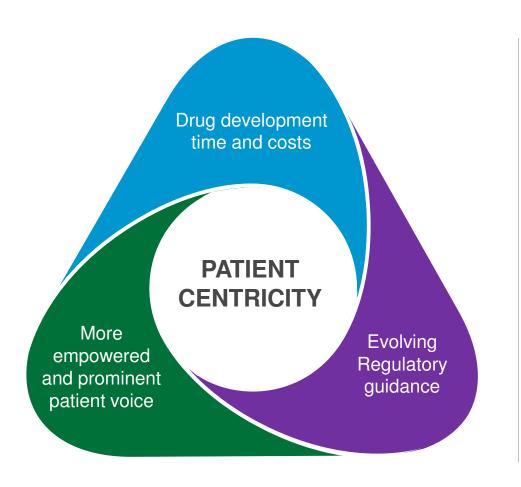
### **PATIENT CENTRICITY**

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



## 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















Abbott Genentech



**Bristol-Myers Squibb** 

>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

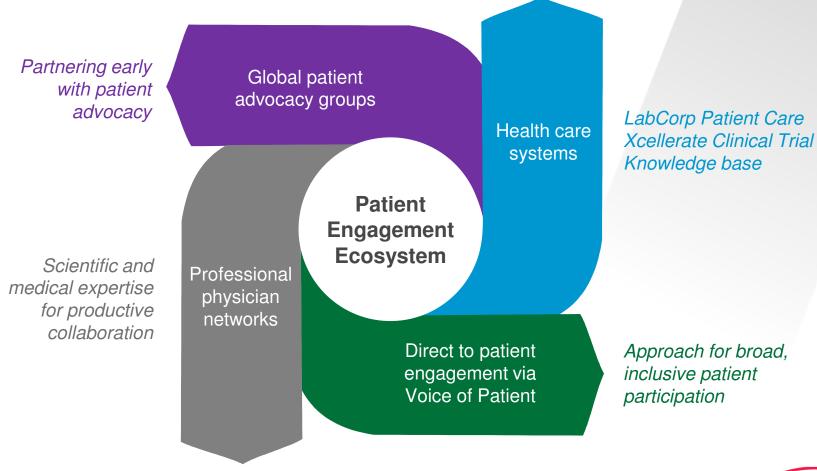
Source: The Patient-Centered Clinical Trial, A New Paradigm, A Thought Paper on Organizational Change, Joyce Avedisian, PhD, <a href="https://www.patientclinicaltrials.com">www.patientclinicaltrials.com</a>. Edited by eyeforpharm.



5 | Patient Centricity - September 2017

## 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**

18 - 34       14%       Female       58%         35 - 44       17%       Male       41%         45 - 54       21%       Unspecified       <1%	18 - 34       14%       Female       58%         35 - 44       17%       Male       41%         45 - 54       21%       Unspecified       <1%         55 - 64       25%       S4. Respondent Locations by Zip Code         Living Description*       %         Suburban       61%         Urban       19%         Rural       17%	Age	0/.	Gender	%	
35 – 44 17% Male 41% 45 – 54 21% Unspecified <1% 55 – 64 25%  Living Description* % Suburban 61% Urban 19% Rural 17%	35 – 44 17% Male 41% 45 – 54 21% Unspecified <1% 55 – 64 25% S4. Respondent Locations by Zip Code Living Description* % Suburban 61% Urban 19% Rural 17%		%	Gerider		
45 – 54 21% Unspecified <1%  55 – 64 25% S4. Respondent Locations by Zip Code  Living Description* %  Suburban 61%  Urban 19%  Rural 17%	45 – 54 21% Unspecified <1%  55 – 64 25% S4. Respondent Locations by Zip Code  Living Description* %  Suburban 61%  Urban 19%  Rural 17%	18 – 34	14%	Female	58%	
55 – 64  Living Description*  Suburban  Urban  19%  Rural  17%  S4. Respondent Locations by Zip Code	55 – 64  Living Description*  Suburban  Urban  19%  Rural  17%  S4. Respondent Locations by Zip Code	35 – 44	17%	Male	41%	
Living Description* %  Suburban 61%  Urban 19%  Rural 17%	Living Description* %  Suburban 61%  Urban 19%  Rural 17%	45 – 54	21%	Unspecified	<1%	
Suburban 61% Urban 19% Rural 17%	Suburban         61%           Urban         19%           Rural         17%	55 – 64	25%	S4. Respondent Locations by Zip Code		
Urban 19% Rural 17%	Urban 19% Rural 17%	Living Description*	%			
Rural 17%	Rural 17%	Suburban	61%			
		Urban	19%			
Prefer not to answer 2%	Prefer not to answer 2%	Rural	17%			
		Prefer not to answer	2%			
				11/10/11		



