



Transplant Life
Foundation



TRIO



Transplant
Families



HEARTBROTHERS
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Protect Access to Non-Invasive Testing for Transplant Patients

SURVEY RESULTS REPORT

Introduction

- *The **Protect Access to Non-Invasive Testing for Transplant Patients Survey** was deployed on April 10, 2023, to post-transplant patients affiliated with Transplant Life Foundation, TRIO, Transplant Families, and the HeartBrothers Foundation™.*
 - ***Survey Monkey** was the platform used to collect responses to 22 multiple choice questions and two open-ended response prompts.*
 - *The survey closed on April 20, 2023, with a **sample size of 1,173** participants.*
 - *A sample size of **100 indicates a statistically significant** response.*
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Patient profiles:

- **Kidney** the was most reported organ transplant (50%); with heart as the next most reported transplant (25%).
- **Older adults** were the largest cohort of respondents; 65+ years old (34%) and 55-64 years old (nearly 30%).)
- **Populous areas** best described where respondents live; city (52%); urban area between 5,000-75,000 (nearly 37%).)
- **Annual household income** was near evenly distributed between **\$25,000-\$150,000+** amongst respondents who elected to answer.

Key Findings

Experience with post-transplant surveillance:

- **Transplanted organ rejection is a concern** (57% worried about rejection frequently or very frequently.)
- **Receiving a non-invasive testing is very common** (nearly 70%) have received a non-invasive test to check the status of their organ's health (or for potential rejection).
- **Non-invasive testing is overwhelming preferred** (nearly 95%) compared to a traditional tissue biopsy.
- **Traditional tissue biopsy impacts quality of life** or has otherwise been burdensome (57% agree or strongly agree.)

Insurance coverage for post-transplant non-invasive testing:

- **Insurance coverage for routine non-invasive testing is overwhelmingly viewed as important** (98%.)
- **Reduced insurance coverage for non-invasive testing would negatively impact post-transplant care** (95% agree or strongly agree.)
- **Paying out of pocket for non-invasive testing would be financially burdensome** (over 90% agree or strongly agree.)

Key Findings Continued

Medicare-related coverage decisions:

- **There is near unanimous support for Medicare coverage for non-invasive testing** on an ongoing surveillance/monitoring basis (98% agree or strongly agree that coverage is important.)
- **There is near unanimous agreement that patients should be consulted** as part of the process for determining new or making changes in Medicare coverage policies (97% agree or strongly agree.)
- **There is a high level of concern that the recent Billing Article limits coverage** of non-invasive testing and physicians' options to provide the best care for transplant patients (95%.)

Willingness to advocate for coverage:

- **There is strong willingness to get involved in advocacy for coverage** of non-invasive tests (only 10% reported unwillingness to advocate.)
- **Signing a petition** advocating for coverage was the most preferred advocacy activity (82%).
- **Signing a letter to a policymaker/lawmaker** advocating for coverage was the next most preferred advocacy activity (nearly 44%).

Sample of Verbatim Responses to Open-Ended Prompts

Negative experience with tissue biopsy:

- *“My wife was severely traumatized from a kidney biopsy that was required that could have been avoided had she had AlloSure test access at the that time.”*
- *“I had a VATS [lung biopsy] and suffered for a long time afterwards.”*
- *“It [biopsy] has caused extreme anxiety... procedure feels like torture.”*
- *“Tissue biopsies are very costly, and they have a risk of infection and complications, up to and including death to the patient. They are very burdensome on family members who must often travel long distances, take a full day off from work or school, and the recovery to the patient may be challenging.”*
- *“The procedure was painful due to bleeding after.”*

Insights about non-invasive tests:

- *“They are crucial for post-transplant monitoring.”*
- *“They must be part of the routine test for every transplanted organ.”*
- *“The testing is an essential part to ensure the best treatment for a transplanted organ.”*
- *“I have had two exacerbations post-transplant; pneumonia and COVID-19. AlloSure Lung was part of ensuring there was no acute or chronic rejection.”*
- *“Biopsies, while routine, carry risk due to their invasiveness. Simple blood testing carries much less risk. I can assure you as a transplant recipient, I’m all about reducing health risks.”*
- *“I believe anything non-invasive is better for one’s mind and body.”*
- *”My son has gone into rejection before, and monthly blood monitoring is essential for his wellbeing.”*

