

# Minority Affairs Committee Report

June 28-29, 2011

OPTN/UNOS Board of Directors Meeting

OPTN



# Highlights of MAC Activities

- **Survey on Referral to Liver Transplantation**
- **MAC Transplant Options Subcommittee**

# Results of National Survey on Referral to Liver Transplant: The Transplant Program's Perspective

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# Background

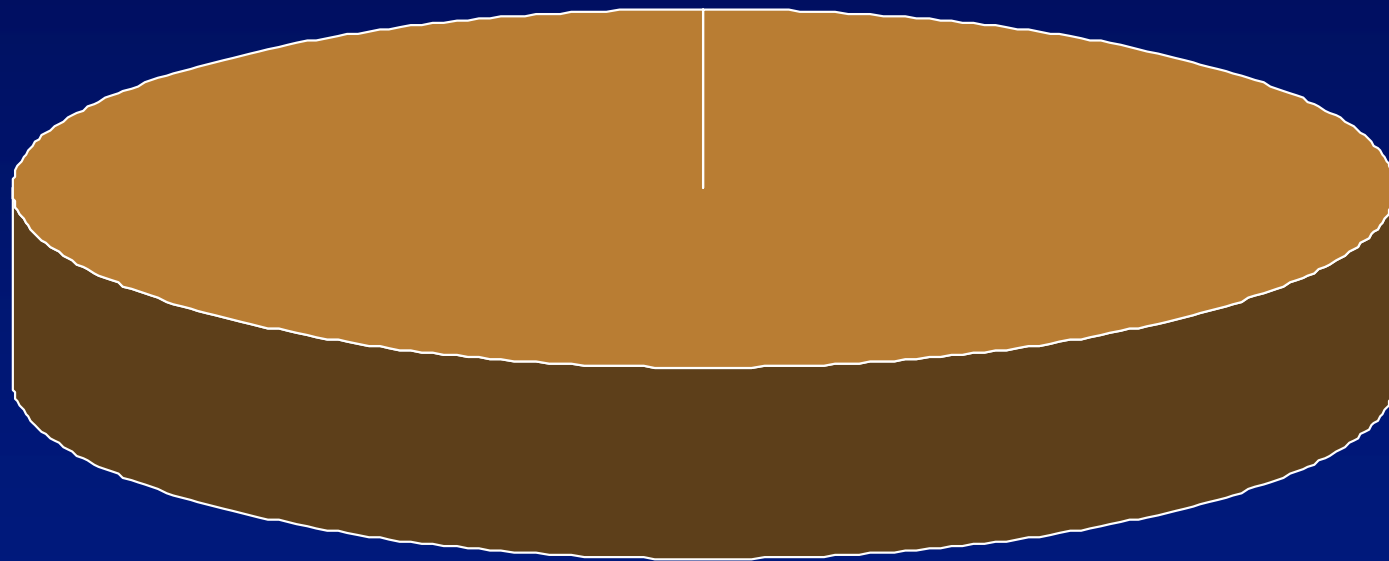
- Various data reviewed by the committee have shown higher MELD/PELD scores for minorities at wait listing and a lower overall wait listing rate, particularly for African Americans.
- The committee has been interested in determining the reasons for this variability.
- While there is little data regarding the timing and frequency of referral for liver transplant evaluation, practice patterns appear to vary widely.
- As a result, the Minority Affairs Committee conducted an on-line survey to study the timing and rate of ESLD patient referral for transplant evaluation.

# Data and Methods

- Data were collected using the Key Survey software.
- The survey was sent to 278 Program Directors at 130 liver transplant programs.
- The survey was launched on 11/3/10 and reminder emails were sent on 11/16/10, 11/29/10, and 12/1/10.
- Survey was closed on January 7, 2011.
- A total of 69 surveys were completed.

# Does your program monitor patient referrals for evaluation for transplantation?

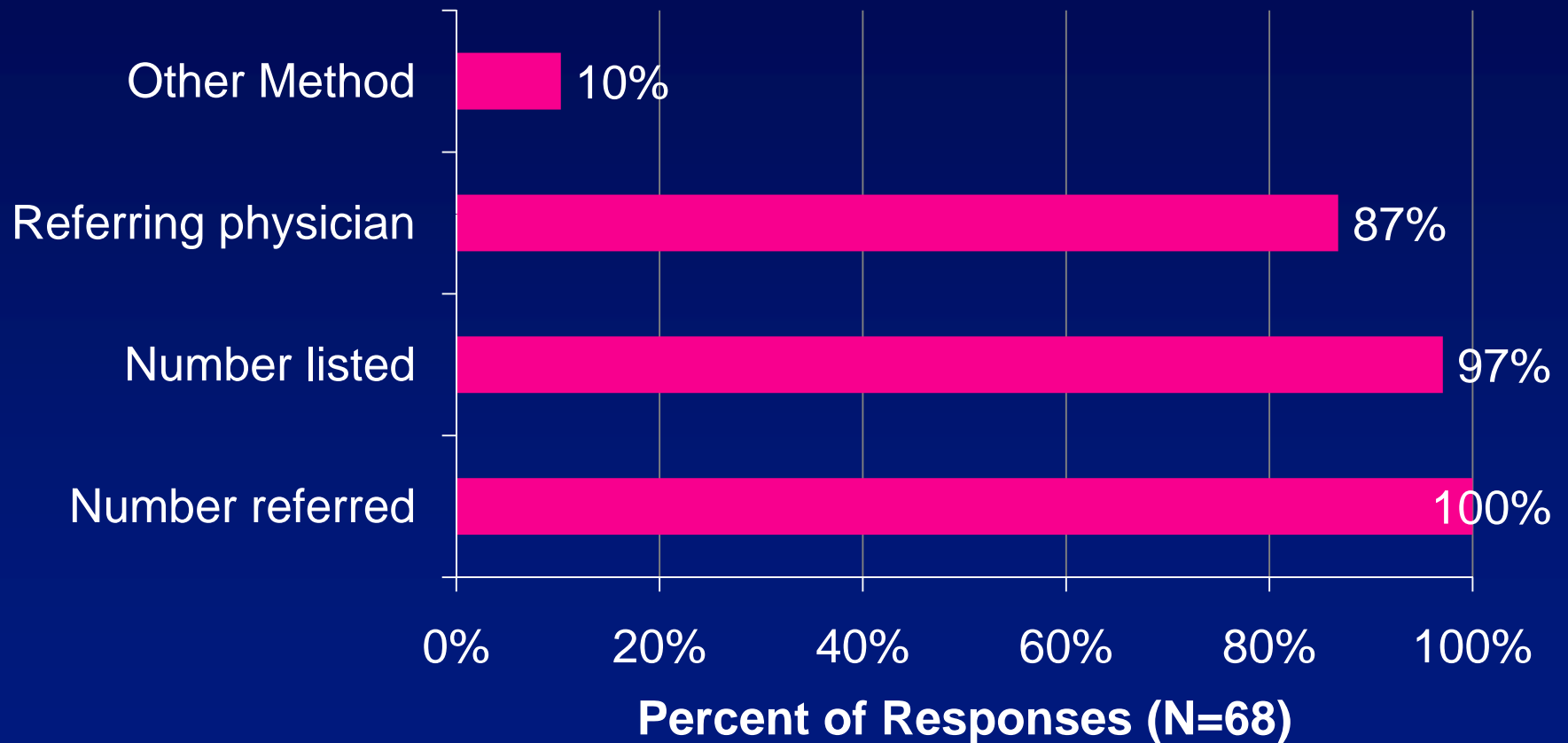
N=69



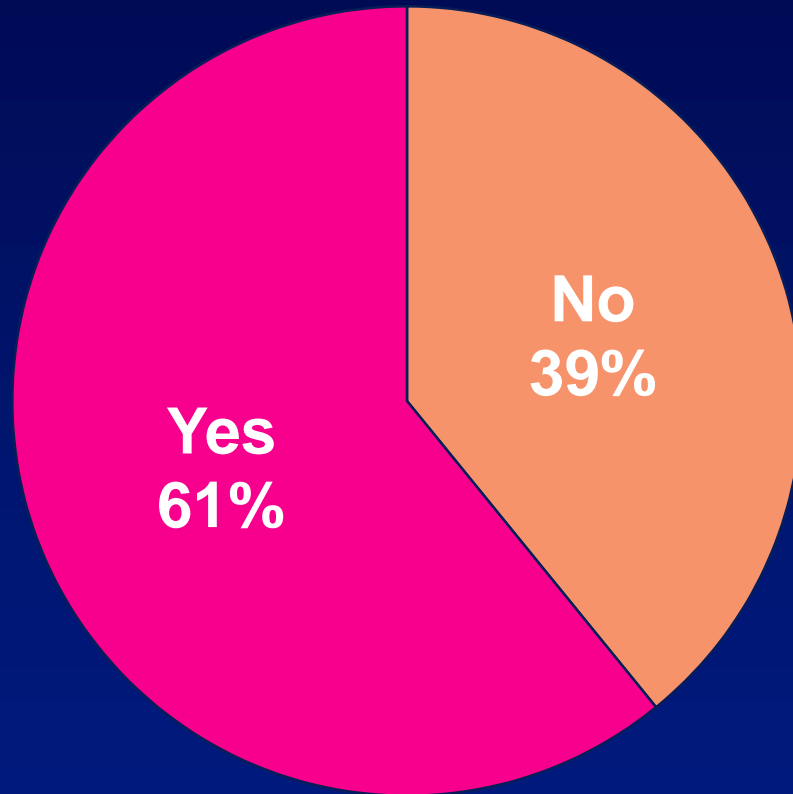
Yes  
69 (100%)

# Methods Used to Monitor Patient Referrals

(Select all that apply)



