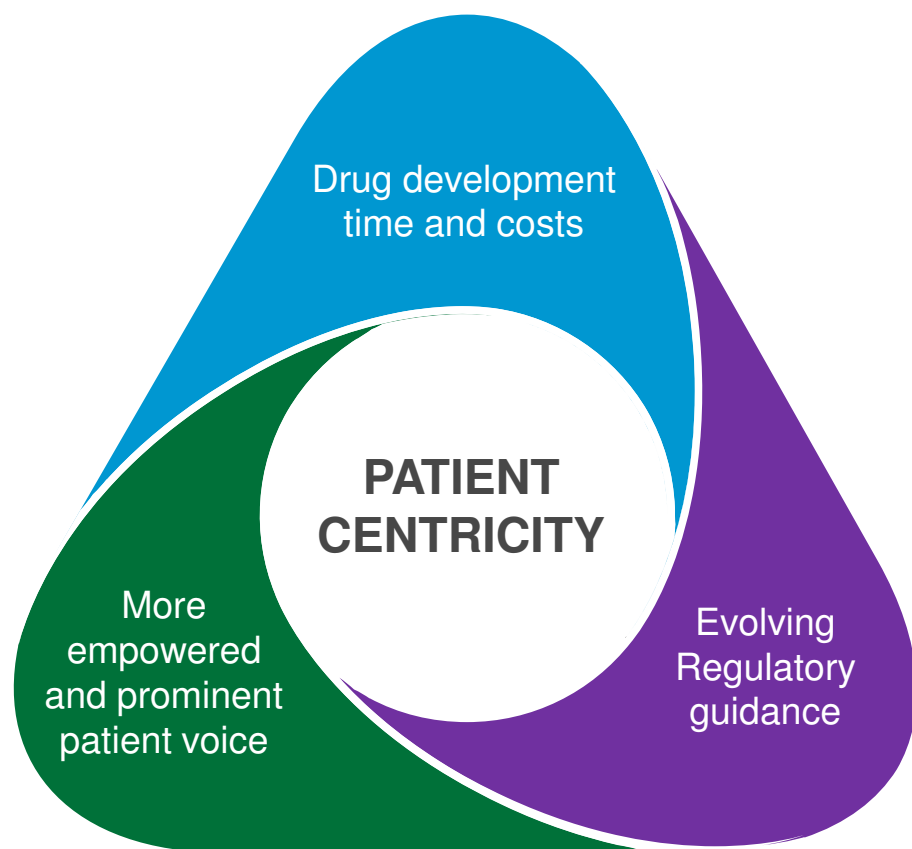


# PATIENT CENTRICITY

Leone Atkinson, MD, PhD

# A New Paradigm



A changing landscape is forcing the pharmaceutical industry to put the patient, not the product, at the center of all drug development efforts.

# The Industry Understands the Mandate to Change

## PATIENT CENTRICITY IMPERATIVE



Pharma must better **incorporate the patient voice in the drug develop** paradigm



In the future, the patient voice (through various channels) will **drive our clinical development activities/strategy**



By the year 2035, drug development will be **dictated and driven significantly by patient input**

Total n=140 senior level clinical development outsourcing decision makers

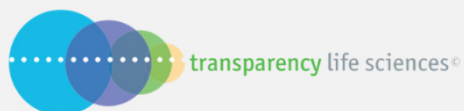
3 | Patient Centricity - September 2017

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# Current Approaches Underway – Pharma

## SPONSORS ARE BECOMING MORE PATIENT CENTRIC

### Crowd sourcing innovative solutions



**>2.4million** posts about **40,000** drugs and conditions across **tens of thousands** of sites, forums and blogs have been collected and analyzed



**10,000** patient clinical trial pilot



patientslikeme®



**>40** pharma companies have become partners to understand what its like for their **~500,000** patients to live with over **2,700** diseases

“We can hit a button and send out a survey to ALS patients and get results back in 2 weeks”

***Our clients are coming to Covance to ask about our patient centric approaches***

# The Patient Centric Clinical Trial

100 PHARMA EXECUTIVES CONVENED AND MAPPED OUT THE FOLLOWING 'EXEMPLARY' ORGANIZATIONAL APPROACH FOR A PATIENT CENTRIC CLINICAL TRIAL.



## Designing the Trial

- ▶ **Engage**
  - Patients and partners
  - Patient advocate groups
  - Physicians
  - Virtual patient communities
- ▶ **Obtain input on:**
  - ▶ Effects on quality of life
  - ▶ Protocol
  - ▶ Eligibility criteria
  - ▶ Study procedures
  - ▶ Training materials



## Planning & Recruiting

- ▶ **Define roles clearly**
  - Clinical trial team
  - Patient advocates
  - Patient partners
- ▶ **Work collaboratively**
- ▶ **Match right patient to right trial**
- ▶ **Educate patient**
  - Enables informed decision
  - Provide support
- ▶ **Minimize patient burden**
  - ▶ Virtual site visits
  - ▶ Visiting Nurse
  - ▶ Local laboratory
  - ▶ Mobile e-diary