Appendix: Individual Responses

- Patient profiles (Q1-8)
- Experience with post-transplant surveillance (Q9-13)
- Insurance coverage for post-transplant non-invasive testing (Q14-16)
- Medicare-related coverage decisions (Q17-20)
- Willingness to advocate for coverage (Q21-22)

Patient Profiles

1. [What is your connection to the person who has had an organ transplant?](#)
2. [What type of organ transplant did the patient have?](#)
3. [How many transplants has the patient had?](#)
4. [What is the gender identity of the transplant patient?](#)
5. [What is the age of the transplant patient?](#)
6. [What is the race of the transplant patient?](#)
7. [What best describes the area where the transplant patient lives?](#)
8. [What is the patient's estimated household income currently?](#)

Q1: What is your connection to the person who has had an organ transplant?

ANSWER CHOICES	RESPONSES	
I have had a transplant	78.86%	925
I am the spouse of someone who has had a transplant	5.20%	61
I am a close family member of someone who has had a transplant	12.79%	150
I am a close friend or partner of someone who has had a transplant	1.96%	23
None, I am not connected to anyone who has had a transplant	0.09%	1
Other	1.11%	13
TOTAL		1173

Q2: What type of organ transplant did the patient have?

ANSWER CHOICES	RESPONSES	
Heart	25.15%	295
Kidney	50.13%	588
Liver	20.03%	235
Lung	8.70%	102
Pancreas	2.81%	33
Other	1.02%	12
TOTAL		1265

Q3: How many transplants has the patient had?

ANSWER CHOICES	RESPONSES	
One	85.51%	1003
Two	11.42%	134
Three	2.56%	30
Four+	0.51%	6
TOTAL		1173

Q4: What is the gender identity of the transplant patient? (I/They identify as a)

ANSWER CHOICES	RESPONSES	
Male	51.75%	607
Female	48.00%	563
Other, I/They don't identify as male or female	0.26%	3
TOTAL		1173

Q5: What is the age of the transplant patient?

ANSWER CHOICES	RESPONSES	
Under 18	7.33%	86
18-24	2.90%	34
25-34	3.58%	42
35-44	6.56%	77
45-54	15.17%	178
55-64	29.58%	347
65+	34.10%	400
Prefer not to answer	0.77%	9
TOTAL		1173

Q6: What is the race of the transplant patient?

ANSWER CHOICES	RESPONSES	
White	77.92%	914
Black or African American	9.46%	111
Hispanic or Latino	4.43%	52
Asian or Asian American	3.84%	45
American Indian or Alaska Native	0.51%	6
Native Hawaiian or other Pacific Islander	0.34%	4
Prefer not to answer	3.50%	41
TOTAL		1173

Q7: What best describes the area where the transplant patient lives?

ANSWER CHOICES	RESPONSES	
An area with a population under 5,000 (rural)	9.29%	109
An area with a population over 5,000 but under 75,000 (urban)	36.83%	432
A city where the population is over 75,000	52.34%	614
Other	1.53%	18
TOTAL		1173

Q8: What is the patient's estimated household income currently?

ANSWER CHOICES	RESPONSES	
\$0	0.85%	10
\$1 - \$9,999	3.16%	37
\$10,000 - \$24,999	7.25%	85
\$25,000 - \$49,999	13.31%	156
\$50,000 - \$74,999	13.31%	156
\$75,000 - \$99,999	12.37%	145
\$100,000 - \$149,999	13.99%	164
\$150,000 and greater	13.82%	162
Prefer not to answer	21.93%	257
TOTAL		1172