# Do you determine or monitor the percentage of eligible patients referred for transplant?

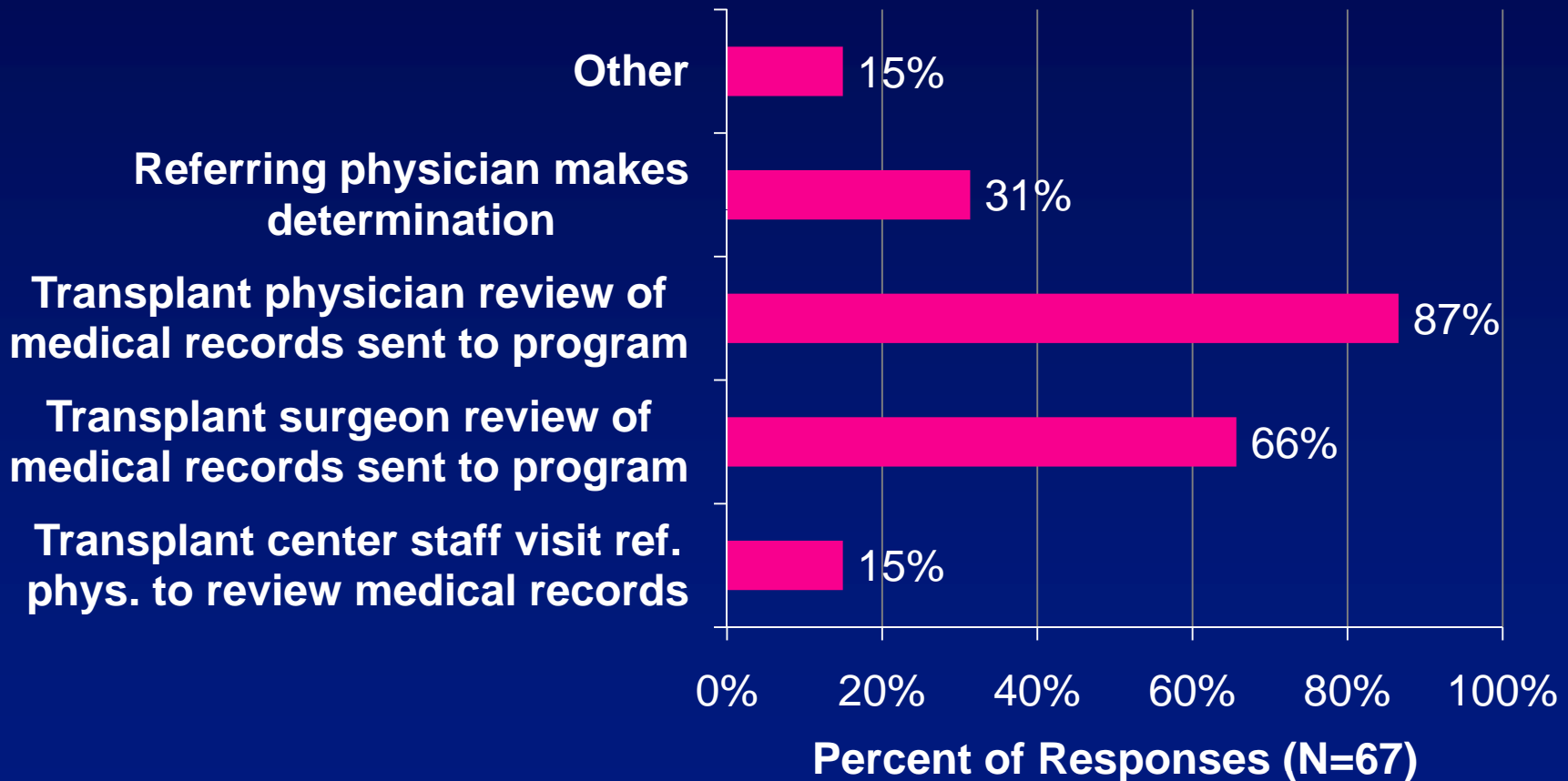


Number of Responses = 69



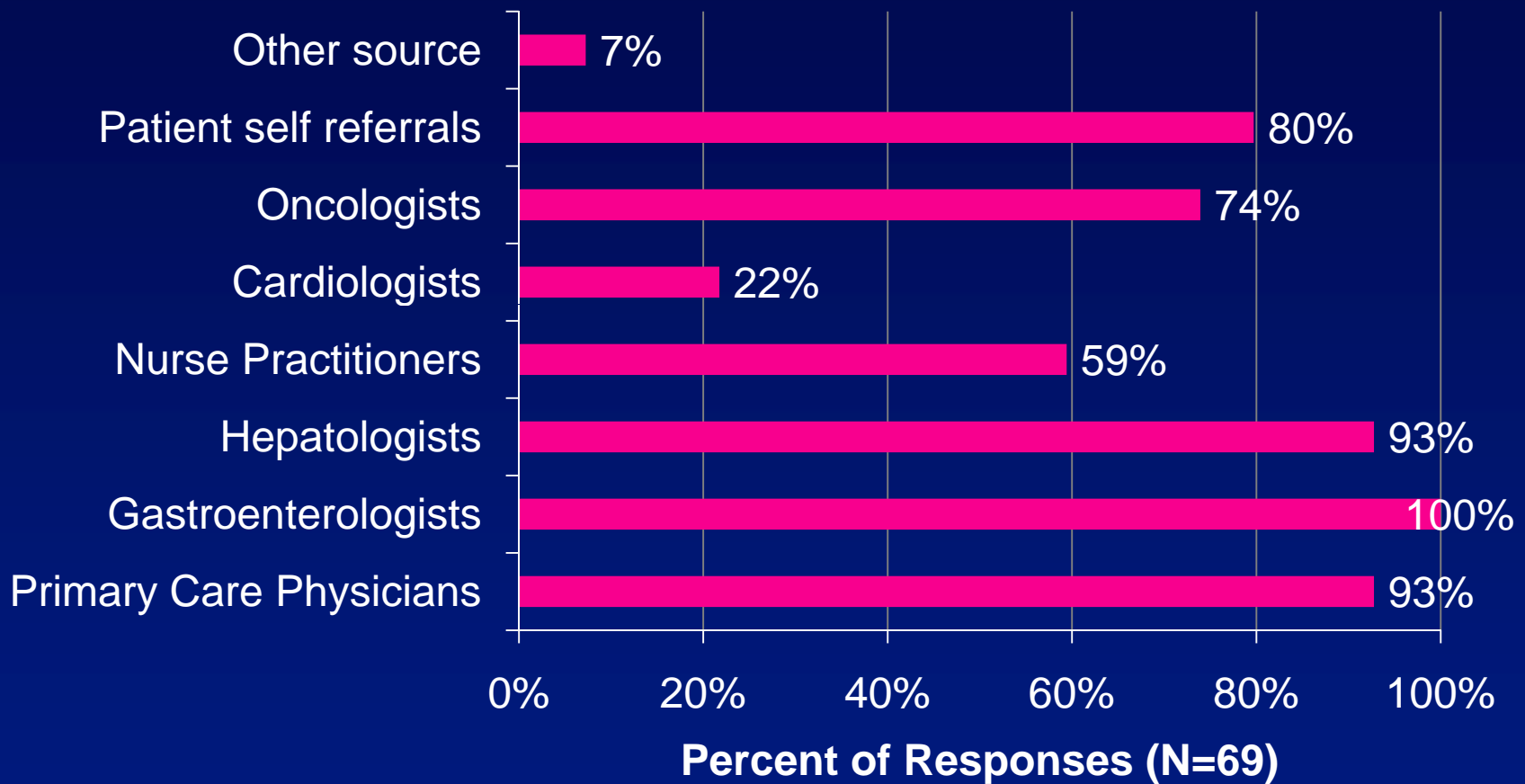
# Methods to Determine Patient Eligibility for Referral

(Select all that apply)



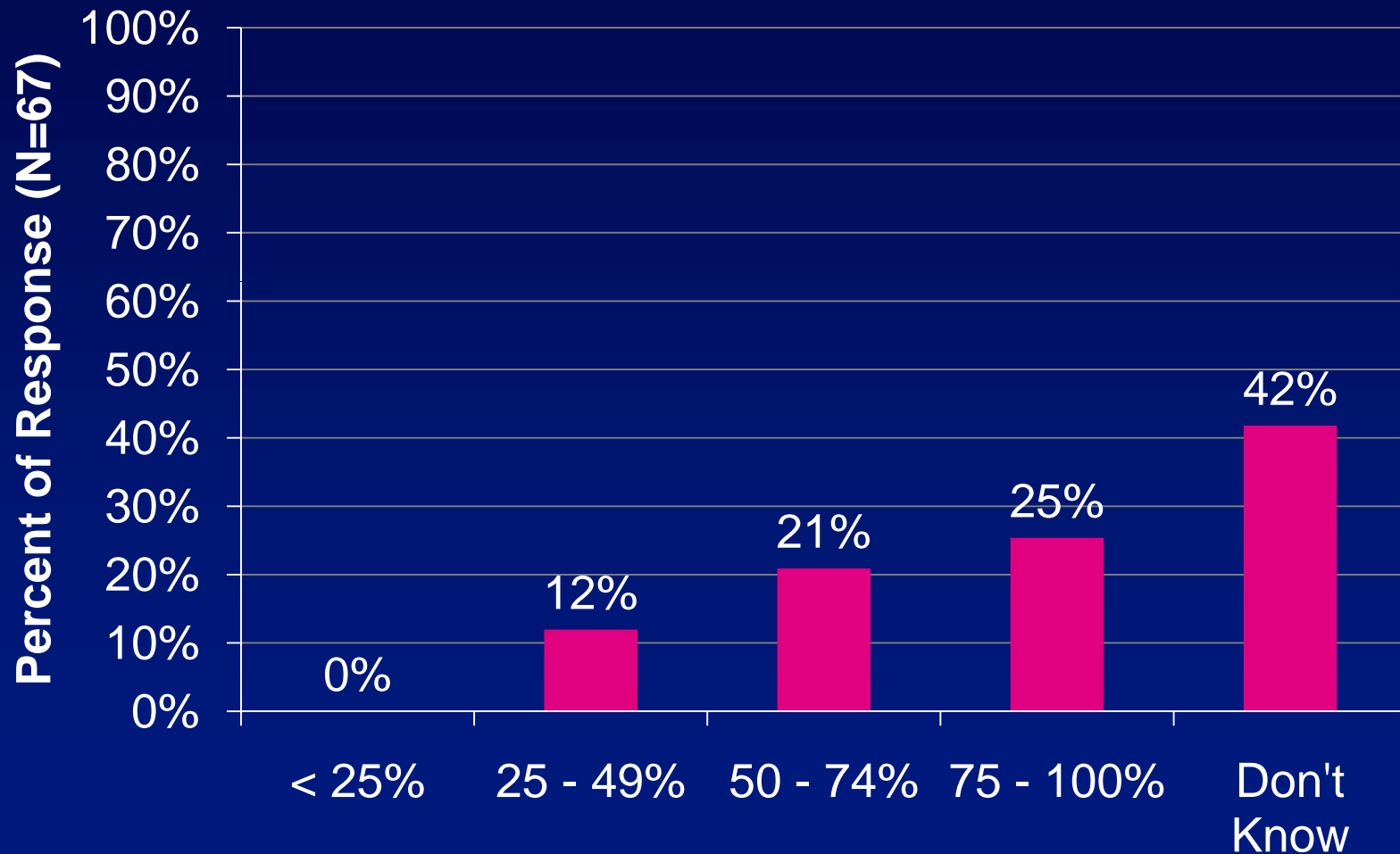
# Where Do You Get Your Referrals From?

(Select all that apply)



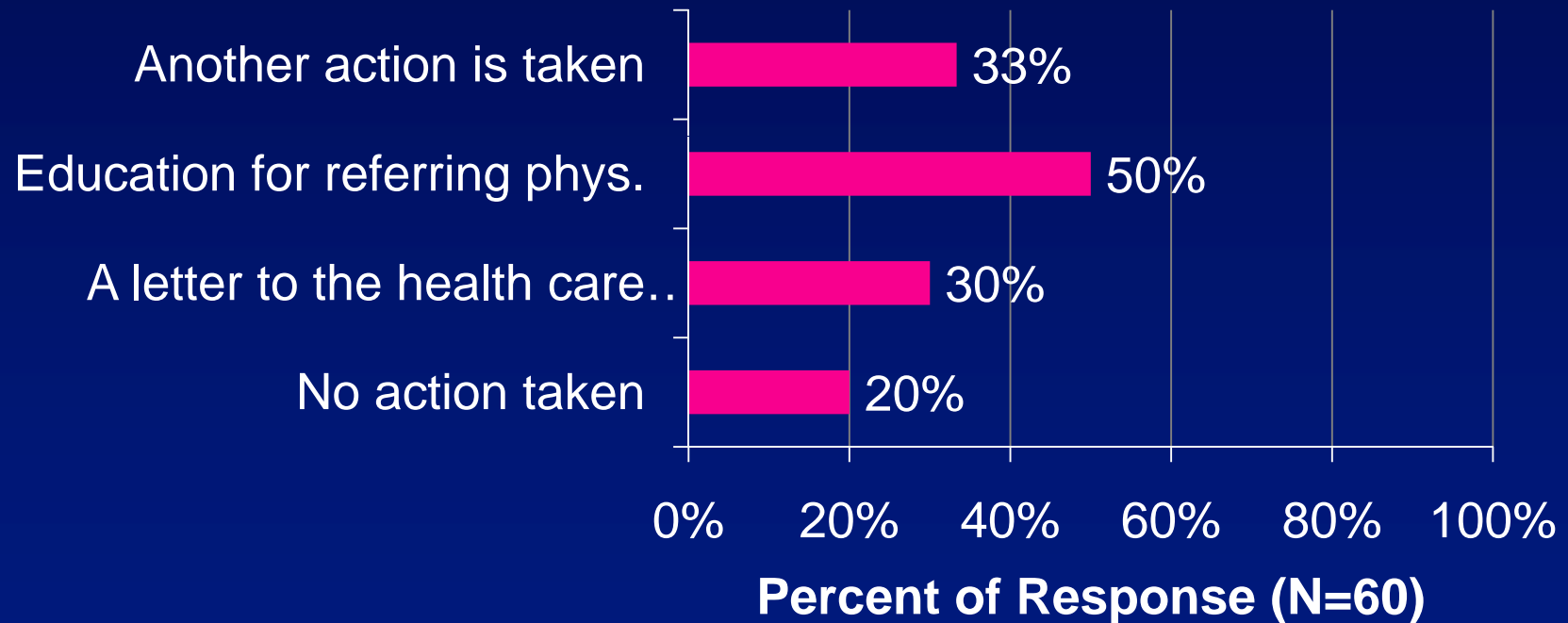
Other Responses: Case Managers, Social Workers,  
and Multidisciplinary Team