## Conducting the Trial

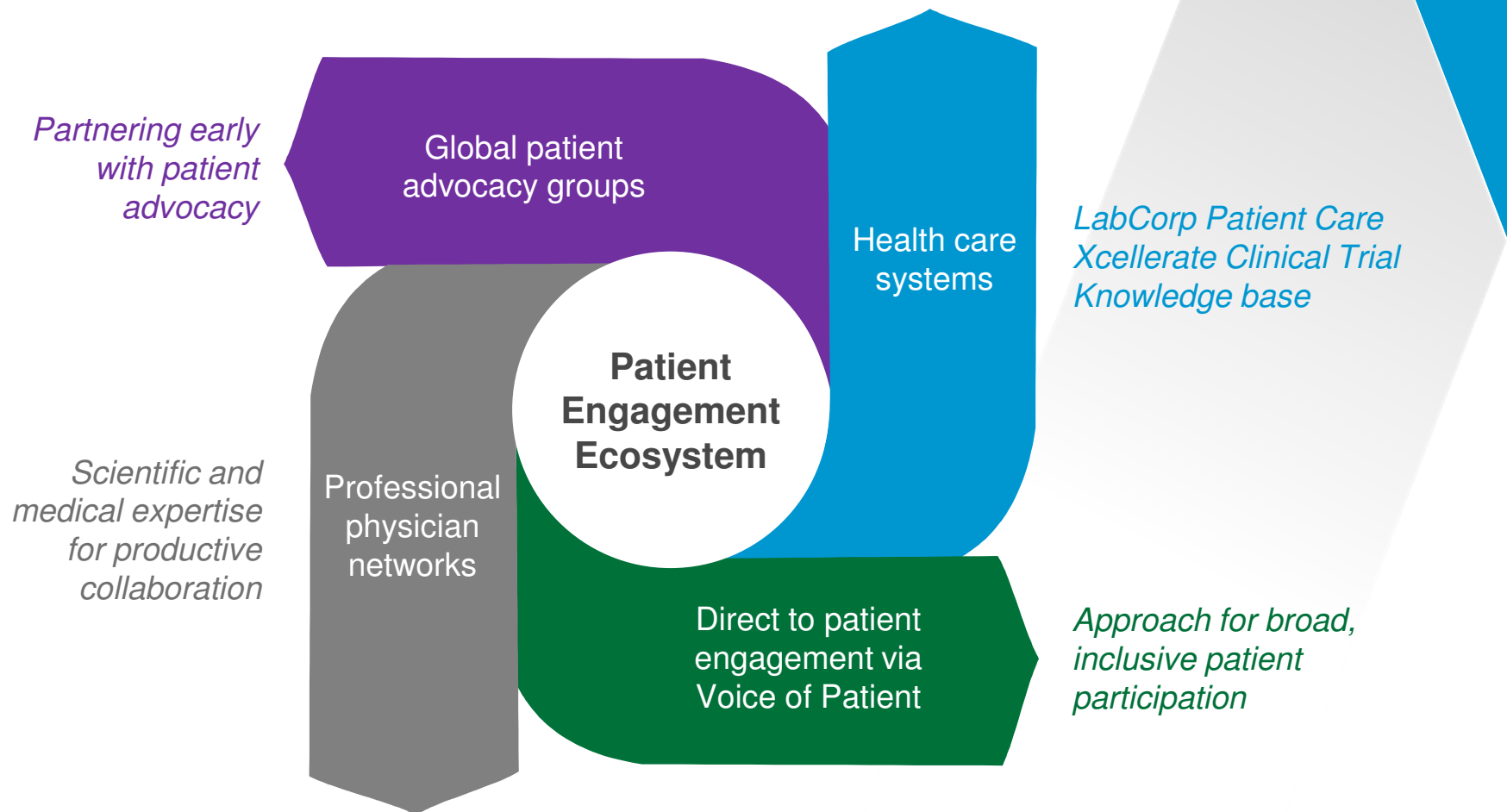
- ▶ **Align on key goals**
- ▶ **Patient's journey**
  - ▶ Include site and support staff
- ▶ **Communicate**
  - ▶ Relevant patient data
  - ▶ Patient reactions
  - ▶ Problems
  - ▶ Best practices

Source: The Patient-Centered Clinical Trial, A New Paradigm, A Thought Paper on Organizational Change, Joyce Avedisian, PhD, [www.patientclinicaltrials.com](http://www.patientclinicaltrials.com). Edited by eyeforpharm.

