $p<0.001$) were less likely to have less-than-annual pre-donation PCP visits (Table 3A).

Post-donation PCP Visits

Among all participants, 18.6% reported seeing a PCP less-than-annually after kidney donation (Table 2). Among these, 30.0% (5.3% of all donors), reported *never* visiting a PCP post-donation, and the remaining 70.0% (12.3% of all donors) reported at least one PCP visit post-donation. The strongest predictor of less-than-annual follow-up visits was having less-than-annual PCP visits before donation (aOR = 10.315.222.7, $p < 0.001$) (Table 3B). After adjusting for pre-donation PCP visits, having less than college education (aOR = 1.21.82.6, $p < 0.01$) and being a non-partnered male (compared to being a partnered male) (aOR = 1.22.13.8, $p < 0.05$), and being a non-partnered male compared to being a partnered female (reference) (aOR = 1.01.83.2, $p < 0.05$) were independently associated with less-than-annual post-donation follow-up.

When we removed pre-donation habits from the analysis and considered demographics alone, men in general were still more likely to have less-than-annual post-donation PCP visits (aOR = 1.21.62.3, $p < 0.01$); non-partnered men were still twice as likely as partnered men to report this (aOR = 1.42.33.8, $p < 0.01$). This association was amplified for non-partnered men compared to partnered women (2.43.96.3, $p < 0.001$). Partnered status was not associated with less-than-annual follow-up visits for women. Having less than college education was also still associated with less-than-annual PCP visits post-donation (aOR = 1.31.82.5, $p < 0.001$). (Table 3B).

Concordance of PCP Visits Before and After Donation

Of the 206 donors who reported less-than-annual PCP visits after donation, 70.0% reported seeing their PCP less-than-annually before donation. Donors with less-than-annual visits pre-donation were more likely to report less-than-annual PCP visits post-donation (50.5% vs. 7.1%, $p < 0.001$). After adjusting for gender, race, education, smoking history, and time to survey, having less-than-annual pre-donation PCP visits was strongly predictive of having less-than-annual post-donation PCP visits (aOR = 9.814.421.0, $p < 0.001$) (Table 3B). This suggests that pre-donation visit frequency may mediate the association between demographic characteristics and *post*-donation PCP visit frequency. In other words, donors who are less likely to visit a PCP annually post-donation (e.g. non-partnered males) are less likely to visit a PCP annually *in general*, and their decreased PCP visit frequency post-donation continues a behavioral pattern that predates their kidney donation. The sensitivity and specificity of less-than-annual pre-donation PCP visits predicting less-than-annual PCP visits post-donation were 69% and 86%, respectively. Positive predictive value (PPV) for less-than-annual PCP visits pre-donation predicting less-than-annual PCP visits after donation was 51% and the negative predictive value (NPV) was 93%.

Changing PCP Visit Habits After Kidney Donation

Of the 283 donors who had less-than-annual PCP visits before donation (24.2% of all donors), 143 (50.5%) continued to have less-than-annual visits after donation. Among these 283 donors, time from donation to interview was the only variable associated with likelihood of increasing to at-least-annual PCP visits after donation (OR per year since donation = 1.011.051.10, $p = 0.02$, Table 4). This means that with each year after donation, among donors who reported less-than-annual pre-donation PCP visits, there was a 0.01% increase

in odds of at-least-annual PCP visits after donation. There was no association between age at follow-up ($p=0.6$), gender ($p=0.8$), race ($p=0.2$), education ($p=0.2$), or smoking history ($p=0.9$) and switching from less-than-annual PCP visits pre-donation to at-least-annual visits post-donation (Table 4A).

Of the 887 donors who reported visiting a PCP at-least-annually before donation (75.8% of all donors), 63 (7.1%) reported less-than-annual PCP visits after donation. Lack of college education ($aOR = 1.32.23.8$, $p<0.01$) was associated with greater risk of switching from at-least-annual visits before donation to less-than-annual visits after donation (Table 4B).

Discussion

In this single center, retrospective study of a large and diverse ($N=1170$) population of live kidney donors across four decades, we determined patterns and correlates between donor demographics and PCP visit frequency. The strongest predictor of less-than-annual post-donation PCP visit frequency was less-than-annual *pre*-donation PCP visits. Men, especially non-partnered men, and donors with less than college education were more likely to have less-than-annual PCP visits post-donation. Partnered status (marriage or cohabitation) reduced the risk of less-than-annual visits for men, but did not reduce this risk for women.

We found that 24.2% of donors had less than annual PCP visits before donation, with 6.0% never having a PCP visit before donation. Among them, men (58.3%) were more likely than women (41.7%) to have less-than-annual PCP visits pre-donation. These findings were similar to the 2012 National Health Interview Survey (NHIS) which reported that 20% of Americans saw a PCP less-than-annually, with more men (25%) than women (12%) reporting having less-than-annual visits.²⁹ This is interesting given that pre-donation donors are a very healthy subset of the general population, yet we found that they had similar PCP visit habits to those of the (on average sicker) general population.