# What Percentage of Medically Eligible Patients are Referred?



# What Actions Do You Take When You Find Out a Medically Eligible Patient is Not Referred?

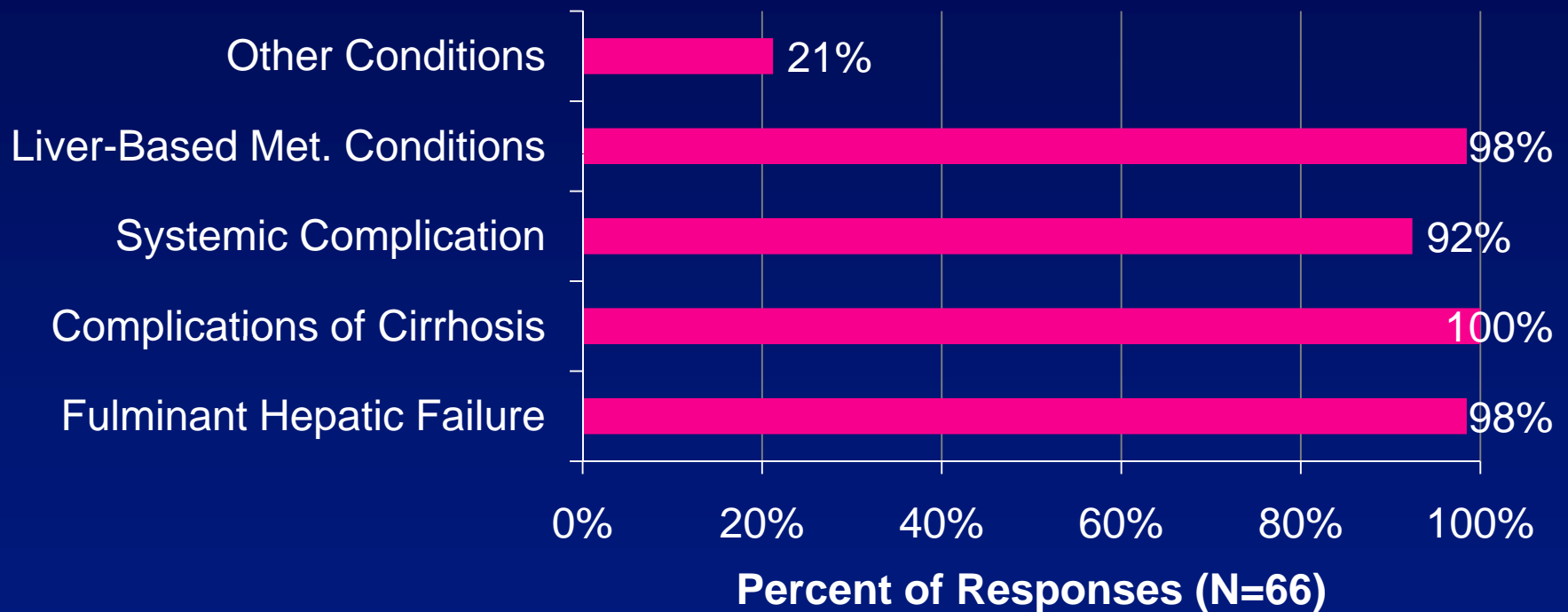
(Select all that apply)



Other Responses: Contacting Referring Physician via Phone

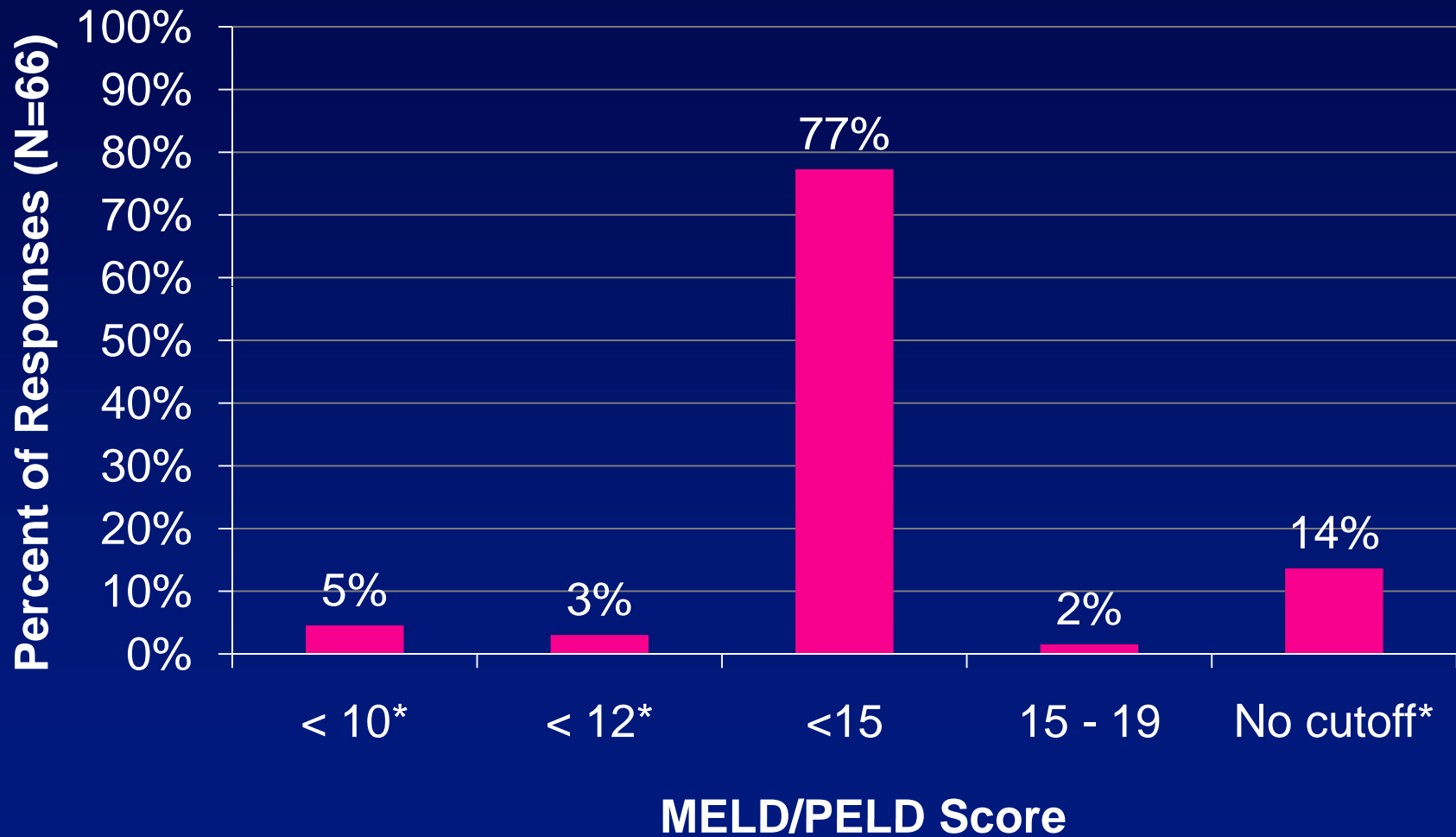
# Indications That Patient is Medically Eligible for Referral

(Select all that apply)



Other Responses: Tumors, HCC, Liver Cancer, and Growth Failure

# What MELD/PELD Score Cut-off Does Your Program Consider to be Early Referral?

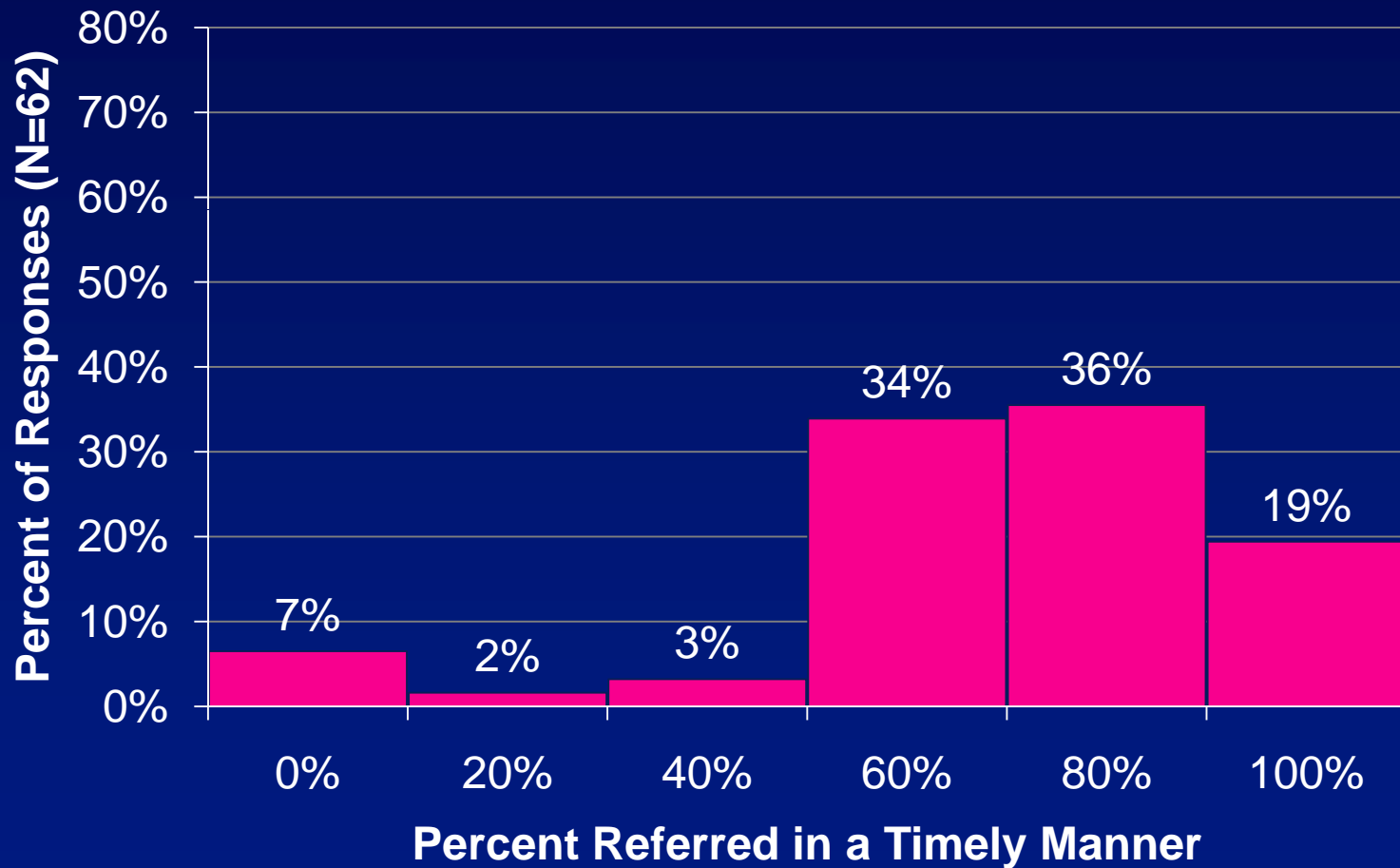


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\* Not option on survey but indicated in other text field