**COVANCE**  
SOLUTIONS MADE REAL®

# Our Patient Centric Approach

**COVANCE'S BROAD ECOSYSTEM OF ENGAGEMENT PARTNERS COMBINED ENABLES A TOUCH POINT TO PATIENTS THAT CAN BE LEVERAGED WITH MASSIVE SCALE TO HELP ENHANCE CLINICAL TRIAL CONDUCT.**

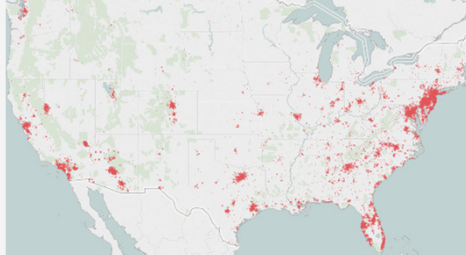


# Voice of the Patient: LabCorp Opt-In Patient Survey

## METHODOLOGY

- ▶ Survey sent once per month via email to interested LabCorp patients
- ▶ Quantitative web-based survey, 5 - 10 minutes in length
- ▶ No honorarium for completion
- ▶ Data collection ongoing since January 2017
- ▶ Sample to date (1 September 2017)
  - **Completed surveys = 10,154**
- ▶ Sample sizes vary by question since respondents can exit survey at any time

## DEMOGRAPHICS

Age	%	Gender	%
18 – 34	14%	Female	58%
35 – 44	17%	Male	41%
45 – 54	21%	Unspecified	<1%
55 – 64	25%	<b>S4. Respondent Locations by Zip Code</b>	
Living Description*	%		
Suburban	61%		
Urban	19%		
Rural	17%		
Prefer not to answer	2%		