### 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

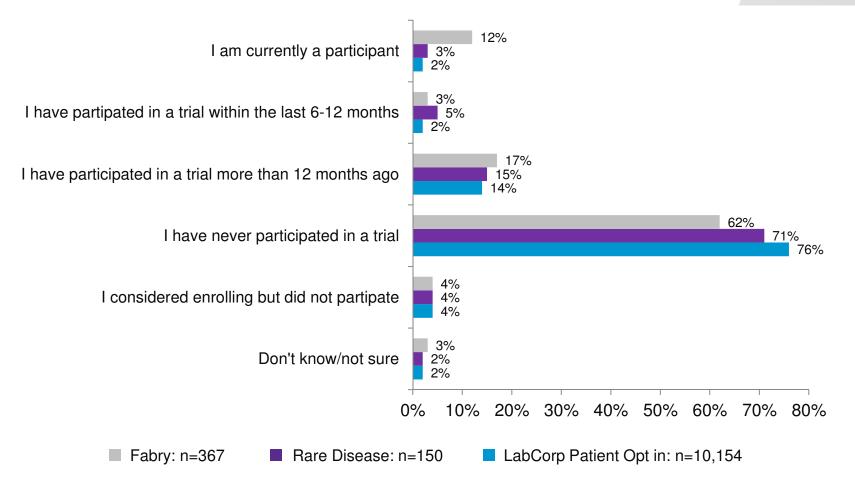
Sample size = 367 patients globally

Final data analysis ongoing



## Clinical Trial Experience

#### NOT SURPRISING, MOST PATIENTS ARE TRIAL NAIVE

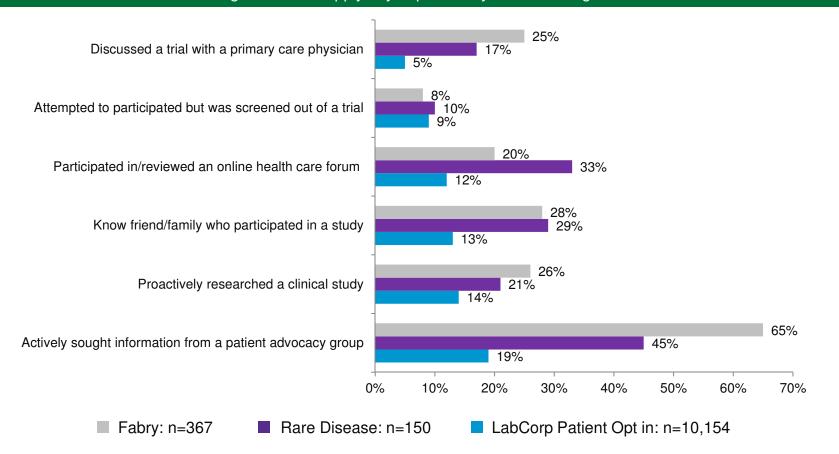




## Information Seeking Activities

#### 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? 86% Having the ability to provide your feedback on the 91% clinical trial experience 87% 93% Knowing that you will have access to the drug after the 92% study is completed 82% 85% Knowing that treatment options are currently limited for 82% your particular condition/disease state. 85% Knowing that the clinical trial is approved/sponsored/affiliated with a patient advocacy 79% group that you support/have awareness of 76% ■ Rare Disease: n=150 ■ Fabry: n=367 ■ LabCorp Patient Opt in: n=10,154