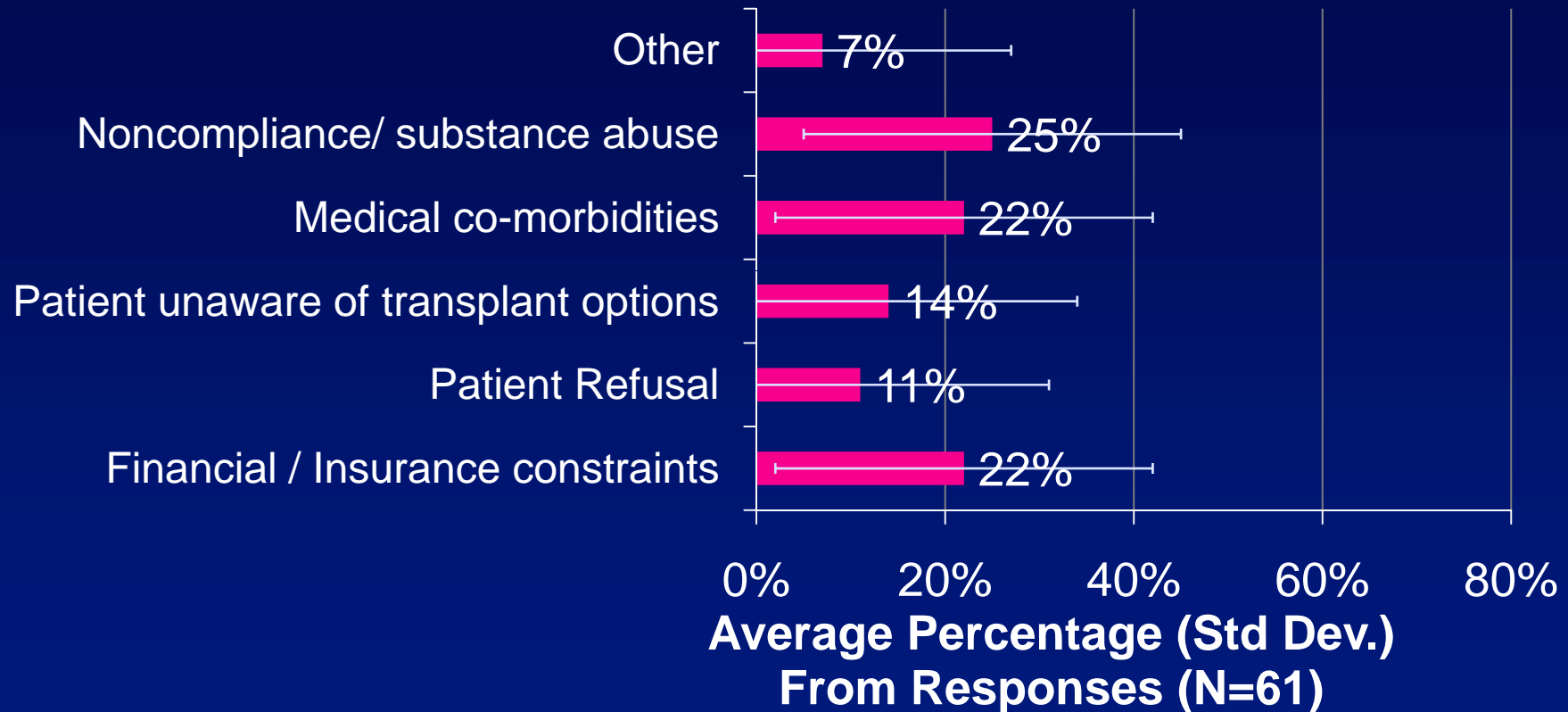


# Among All Medically Eligible Patients Referred, What Percentage are Referred in a Timely Manner (as defined according to your program's definition)?



# Primary Reasons for Delayed Referral

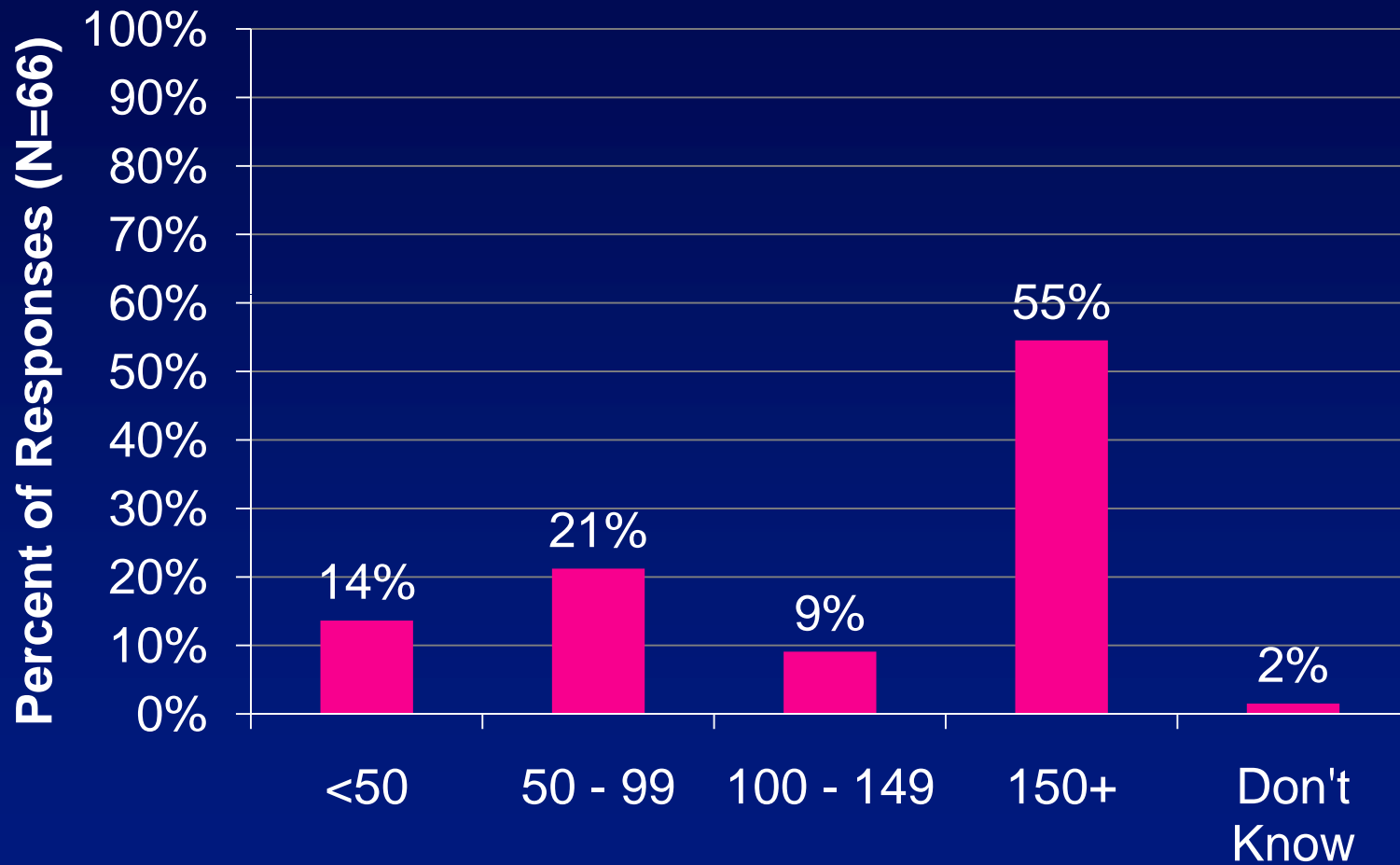
(Approximate Percentage)



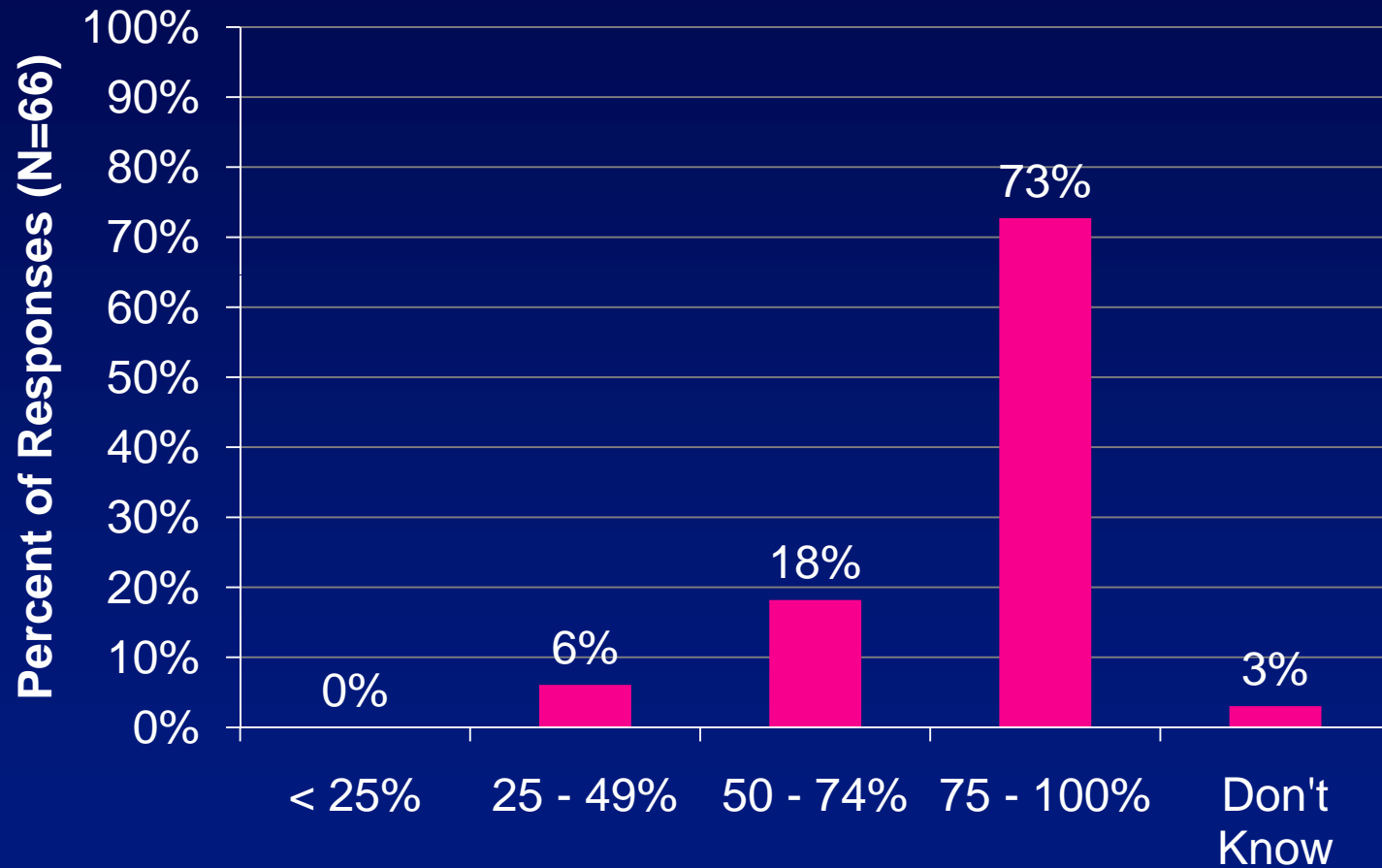
Other Reasons: Referring physician not aware of transplant options  
or need for early referral