# Voice of the Patient in Rare Disease



## Rare Disease Survey

Survey invitations distributed via market research company

Quantitative web-based survey, 5-10 minutes in length

Respondents not given honorarium for completion

Data collection September 8-15, 2016

Sample size = **150 US patients**



## Fabry Patient Survey

Survey invitations distributed in collaboration with advocacy groups

Quantitative web-based survey, 10-20 minutes in length

Respondents not given honorarium for completion

Data collection January to August 2017

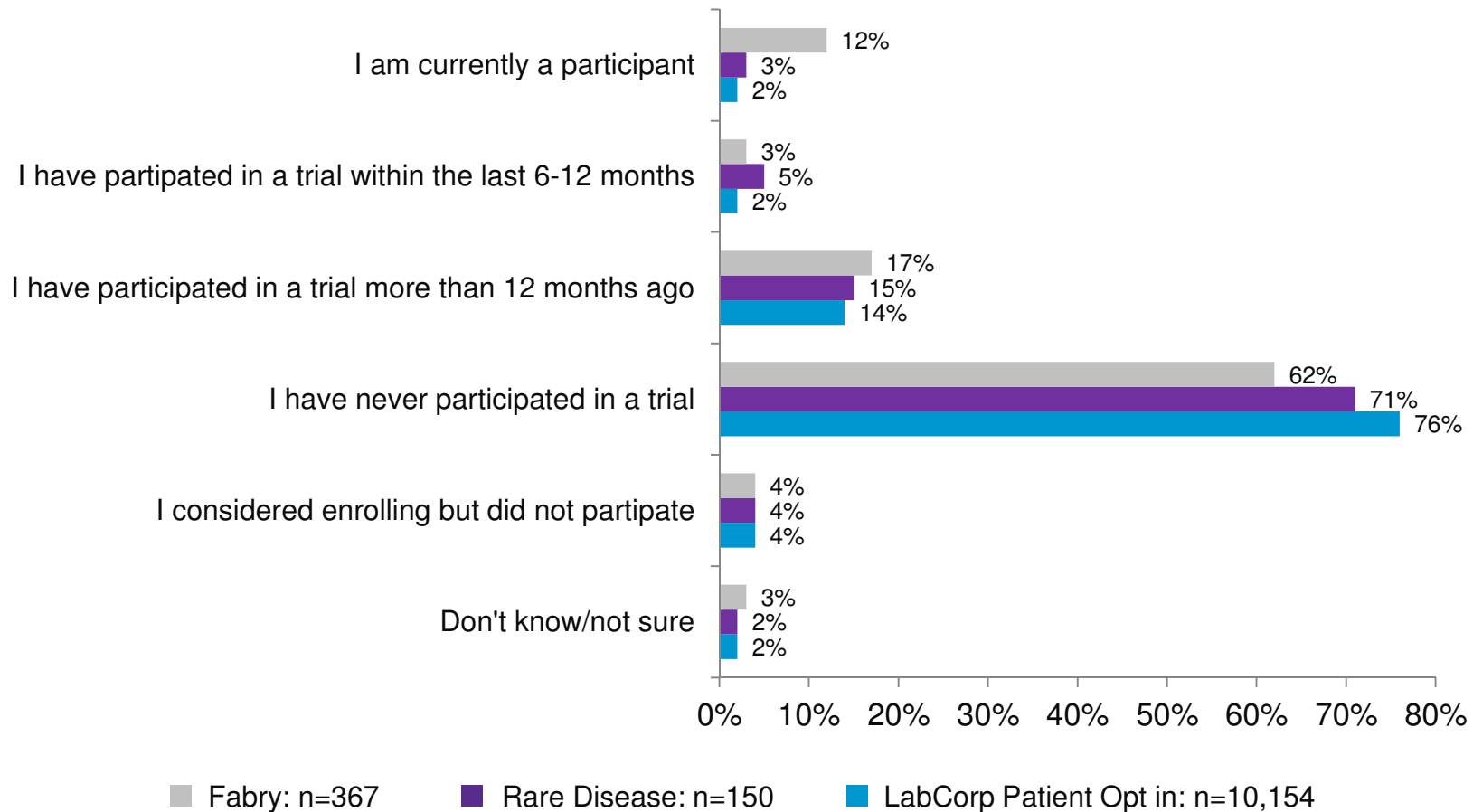
Sample size = **367 patients globally**

Final data analysis ongoing



# Clinical Trial Experience

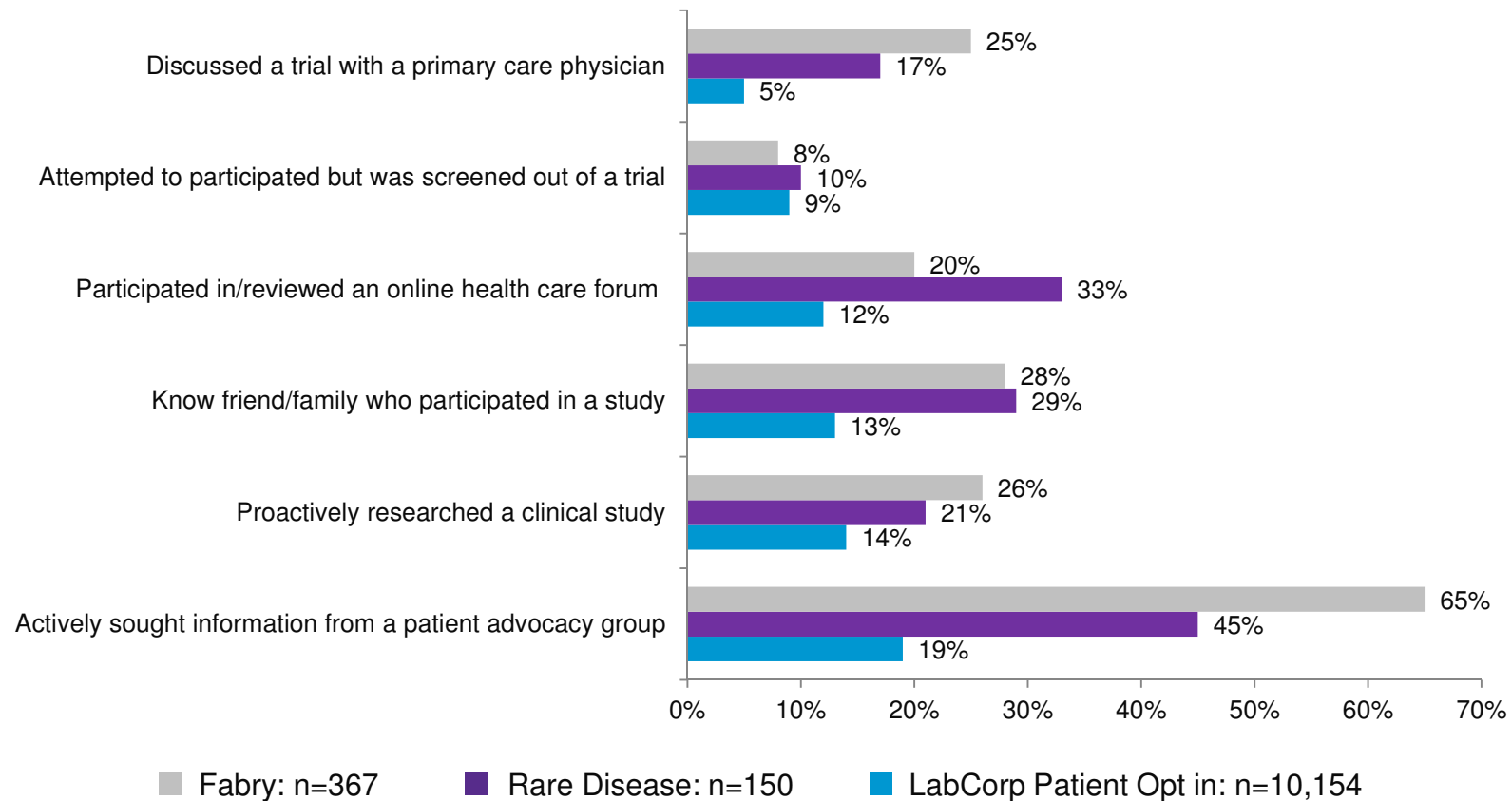
## NOT SURPRISING, MOST PATIENTS ARE TRIAL NAIVE