Beliefs about the utility of the periodic health examination are known to influence the likelihood of receiving preventive services. In fact, 94% of PCPs report using the annual visit to counsel patients about preventive health services and improve patient-physician relationships.²¹ In a population-based telephone survey, Cherrington et al. found that participants who were male, younger, without health insurance, and Caucasian were more likely *not* to endorse the periodic health examination, independent of socioeconomic differences.³⁰ The donors in our study seemed to have a similar pattern as those in this population-based study, namely that younger males and donors with less educational attainment were more likely to have less-than-annual PCP visit follow-up. Moreover, we have previously reported that male donors and African-American donors are at increased risk of ESRD; as such, these donors' decreased rate of PCP follow-up is particularly worrying. This emphasizes the need to identify those live donor candidates at risk of inadequate follow-up and proactively improve pre-donation education about the need for long-term follow-up during the screening and evaluation process.

Most transplant centers (78%) agree that long-term follow-up should be performed by PCPs, but they note that data obtained are rarely relayed back to the transplant center.¹⁹ A 2015

registry-based study from Schold et al. reported that live donors who were younger, African-American, lacked insurance, and had lower educational attainment were more likely to have missing laboratory and clinical follow-up data during the 6, 12 and 24 month required UNOS/OPTN reporting period.¹⁵ Our findings in the present study that live kidney donors with similar characteristics (male, with less educational attainment) were less likely to have post-donation PCP visits may indicate a larger problem with access to healthcare and the promotion of health maintenance behaviors, rather than limitations of missing follow-up data.

Other small single-center studies have explored PCP visits post-donation.^{9,31} Glotzer et al. compared 83 live donors to evaluated non-donor controls across one decade post-donation and reported that most (86%) of their donors “continue to undergo annual follow-up” with a PCP.⁹ In a retrospective survey of 276 live kidney donors who were at least three years post-donation, Weng et al. had similar time-to-follow-up (mean = 4.86.2_{7.8} years) and found that 88% of donors had seen a physician in the past year, with 79% having specifically seen a “general doctor” within the prior year. In this study, lack of PCP visit follow-up in the past year was more likely for live kidney donors who were younger, lacked health insurance, and had infrequent contact with their recipient.³¹ Together, national data and the experiences of single centers suggest that certain risk factors including sex, race, education, marital status, and history of health maintenance could be used to identify live kidney donors that are at risk of having infrequent post-donation follow-up.

Historically, lack of access to health insurance may have presented a barrier to PCP utilization for some donors. A study of donor health insurance by Rodrigue and colleagues reported that 16% of donors were uninsured at the time of donation; young donors, male donors, and nonwhite donors were at increased risk of lacking health insurance.³² Our group has previously reported difficulties among live kidney donors in obtaining or changing health insurance after donation.¹³ This further highlights the importance of follow-up for all donors, but especially those with identifiable risk factors for infrequent health utilization before and after donation. Prioritizing follow-up care for all donors can be supported by increased and improved donor engagement with the transplant center attained by care coordination supported by PCPs. Data on post-donation risk further supports the case for closer post-donation health monitoring and prioritizing supportive health maintenance behavior promotion, which includes preventive health services. Recent OPTN requirements for post-donation follow-up, implemented in 2013, may also lead to increased PCP utilization by donors.

Our study is limited in that ascertainment of PCP visit frequency was via self-report; as such, responses may be subject to recall or social desirability bias. However, this bias would likely affect all subgroups equally, meaning for example that both men and women, or partnered and non-partnered donors would be affected equally. This thereby minimizes bias in our inferences about the association between various donor characteristics and PCP visit frequency. Furthermore, our data do not disambiguate wellness visits from visits due to medical problems. Finally, it is necessary to note that despite being in the era of strict follow-up requirements, study participation was lowest in the last two years of the study (2012–2013). One possible contributing factor is that more recent donors, who already felt

engaged with the transplant center through efforts to adhere to the stricter follow-up requirements, may have felt burdened by increased communications and so might have been less eager to participate in research that has the advantage of engaging the donor with the transplant center but the disadvantage of participation burden.

In conclusion, the strongest predictor of having at-least-annual PCP follow-up post-donation is a history of at-least-annual PCP visit patterns before donation. Live kidney donors with less than a college education and men in general were more likely to have less-than-annual PCP visits post-donation, even after adjusting for pre-donation PCP visit habits. We recommend that all donors should be routinely asked about their PCP visit habits during the donor evaluation process, and those who have infrequent visits should be especially counseled about the importance of maintaining annual long-term follow-up after their kidney donation. Post-donation counseling is necessary to promote the health of all live donors, but enhanced educational and follow-up efforts by transplant teams and PCPs may be needed for patients with increased risk factors. Improving donor surveillance would increase our understanding of the long-term risks associated with live kidney donation, and could improve long-term health outcomes for individual donors.

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ABBREVIATIONS

AKD	After Kidney Donation
CKD	Chronic Kidney Disease
ESRD	End Stage Renal Disease
LKD	Live Kidney Donation
PCP	Primary Care Provider

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Figure 1.