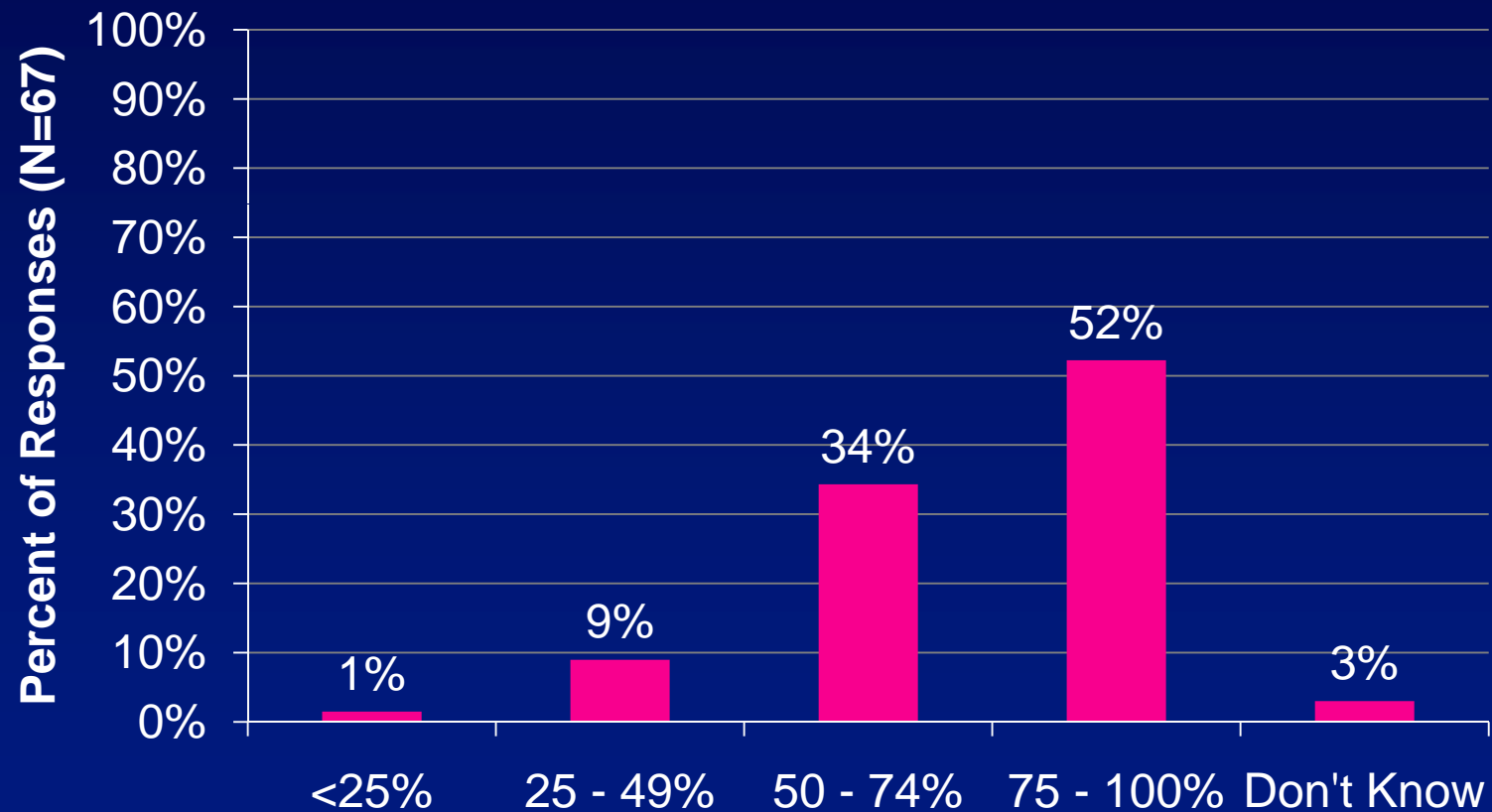
# Approximately How Many Referrals Do You Receive a Year?



# Approximately What Percentage of Patients Referred Comes in for an Evaluation?

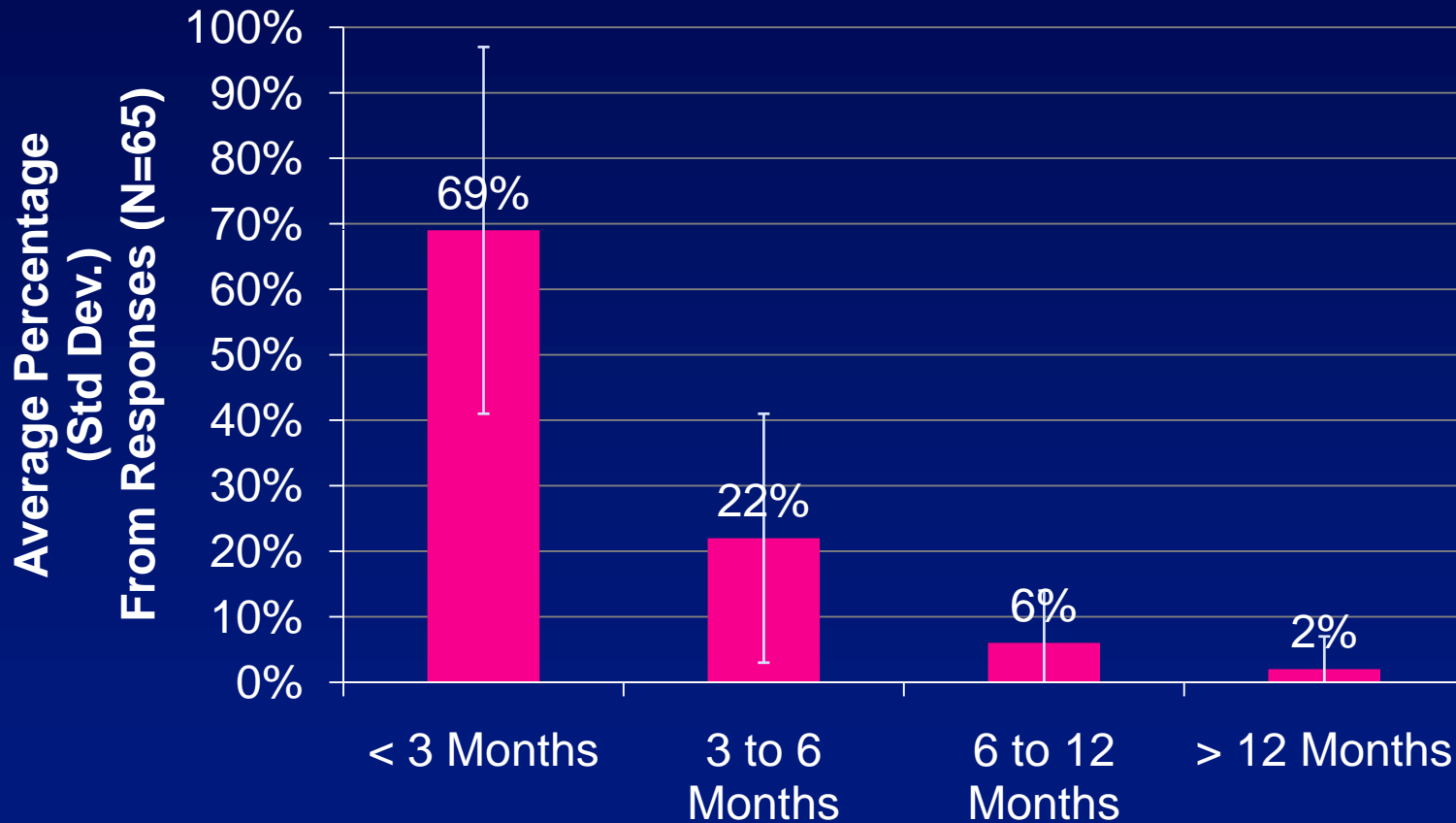


# Approximately What Percentage of Patients that Present for Initial Evaluation Completes the Evaluation Process?



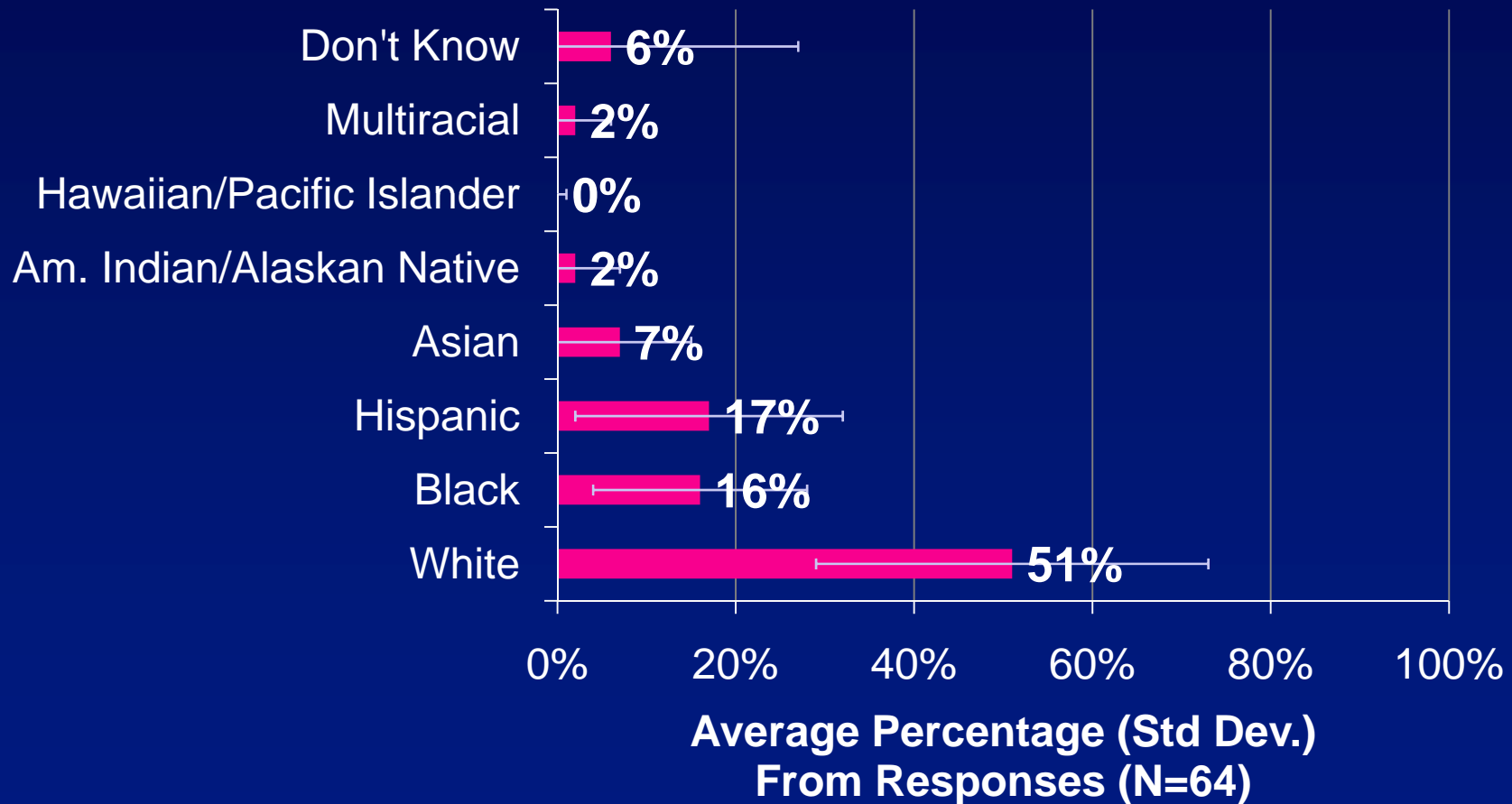
# Time From Referral to Completion of Evaluation

(Approximate Percentage)



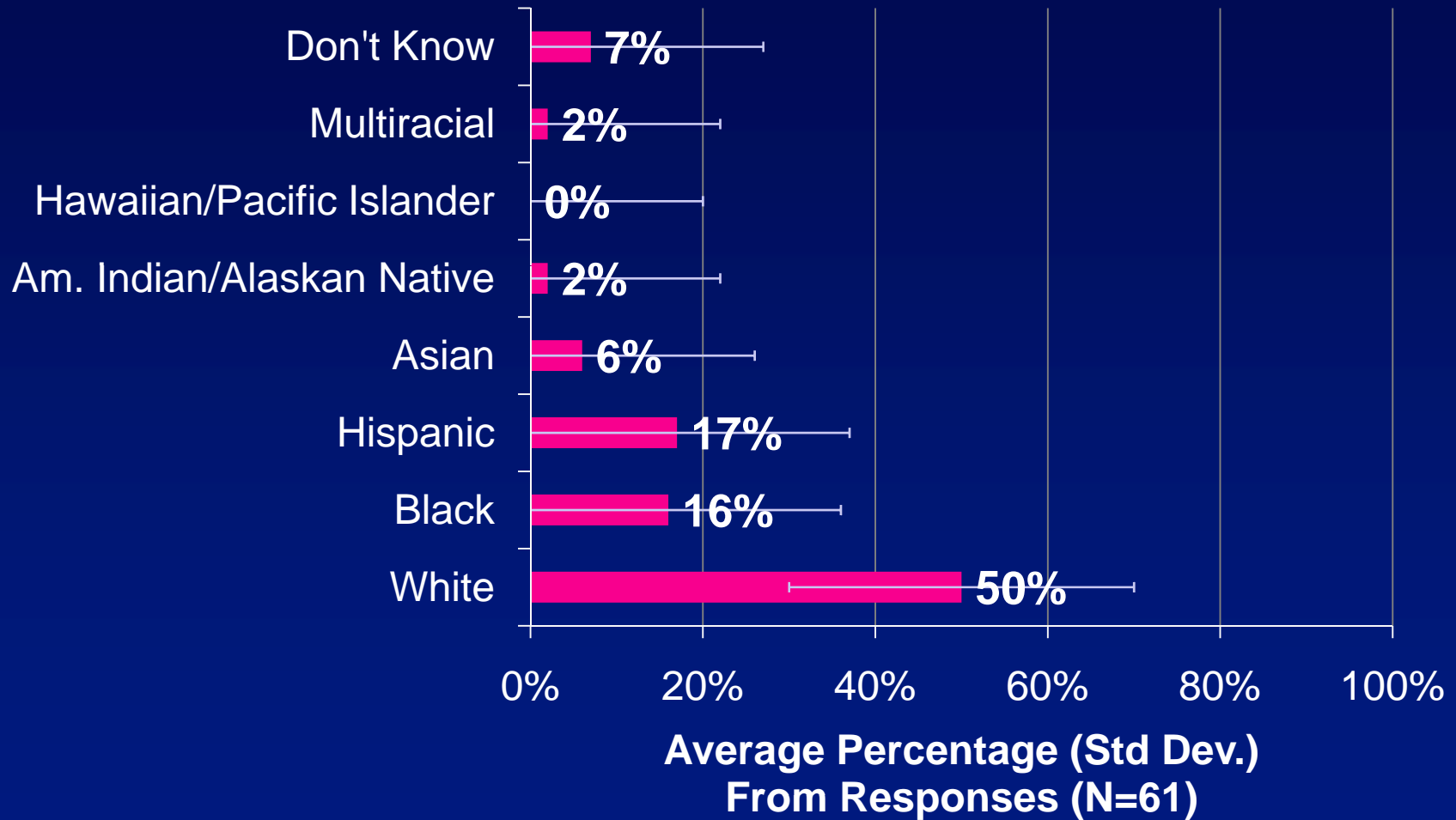
# Ethnic Representation of Patients on the Waiting List