# Information Seeking Activities

## PATIENT ADVOCACY GROUPS ARE A TRUSTED SOURCE

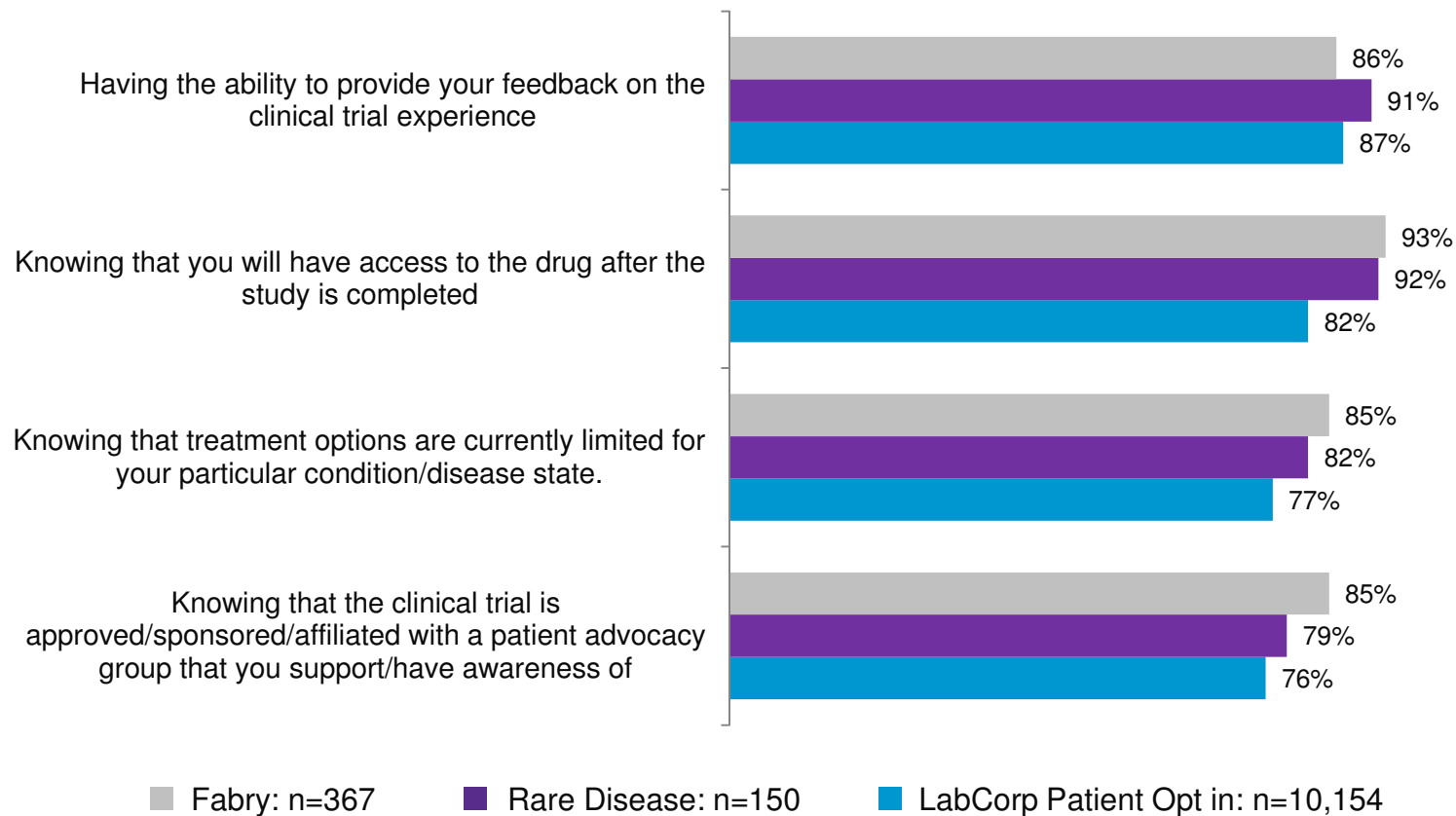
Q: Which of the following statements apply to you personally when thinking about the last 12 months?