# Main Barriers to Clinical Trial Participation

#### POTENTIAL SIDE EFFECTS ARE KEY CONCERN

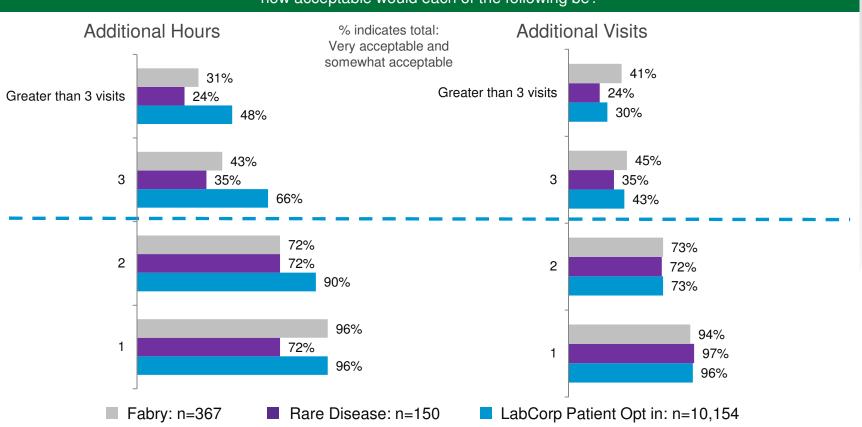
Q: What would be the number one thing keeping you from possibly participating in a clinical trial? 35% Potential side effects 49% 48% 15% Time required 9% 16% 10% Distance 6% 12% 7% Uncertainty regarding insurance coverage 10% 9% 2% Compensation 4% 4% 10% 0% 20% 30% 40% 50% 60% ■ Fabry: n=367 ■ Rare Disease: n=150 ■ LabCorp Patient Opt in: n=10,154



## 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?

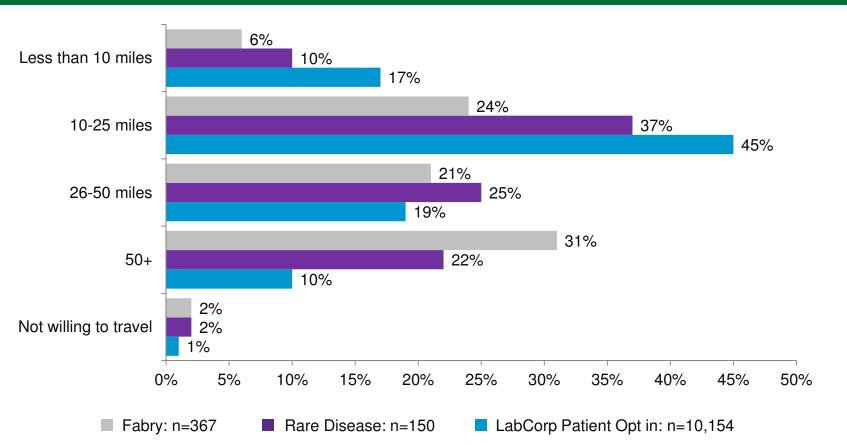




## Distance Willing to Travel

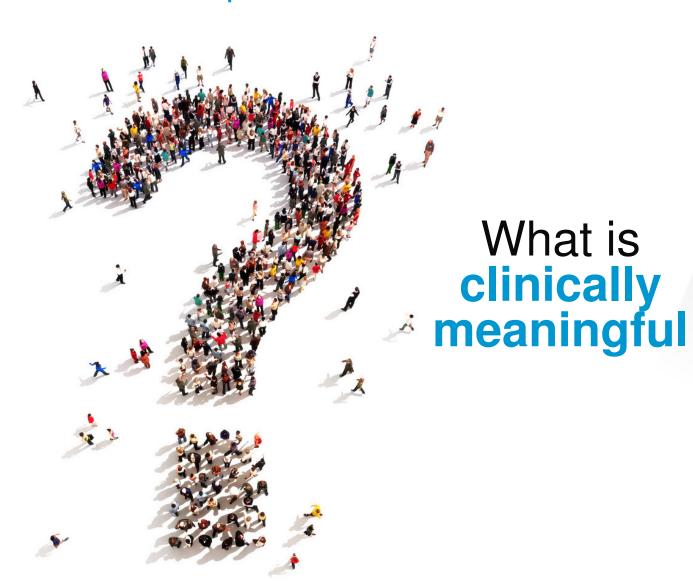
#### RARE DISEASE PATIENTS ARE WILLING TO TRAVEL FURTHER

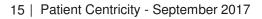
Q: All things being equal, how far would you be willing to travel in order to participate in a clinical trial?





# Patient Perspective on their Disease







# Capturing Voice of the Patient in Clinical Trials

**GOAL** Identified Patient Educated Patient Engaged **Patient** Invested **Patient** 

**PURPOSE** Design **Awareness** Participation Data Acquisition

TIMING

Prior to study start

After consent

Upon study completion



## 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

Covance LabCorp Sponsors

Academic Biotech Regulatory Clinical Large Strategy **Operations** Midsize Virtual Medical Genomics **Patient** Genetic Counselling **Engagement** 

Industry Partners to Better Serve Patients with Rare Disease

Complementing

COVANCE.

SOLUTIONS MADE REAL