(Approximate Percentage)



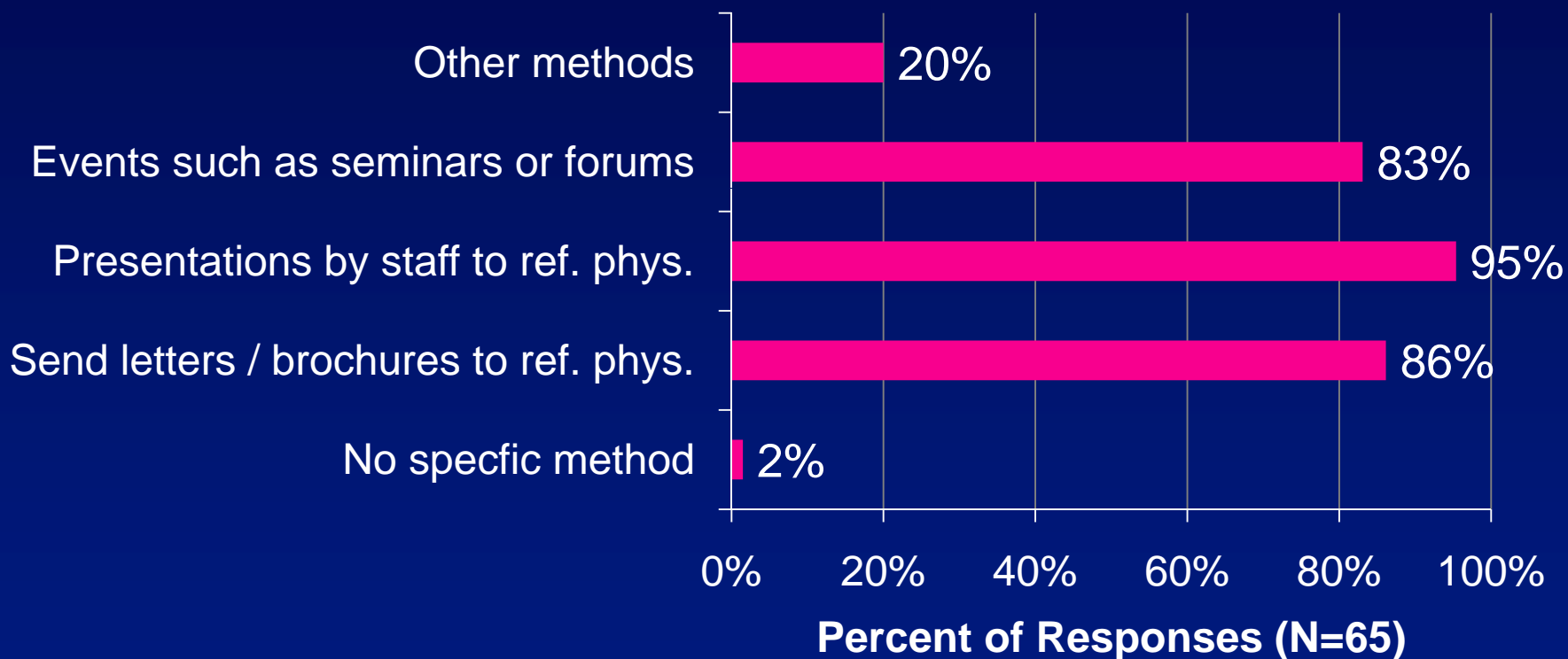
# Ethnic Representation of Referrals

(Approximate Percentage)



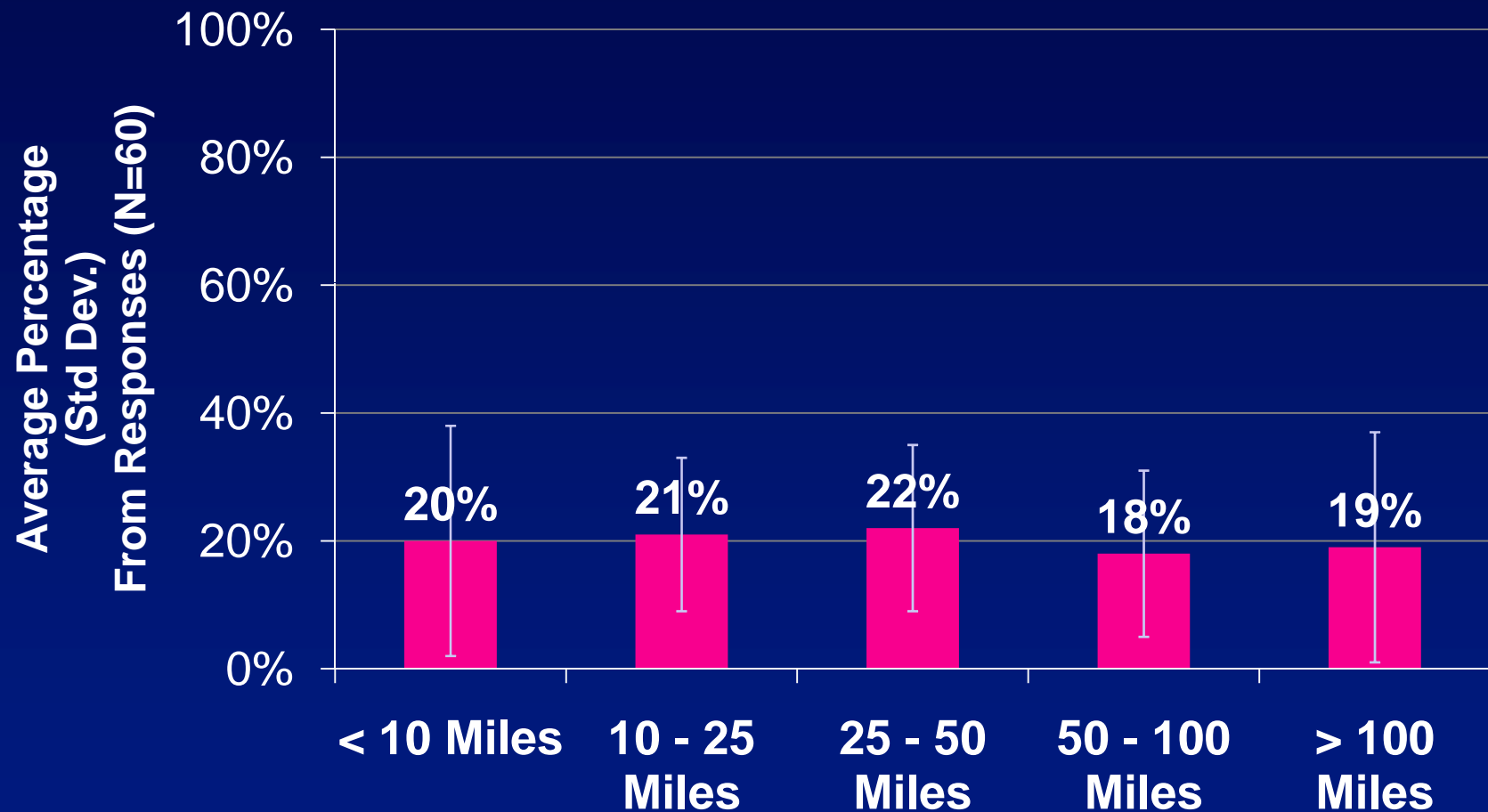
# What Methods Do You Use to Enhance Referrals?

(Select all that apply)



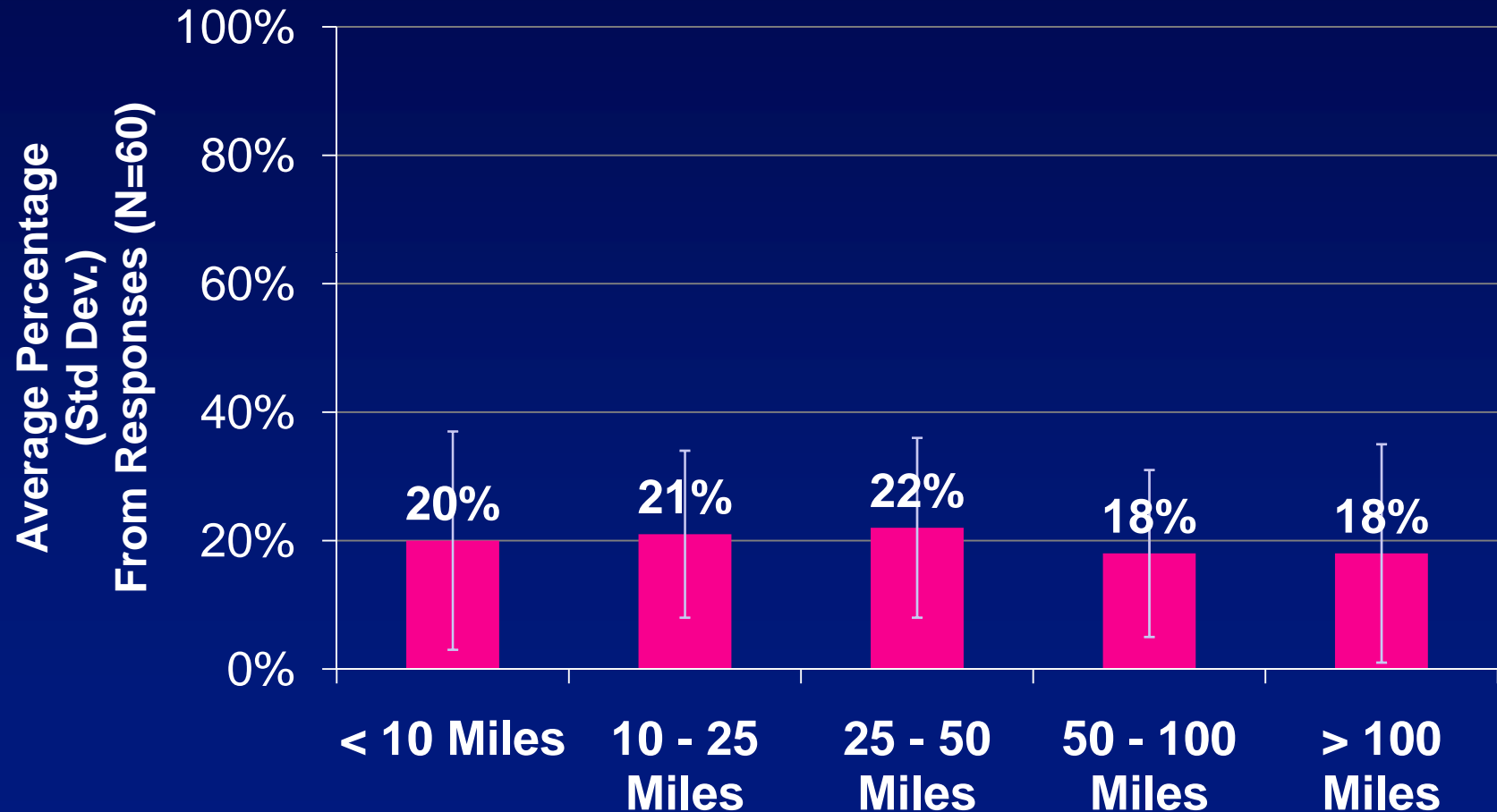
Other Responses: Visits to Referring Phys., Fairs/Fundraisers, and Outreach Programs