# Key Drivers for Clinical Trial Participation

## ABILITY TO PROVIDE FEEDBACK IS IMPORTANT

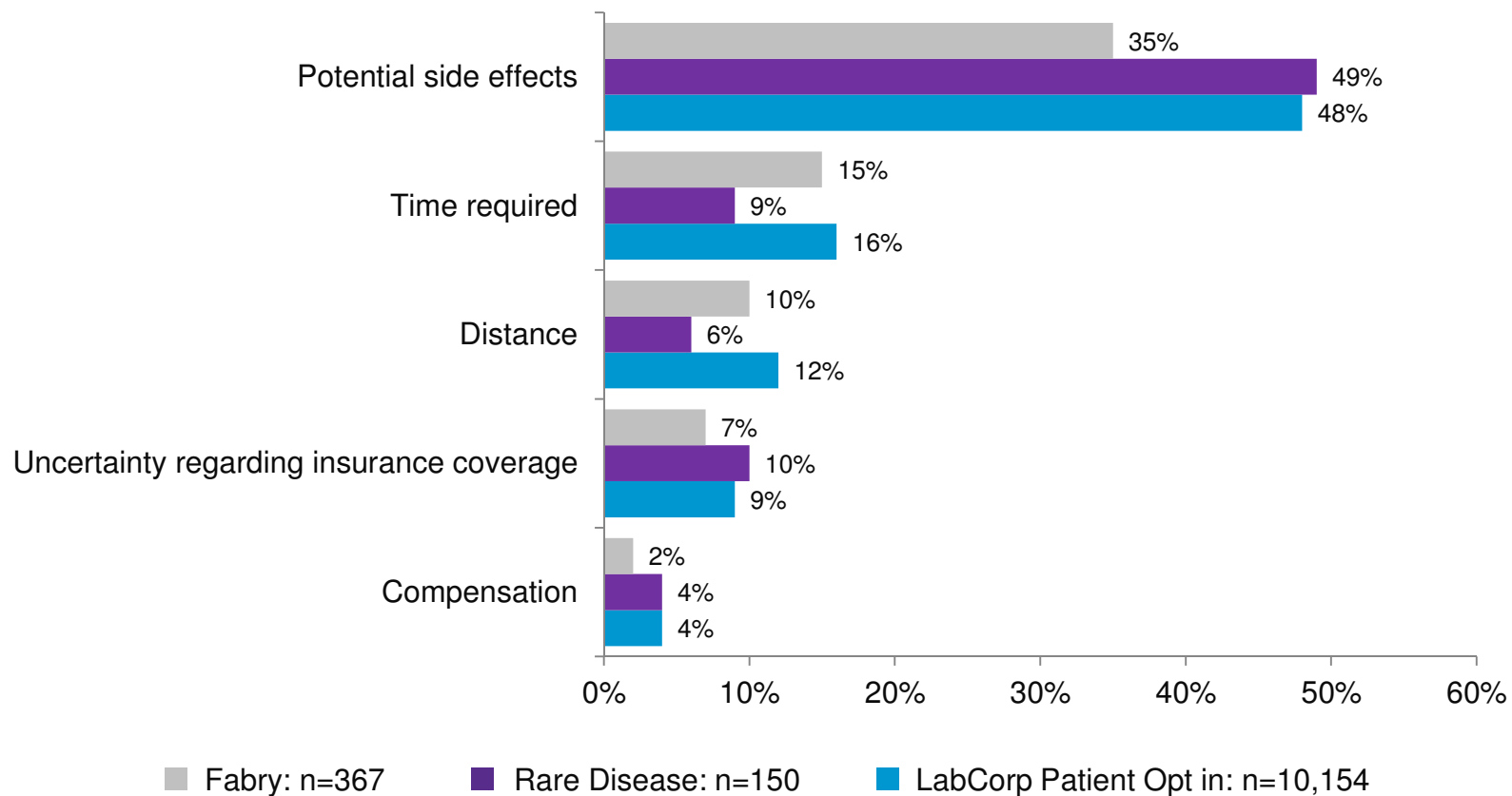
Q: To what extent would each of the following impact your willingness to participate in a clinical trial?



# Main Barriers to Clinical Trial Participation

## POTENTIAL SIDE EFFECTS ARE KEY CONCERN

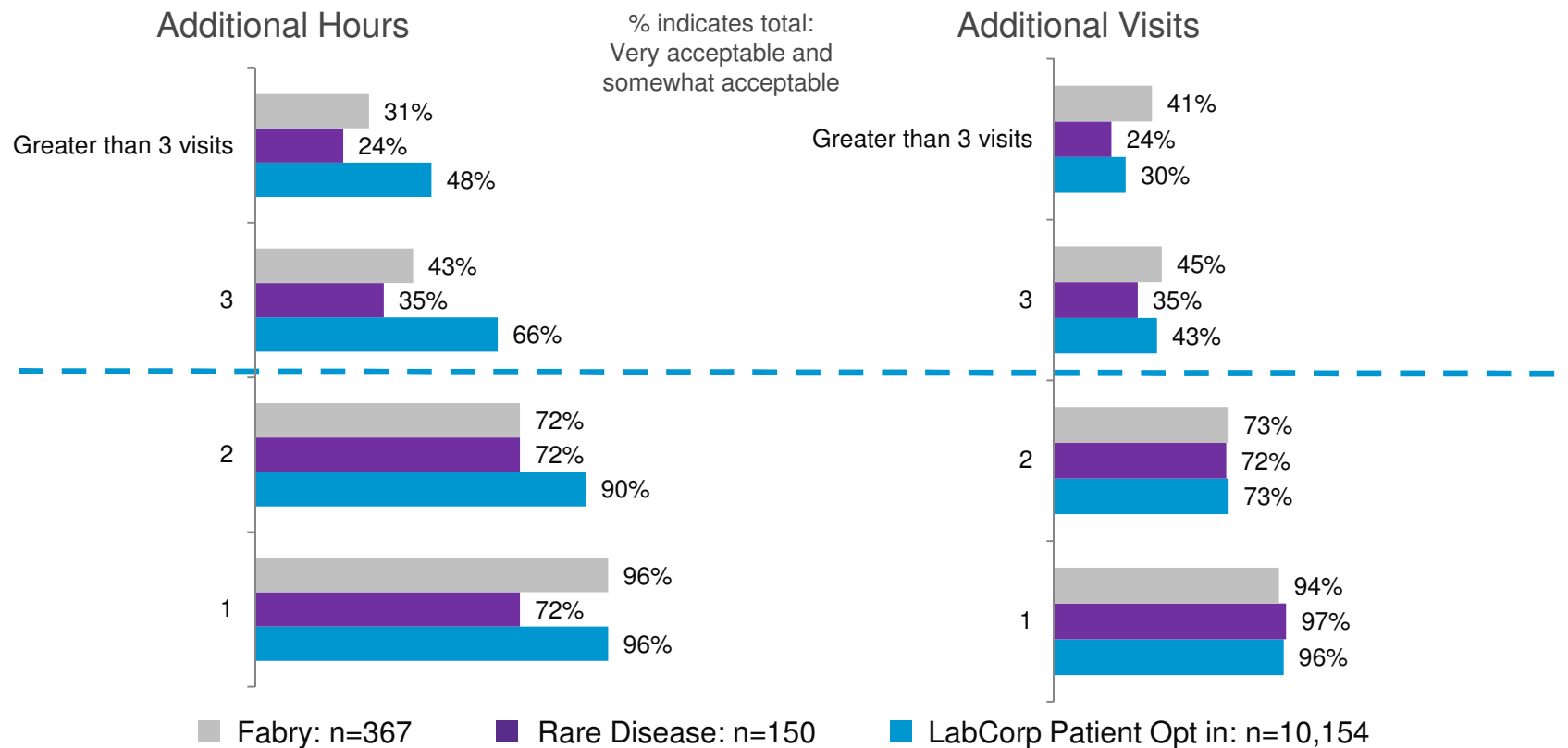
Q: What would be the number one thing keeping you from possibly participating in a clinical trial?