Experience with post-transplant surveillance

9. Has the transplant patient received non-invasive (simple blood test) testing to check the status of the organ's health (or potential rejection)? For example, donor-derived cell-free DNA (dd-cfDNA), AlloSure®, Viracor TRAC®, Prospera™, or gene expression...
10. Has a blood test, such as dd-cfDNA, or GEP detected any issues with the transplant patient's transplanted organ? For example, donor-derived cell-free DNA (dd-cfDNA), AlloSure®, Viracor TRAC®, Prospera™, or gene expression profiling (GEP), AlloMap...
11. How often does the transplant patient worry about their body rejecting the transplanted organ?
12. Please indicate your level of agreement with the following statement: Transplant patients would prefer a simple blood test over a tissue biopsy to monitor the health of the transplanted organ.
13. Please indicate your level agreement with the following statement: Invasive biopsies have impacted my quality of life, or otherwise been burdensome to me.

Q9: Has the transplant patient received non-invasive (simple blood test) testing to check the status of the organ's health (or potential rejection)? For example, donor-derived cell-free DNA (dd-cfDNA), AlloSure®, Viracor TRAC®, Prospera™, or gene expression profiling (GEP), AlloMap, TruGraf.

ANSWER CHOICES	RESPONSES	
Yes	69.14%	811
No	13.30%	156
I don't know/not sure	17.05%	200
Other	0.51%	6
TOTAL		1173

Q10: Has a blood test, such as dd-cfDNA, or GEP detected any issues with the transplant patient's transplanted organ? For example, donor-derived cell-free DNA (dd-cfDNA), AlloSure®, Viracor TRAC®, Prospera™, or gene expression profiling (GEP), AlloMap, TruGraf.

ANSWER CHOICES	RESPONSES	
Yes	23.02%	270
No	37.60%	441
I don't know/Not Sure	34.61%	406
Other	4.77%	56
TOTAL		1173

Q11: How often does the transplant patient worry about their body rejecting the transplanted organ?

ANSWER CHOICES	RESPONSES	
Very Frequently	29.50%	346
Frequently	28.47%	334
Occasionally	24.98%	293
Rarely	9.63%	113
Very Rarely	5.03%	59
Never	2.39%	28
TOTAL		1173

**Q12: Please indicate your level of agreement with the following statement:
Transplant patients would prefer a simple blood test over a tissue biopsy to
monitor the health of the transplanted organ.**

ANSWER CHOICES	RESPONSES	
Strongly Agree	86.19%	1011
Agree	8.70%	102
Somewhat Agree	2.22%	26
Neutral	2.05%	24
Disagree	0.68%	8
Strongly Disagree	0.17%	2
TOTAL		1173

Q13: Please indicate your level agreement with the following statement: Invasive biopsies have impacted my quality of life, or otherwise been burdensome to me.

ANSWER CHOICES	RESPONSES	
Strongly agree	34.73%	407
Agree	22.95%	269
Neutral	31.40%	368
Disagree	6.83%	80
Strongly disagree	3.07%	36
If you have had a negative experience undergoing an invasive tissue biopsy, please share here.	16.47%	193
TOTAL		1353

Number of responses higher due to option to select both level of agreement and provide an open ended response.

Insurance coverage for post-transplant non-invasive testing

14. How important do you believe insurance coverage of a routine non-invasive test (simple blood test) has been for checking the health of the transplant patient's organ post-transplant?
15. Please indicate your level of agreement with the following statement: Reduced insurance coverage for a simple blood test that checks the health of the transplant would impact transplant patient's post-transplant care in a negative way.
16. Please indicate your level of agreement with the following statement: Having to pay out of pocket for non-invasive testing (simple blood test) that checks the health of my transplant would be financially burdensome for me/the patient.

Q14: How important do you believe insurance coverage of a routine non-invasive test (simple blood test) has been for checking the health of the transplant patient's organ post-transplant?