# Distance Referred Patients Have to Travel to be Evaluated for Transplant



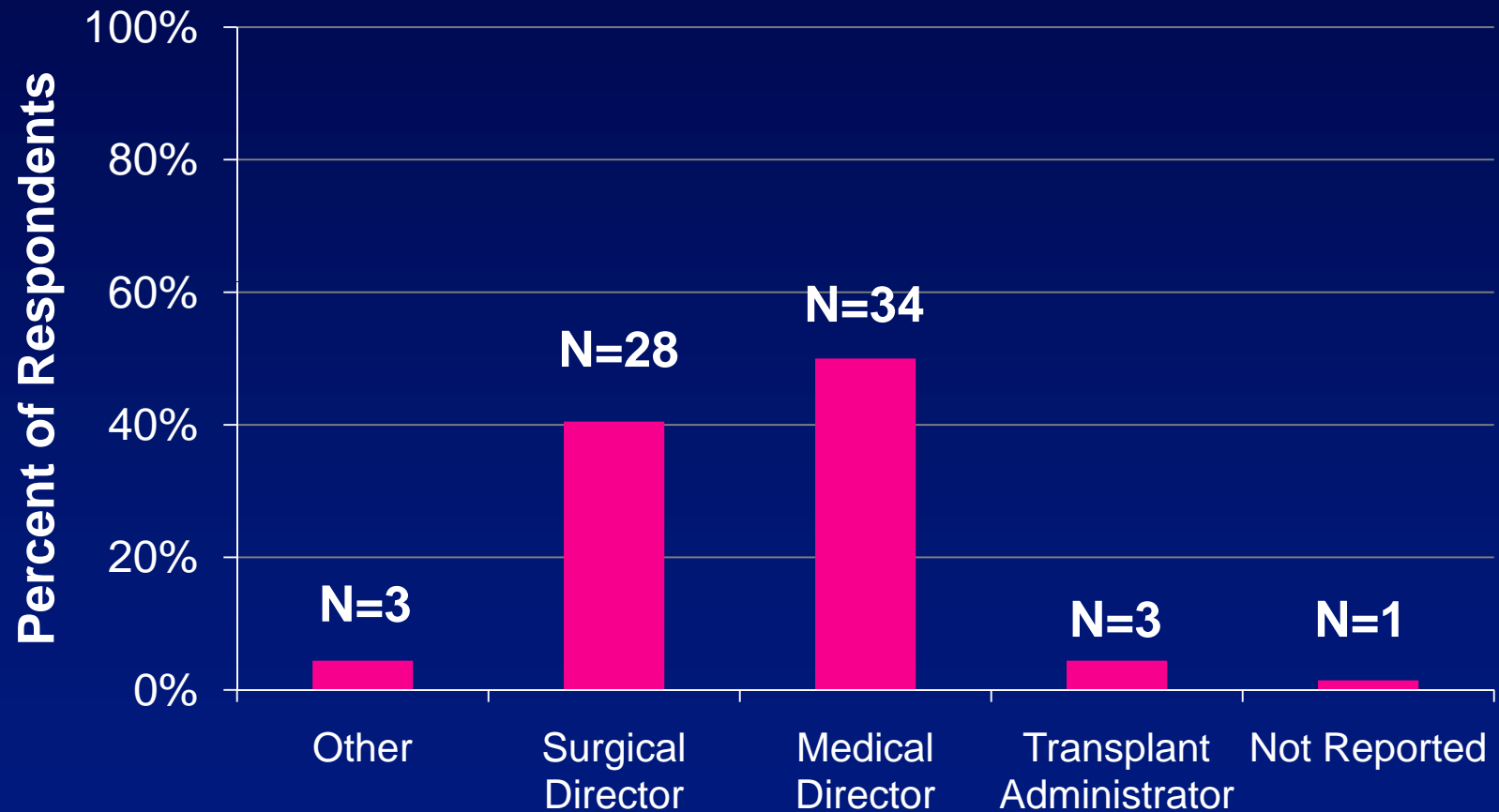


# Distance Referred Patients That Complete Evaluation for Transplant Have to Travel



# **RESPONDENT INFORMATION**

## **Position with Transplant Center**



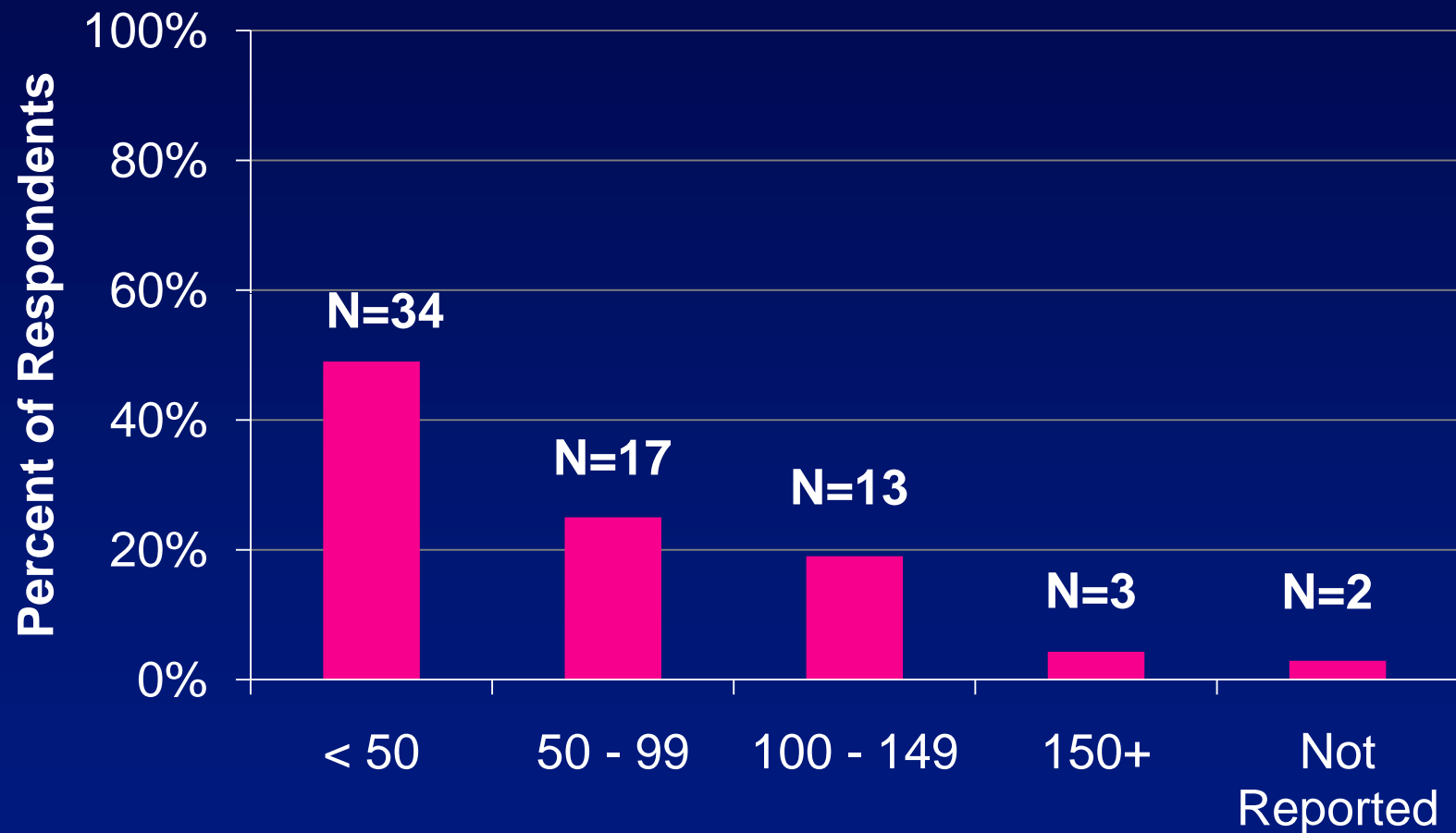
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**Total Number of Surveys = 69**