# Time Requirement for Clinic Visits

## AFTER 2 VISITS AND 2 HOURS, RECEPTIVITY DIMINISHES GREATLY

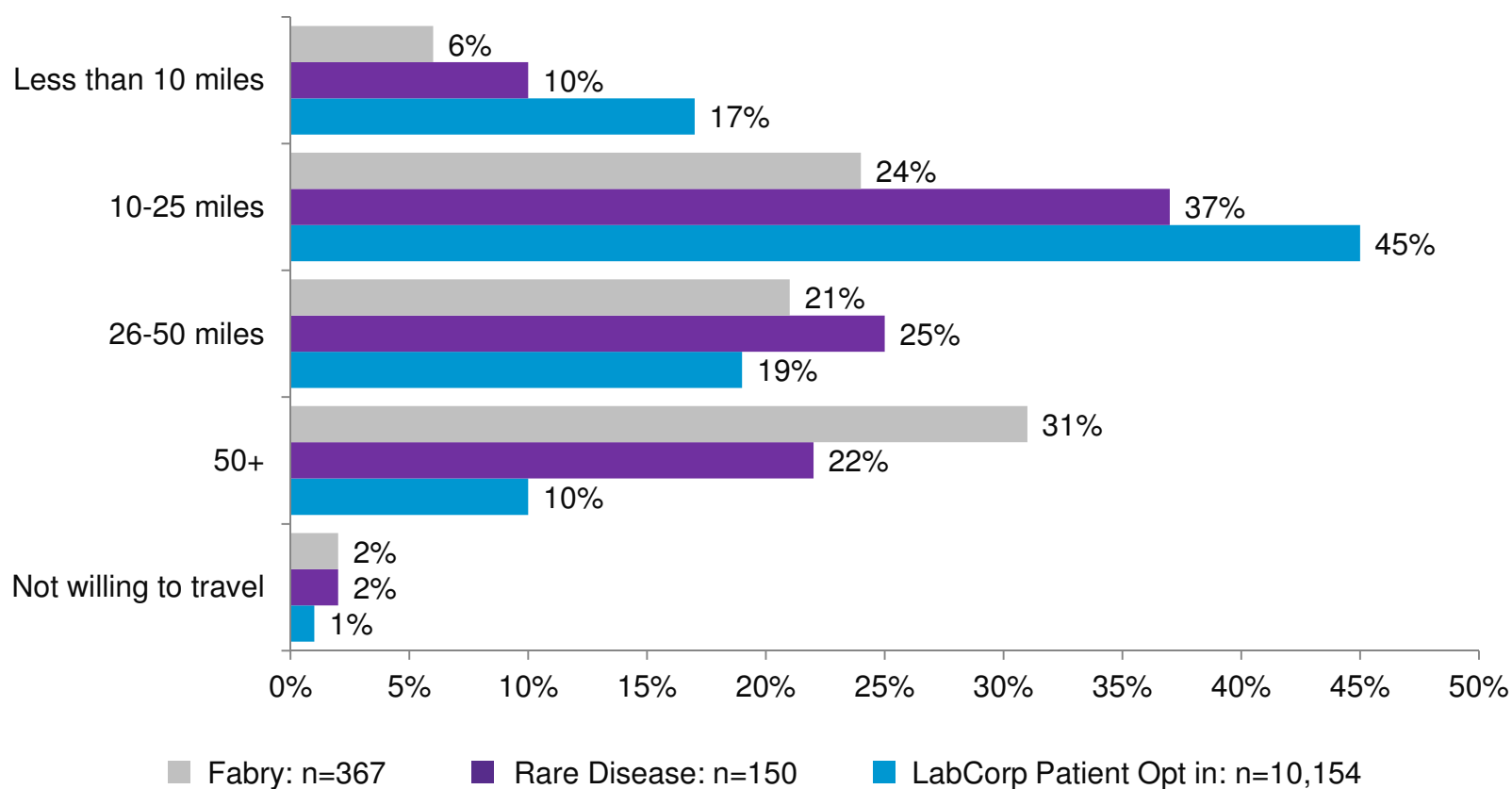
Q: Thinking about your routine health care treatment, if you were to participate in a clinical trial, how acceptable would each of the following be?