Table 1

Live kidney donor study participants between from 1970–2012

	Study Population
N	1170
Male N (%)	438 (37.4)
Race N (%)	
White	963 (82.3)
African-American	160 (13.7)
Asian/Pacific-Islander	24 (2.0)
American Indian/Alaska Native	1 (0.1)
Other	22 (1.9)
Age at Donation, median (IQR), in years	45.2 (36.4 – 52.8)
Age at Follow-up, median (IQR), in years	53.1 (44.3 – 60.5)
Time to Follow-up, median (IQR), in years	6.6 (3.8–11.0)
Smoking history N (%)	477 (40.8)
Education n (%)	
Less than college	420 (35.9)
Associates	133 (11.4)
Bachelors	325 (27.8)
Graduate	292 (25.0)
Marital Status N (%)	
Partnered (Married or Cohabiting)	831 (71.0)
Non-partnered (Single or Divorced)	339 (29.0)

Table 2

Relationship between PCP visits pre- and post-kidney donation. Participants who saw a PCP at least annually pre-donation were more likely to see a PCP at least annually post-donation (92.9% vs 49.5%, χ^2 p<0.001).

Pre-donation PCP visit frequency	Post-donation PCP visit frequency	
	< Annually	Annually
< Annually (N=283)	143 (50.5%)	140 (49.5%)
Annually (N=887)	63 (7.1%)	824 (92.9%)
Total (N=1170)	206 (18.6%)	964 (82.4%)

Table 3

Risk factors for less-than-annual PCP visits pre- and post-donation.

3A: Risk of having less-than-annual PCP visits pre-donation, excluding and including donor's partnership status.

	Partnership Excluded		Partnership Included	
	Odds Ratio	p-value	Odds Ratio	p-value
Male	2.5 3.3 4.4	<0.001	--	--
Partnered Female	--	--	Ref	--
Partnered Male	--	--	2.3 3.2 4.5	<0.001
Non-partnered Female	--	--	0.9 1.3 2.0	0.2
Non-partnered Male (Ref: Partnered Male)	--	--	1.0 1.7 2.6	0.02
Non-partnered Male (Ref: Partnered Female)	--	--	3.4 5.3 8.5	<0.001
African-American	0.2 0.3 0.5	<0.001	0.2 0.3 0.5	<0.001
Age 50+ at Donation	0.5 0.6 0.9	<0.01	0.5 0.6 0.9	0.01
Less than college education	1.0 1.3 1.8	0.07	1.0 1.3 1.8	0.07
Smoking History	0.7 1.0 1.3	1.0	0.7 1.0 1.3	0.9

3B: Risk of having less-than-annual PCP visits post-donation, demographics alone and with pre-donation PCP visit frequency

	Demographics Alone		With Pre-donation PCP Visits	
	Odds Ratio	p-value	Odds Ratio	p-value
Male	1.2 1.6 2.3	<0.01	0.8 1.1 1.6	0.6
Partnered Female	Ref	--	Ref	--
Partnered Male	1.2 1.7 2.4	<0.01	0.6 0.9 1.4	0.5
Non-partnered Female	0.7 1.1 1.8	0.6	0.6 1.0 1.6	1.0
Non-partnered Male (Ref: Partnered Male)	1.4 2.3 3.8	0.001	1.2 2.1 3.8	<0.05
Non-partnered Male (Ref: Partnered Female)	2.4 3.9 6.3	<0.001	1.0 1.8 3.2	<0.05
Less than college education	1.3 1.8 2.5	<0.001	1.2 1.8 2.6	<0.01
African-American	0.5 0.8 1.3	0.4	0.9 1.6 2.7	0.1
Smoking History	0.8 1.0 1.4	0.8	0.7 1.1 1.5	0.7
Time to follow-up (per year)	1.0 1.0 1.0	0.7	1.0 1.0 1.0	0.08
<Annual PCP Visits Before Donation	--	--	9.8 14.4 21.0	<0.001

Table 4

Risk factors for with changing PCP visit frequency

Table 4A: Risk factors for increasing PCP visits to at-least-annually after donation among donors who reported less-than-annual PCP visits before donation. Of 283 donors who reported less-than-annual visits pre-donation, 140 (49.5%) increased to having at-least annual visits after donation.

	Odds Ratio	p-value
Male	0.6 0.9 1.5	0.8
African-American	0.2 0.5 1.4	0.2
Less than college education	0.4 0.7 1.2	0.2
Smoking History	0.6 1.0 1.6	0.9
Non-partnered	0.5 0.8 1.3	0.4
Time to follow-up	1.01 1.05 1.10	0.02

Table 4B: Risk factors for decreasing PCP visits to less-than-annually after donation among donors who reported at-least-annual PCP visits before donation. Of 887 donors who reported at-least-annual visits pre-donation, 63 (7.1%) decreased to having less-than-annual visits after donation.

	Odds Ratio	p-value
Male	0.7 1.2 2.0	0.6
African-American	0.7 1.4 2.6	0.4
Less than college education	1.3 2.2 3.8	<0.01
Smoking History	0.7 1.2 2.0	0.6
Non-partnered	0.9 1.5 2.6	0.2
Time to follow-up	1.0 1.0 1.1	0.7