## RESPONDENT INFORMATION

### Annual Number of Liver Transplants Performed



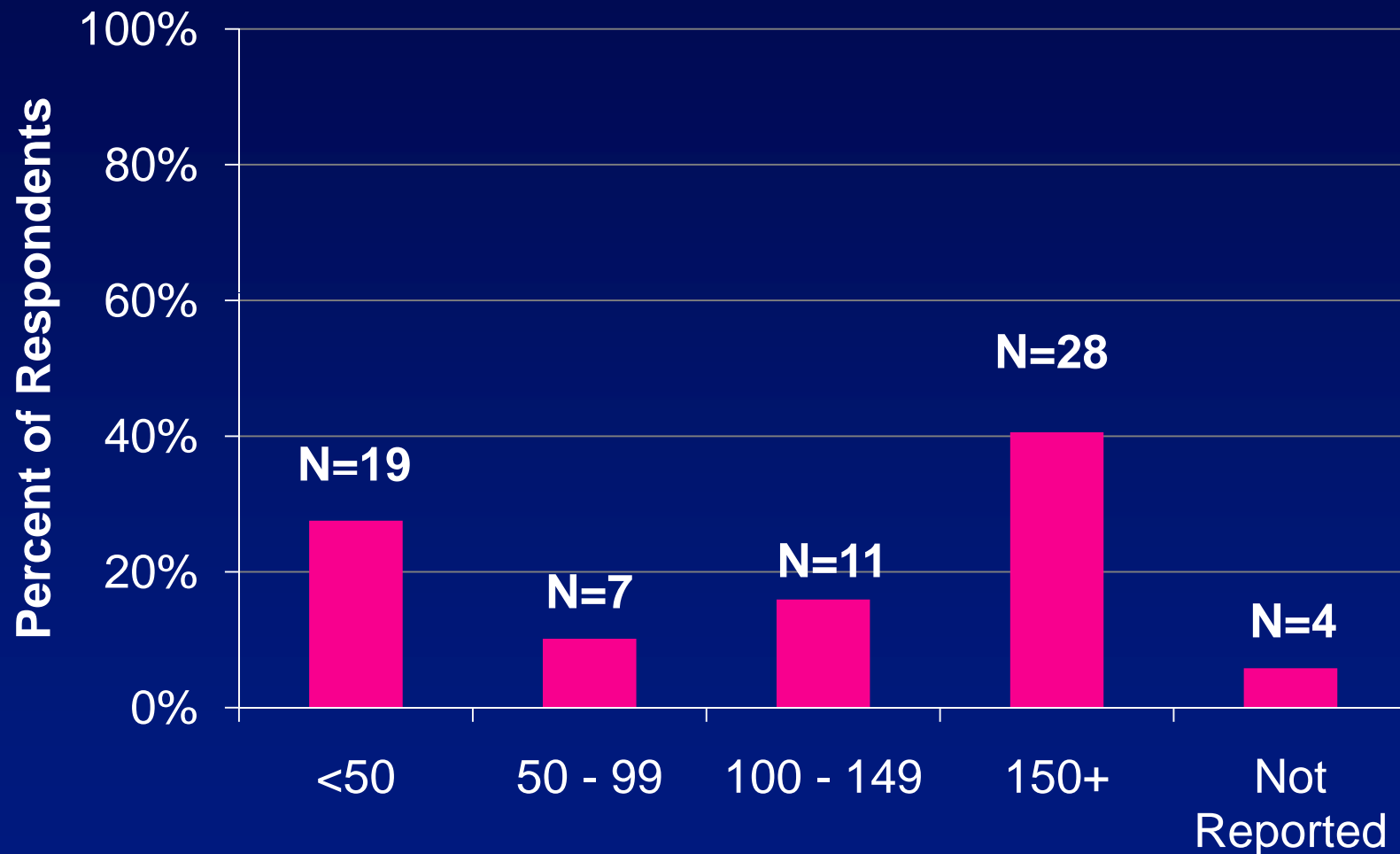
OPTN

Total Number of Surveys = 69



## RESPONDENT INFORMATION

### Annual Number of Hepatobiliary Referrals Received



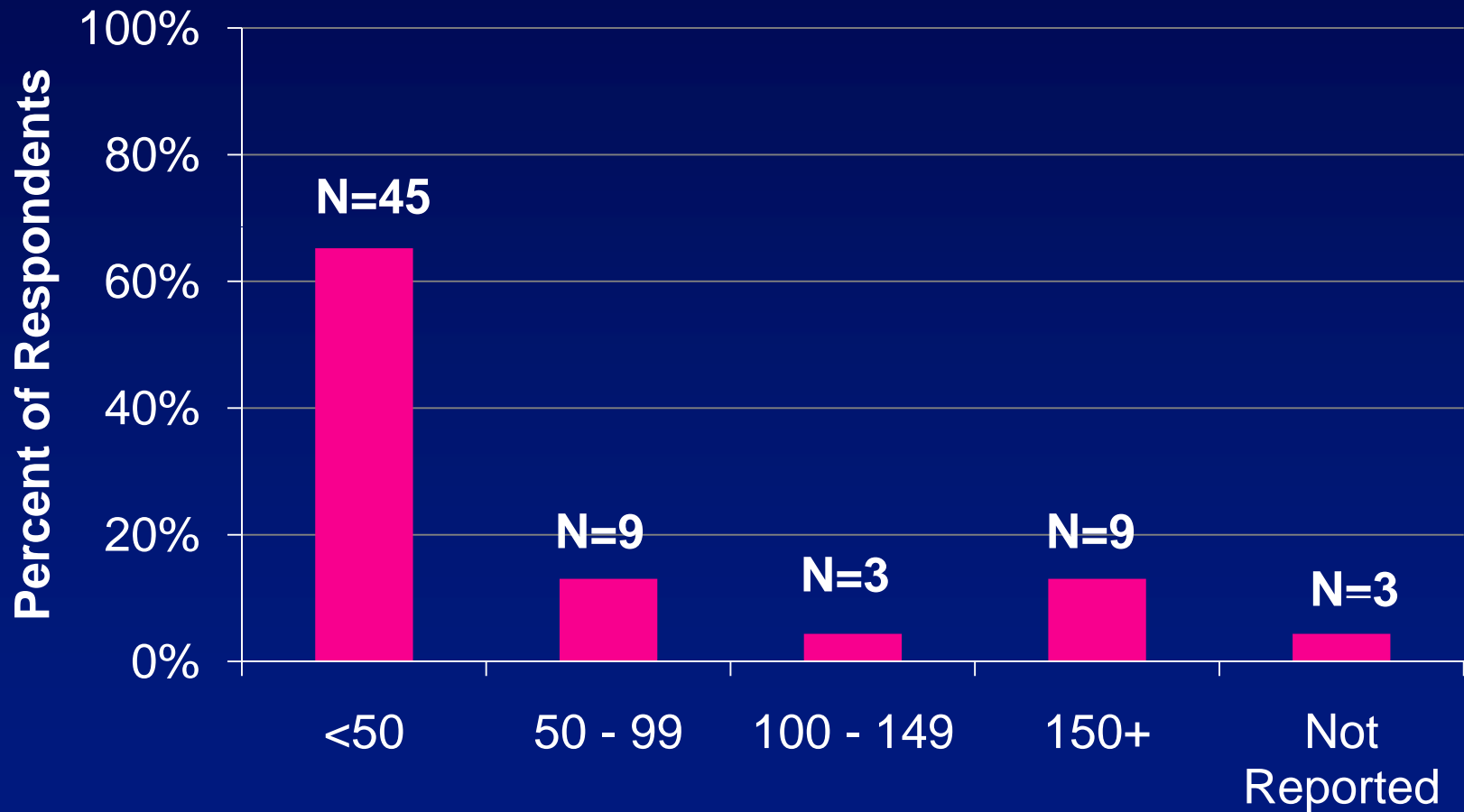
OPTN

Total Number of Surveys = 69



## RESPONDENT INFORMATION

# Annual Number of Hepatobiliary Referrals that go on for Transplant Evaluation



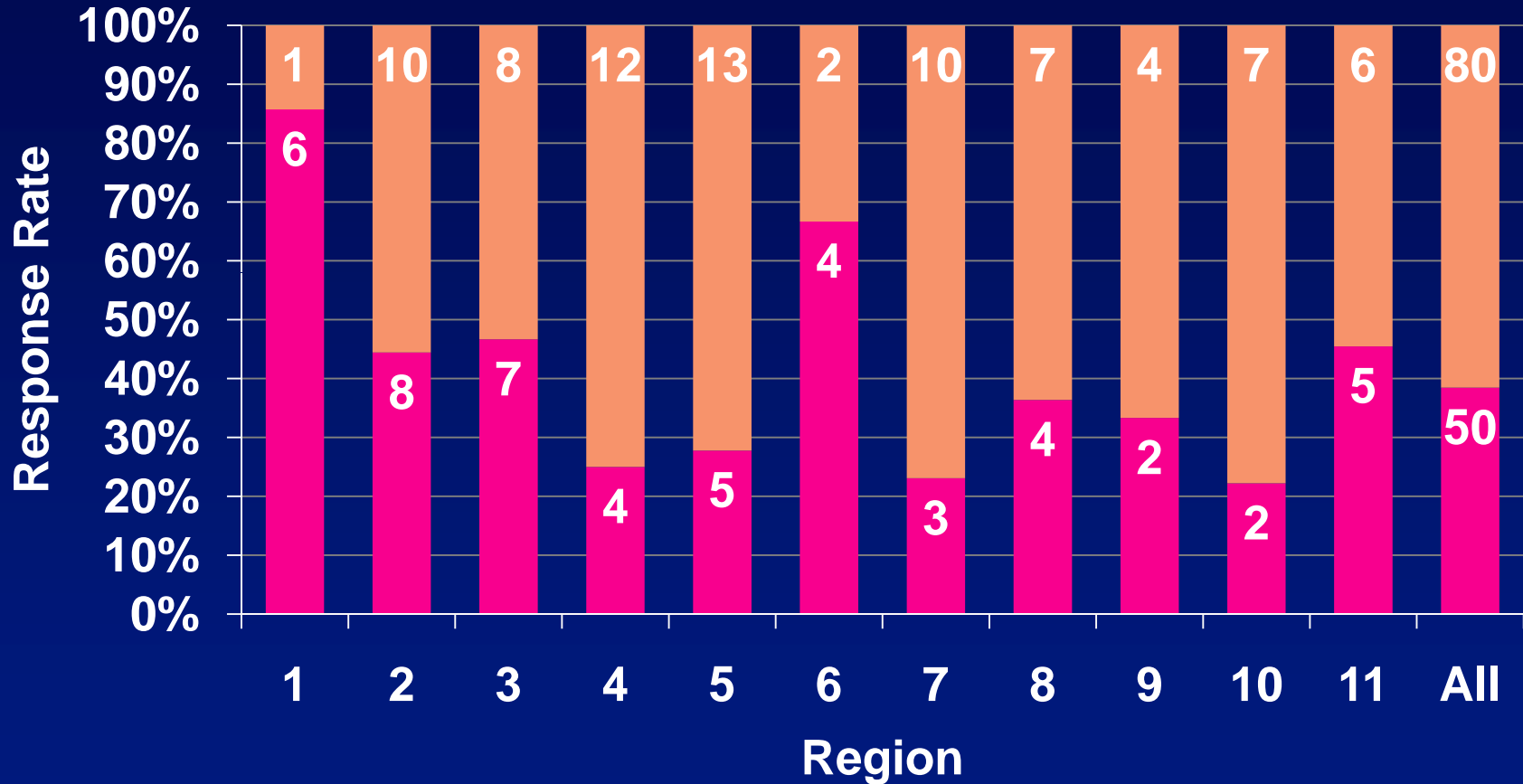
OPTN

Total Number of Surveys = 69



# Survey Response Rate by Region

■ # Centers Responded    ■ # Centers w/ No Response



# Centers Responded = 50 (69 total responses)

Total # of Centers = 130 (278 invitations)

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# Summary

- 100% of respondents monitor patient referrals.
- More than half (61%) monitor the percentage of eligible patients referred
- Almost half (42%) are unsure of the percentage of medically eligible patients referred.
- Transplant physician and surgeon review of medical records is the most common method for determining medical eligibility for referral.
- More than 90% indicate they receive referrals from gastroenterologists, hepatologists and primary care physicians.

# Summary

- 80% take action when they find out a medically eligible patient is not referred.
- More than 90% of the respondents reported complications of cirrhosis, liver based metabolic conditions, fulminant hepatic failure, and systemic complications as indications used to determine that a patient is medically eligible for referral.
- 77% of the respondents specified a MELD/PELD score of <15 as an early referral cut-off point.
- Three most common reasons for delayed referral include non-compliance/substance abuse, medical co-morbidities and financial/insurance constraints.



# Summary

- On average, 70% of referrals complete evaluation in less than 3 months.
- There appears to be no ethnic differences between patients on the waiting list and patients referred.
- Over 80% of the respondents indicate that they use some methods to enhance referrals, such as letters/brochures/presentations to referring physician and events/seminars.
- Distance does appear to have an effect on patients completing evaluation.

# MAC Subcommittee on Education and Awareness of Transplant Options

- Data reviewed by the committee has shown significant delays in referral, wait listing and transplantation of minority patients as compared to their White counterparts.
- Many patients who are appropriate for transplantation are never referred for transplant or are referred late in their disease progression.
- Data also suggests that providers are not well educated enough about transplantation to adequately inform patients about this option.
- Further, referring physicians may not be up to date regarding expanded acceptance criteria for transplant patients.

# MAC Subcommittee on Education and Awareness of Transplant Options

- A MAC *Subcommittee on Education and Awareness of Transplant Options* was formed to develop educational guidelines for appropriate referral to kidney transplantation.
- The guidelines will be disseminated to the transplant community and paired with an implementation strategy to track patient referrals over time.

# MAC Subcommittee on Education and Awareness of Transplant Options

The guidelines will:

- Better define who is an appropriate transplant candidate by including suggested absolute and relative contraindications to transplant.
- Establish the optimal timeframe for patient referral with examples (emphasizing that referral is a continuous process with annual reassessment)
- Emphasize the benefits of transplantation preemptively and in general from a fiscal and societal perspective.

# MAC Subcommittee on Education and Awareness of Transplant Options

- It is intended that the guidelines will eventually pave the way for the development of national standards for referral with specific expectations for providers.
- Activities addressing quality monitoring practices for referring providers would be implemented following the development of the guidelines.

# MAC Subcommittee on Education and Awareness of Transplant Options

- A preliminary draft of the guidelines has been developed using common patient acceptance criteria identified through a review of transplant center practices.
- An expanded subcommittee meeting to include members of additional OPTN committees (Kidney, Patient Affairs and Transplant Administrators) as well as other professional transplant partner organizations (NKF, AST, ASTS, KDOQUI, etc.) will be reconvened to review the draft document.

# Other MAC Activities

- The committee continues to review CPRA data by ethnicity.
- The committee is participating in the review of Policy 6.0: Transplantation of Non-Resident Aliens for relevancy and currency.
- The committee continues to support the concepts included in the Kidney Concept Document with a request for future modeling for unintended consequences to minority patients following implementation.
- To address misperceptions in the media surrounding the concept document, the committee encourages a proactive response to include public/patient education in the mainstream media (television, radio appearances, etc.) where the average public receives the majority of its information.
- The committee has provided feedback to the Kidney Committee with regard to ways to increase minority participation in the KPD Pilot Program.