# Distance Willing to Travel

## RARE DISEASE PATIENTS ARE WILLING TO TRAVEL FURTHER

Q: All things being equal, how far would you be willing to travel in order to participate in a clinical trial?



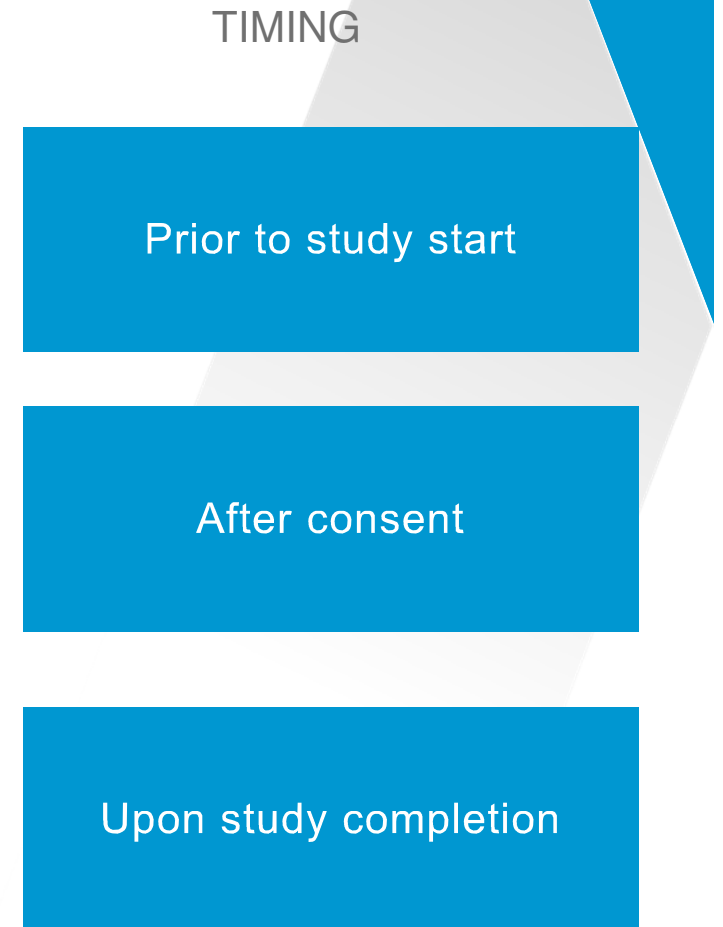
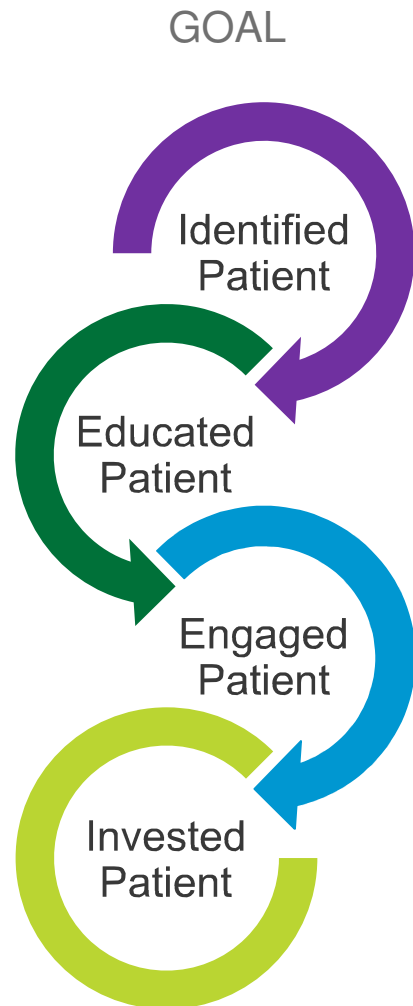
# Patient Perspective on their Disease



What is  
**clinically  
meaningful**



# Capturing Voice of the Patient in Clinical Trials



# Summary

Empower patients in clinical study process

Importance of understanding patient perceptions and motivations for clinical study participation

Allow for meaningful patient input throughout clinical trial process

Acknowledgment and action on patient input

Innovative approaches for data gathering, analytics, interactions and engagement

# Patient Centric Approach: Our Commitment