ANSWER CHOICES	RESPONSES	
Very Important	95.40%	1119
Important	3.41%	40
Somewhat Important	0.68%	8
Slightly Important	0.26%	3
Not Important	0.26%	3
TOTAL		1173

**Q15: Please indicate your level of agreement with the following statement:
Reduced insurance coverage for a simple blood test that checks the health of the
transplant would impact transplant patient's post-transplant care in a negative way**

ANSWER CHOICES	RESPONSES	
Strongly Agree	81.67%	958
Agree	13.55%	159
Neutral	3.32%	39
Disagree	0.68%	8
Strongly Disagree	0.77%	9
TOTAL		1173

Q16: Please indicate your level of agreement with the following statement: Having to pay out of pocket for non-invasive testing (simple blood test) that checks the health of my transplant would be financially burdensome for me/the patient.

ANSWER CHOICES	RESPONSES	
Strongly Agree	75.26%	882
Agree	16.64%	195
Neutral	4.27%	50
Disagree	1.45%	17
Strongly Disagree	1.28%	15
I don't know	1.11%	13
TOTAL		1172

Medicare-related coverage decisions

17. How aware are you of a new Medicare Billing Article addressing the reimbursement and coverage of non-invasive testing (simple blood test) for Medicare patients?
18. Are you concerned that the Billing Article limits coverage of non-invasive testing (simple blood test) and, with it, physicians' options to provide the best care for transplant patients?
19. Please indicate your level of agreement with the following statement: Medicare should cover non-invasive testing (simple blood test) on an ongoing surveillance (monitoring) basis to check the health of the transplanted organ on a regular basis.
20. Please indicate your level of agreement with the following statement: Patients should be consulted as part of the process for determining new or making changes in Medicare coverage policies.

Q17: How aware are you of a new Medicare Billing Article addressing the reimbursement and coverage of non-invasive testing (simple blood test) for Medicare patients?

ANSWER CHOICES	RESPONSES	
Very Aware	5.71%	67
Somewhat Aware	15.00%	176
Slightly Aware	22.25%	261
Not at all aware	57.03%	669
TOTAL		1173

Q18: Are you concerned that the Billing Article limits coverage of non-invasive testing (simple blood test) and, with it, physicians' options to provide the best care for transplant patients?

ANSWER CHOICES	RESPONSES	
Yes	95.31%	1117
No	4.69%	55
TOTAL		1172

**Q19: Please indicate your level of agreement with the following statement:
Medicare should cover non-invasive testing (simple blood test) on an ongoing surveillance (monitoring) basis to check the health of the transplanted organ on a regular basis.**

ANSWER CHOICES	RESPONSES	
Strongly Agree	91.55%	1073
Agree	7.08%	83
Neutral	1.28%	15
Disagree	0.09%	1
Strongly Disagree	0%	0
TOTAL		1172

Q20: Please indicate your level of agreement with the following statement: Patients should be consulted as part of the process for determining new or making changes in Medicare coverage policies.

ANSWER CHOICES	RESPONSES	
Strongly Agree	84.22%	987
Agree	13.14%	154
Neutral	2.22%	26
Disagree	0.43%	5
Strongly Disagree	0%	0
TOTAL		1172

Medicare-related coverage decisions

21. To what extent are you willing to get involved and advocate for coverage of non-invasive (simple blood test) testing? Check all that apply.
22. Can we contact you in the future about opportunities to get involved and advocate for insurance coverage to non-invasive testing (simple blood test)?

Q21: To what extent are you willing to get involved and advocate for coverage of non-invasive (simple blood test) testing? Check all that apply.

ANSWER CHOICES	RESPONSES	
Sign a petition advocating for coverage of non-invasive testing for post-transplant patients	82.95%	973
Write or send a letter to my lawmaker or policymaker	43.99%	516
Attend an in-person meeting with a policymaker or lawmaker	24.89%	292
Provide a video patient testimonial about the importance of non-invasive testing in post-transplant care	15.43%	181
I am not interested in getting involved or advocating at this time	10.49%	123
Other	3.24%	38
TOTAL		2123

Q22: Can we contact you in the future about opportunities to get involved and advocate for insurance coverage to non-invasive testing (simple blood test)?

ANSWER CHOICES	RESPONSES	
Yes	73.91%	867
No	26.09%	306
TOTAL		1173

-END-