



## ***Project PRIORITY: A patient-founded and patient-driven research partnership to gather real-world data on EGFR-positive lung cancer***

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*Patients driving research to save lives*



**@EGFRResisters**

<https://egfrcancer.org/>



**LUNGevity**

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[www.LUNGevity.org](http://www.LUNGevity.org)



## **I have served as a consultant for**

- **AstraZeneca**
- **Boehringer Ingelheim**
- **Amgen**
- **Bristol-Myers Squibb**
- **Celgene**



*Patients driving research to save lives*



## PROJECT PRIORITY

**PATIENT REPORTED INITIATIVE ON  
RESISTANCE, INCIDENCE, TREATMENT  
STUDY**

September 9, 2019

# WHAT IS PROJECT PRIORITY?

- **Patient-founded and patient-driven** research partnership between the EGFR Resisters and LUNGeivity Foundation.
- **Study Objectives:**
  - Understand needs of EGFR-positive lung cancer community
  - Identify areas for improvement in diagnosis and treatment
  - Give voice to patient concerns regarding risk factors, treatments, and symptoms and side-effect management

# COLLECTING REAL-WORLD PATIENT-REPORTED DATA USING A PATIENT EXPERIENCE SURVEY

- Quantitative survey developed with input from patients, caregivers, clinicians, and regulators
- International survey (only in English) open to patients with a diagnosis of EGFR-positive lung cancer and their caregivers
- 130-question survey covering specific domains:

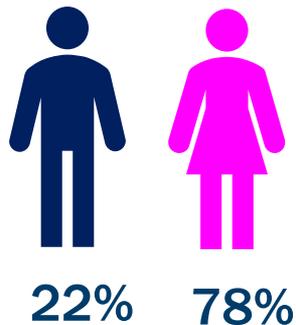


# PARTICIPANT DEMOGRAPHICS

253 participants included in analysis. Study is still accruing

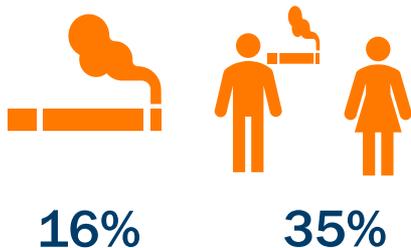


Ex-US: Europe (48%), Australia (23%), Asia (20%), South America (9%)



Variable	US	Ex-US
Diagnosed in the past 5 years	83.2%	85.1%
Average age ( $\pm$ S.D.)	58 (11.9)	54 (10.5)

Active versus environmental tobacco exposure



Likelihood of developing T790M mutation after first-line treatment (using forward regression)



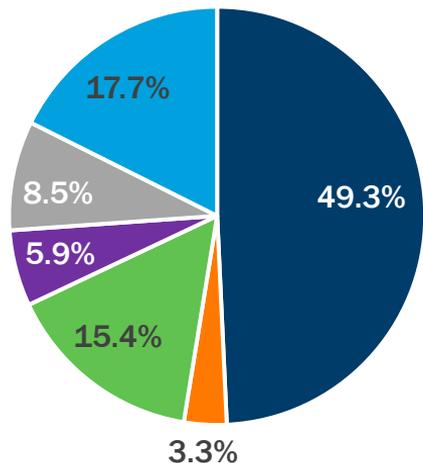
Afatinib, 2.5X



Erlotinib, 3.3X

# EGFR MUTATIONS DETECTED AT DIAGNOSIS AND AT PROGRESSION OR RECURRENCE

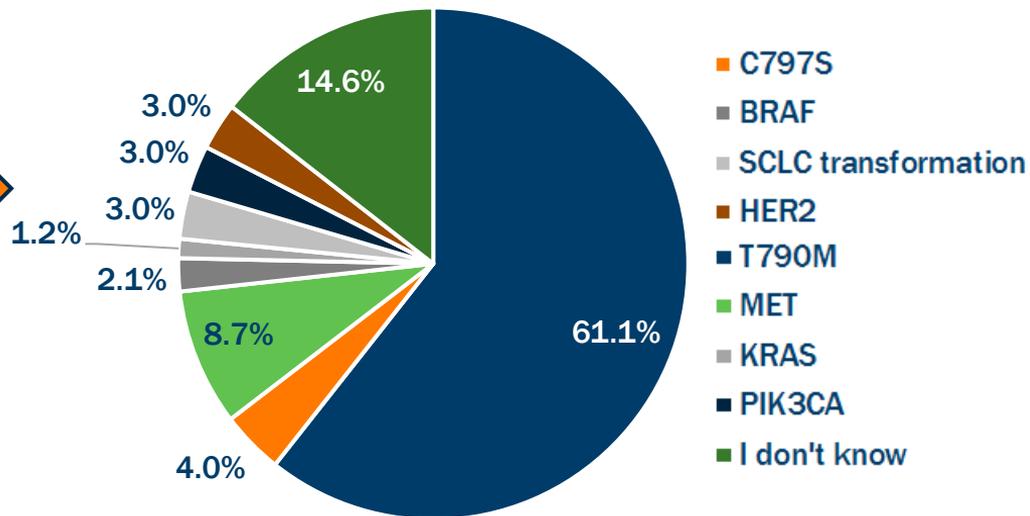
Mutations discovered at diagnosis



31% report development of resistance



Mechanisms of resistance after first line treatment



T790M seen after erlotinib and afatinib  
 C797S and PIK3CA seen after osimertinib  
 HER2 seen after erlotinib and osimertinib

N = 253

N = 78

# DIAGNOSTIC AND TREATMENT JOURNEY OF US AND EX-US PARTICIPANTS



NGS ** at both diagnosis and recurrence		US	Ex-US
NGS tissue	Once	27.3%	8.2%*
	More than once	13.4%	1.4%*
	Never	32.9%	64.4%*
	I do not know	26.3%	26.0%
NGS liquid	Once	29.5%	26.4%
	More than once	15.5%	1.4%*
	Never	39.4%	59.7%*
	I do not know	15.5%	12.5%

\* - significantly different from US respondents at  $p < 0.05$  by Chi-square

\*\* - NGS was defined as any next-generation sequencing panel such as Foundation Medicine

Clinical trial participation		US	Ex-US
Doctor offered clinical trials	Yes	33.7%	22.9%*
	No		
Ever participated in a clinical trial	Yes	21.2%	12.9%*
	No		
Participated in 1 <sup>st</sup> -line trial	Yes	4.8%	1.2%
	No		

\* - significantly different from US respondents at  $p < 0.05$  by Chi-square

# DIAGNOSTIC AND TREATMENT JOURNEY OF US AND EX-US PARTICIPANTS



	Variable	US	Ex-US
<b>No of lines of therapy received</b>	One	41.5%	57.3%*
	Two	28.7%	28.8%
	Three or more	29.7%	13.7%*
<b>First-line therapy</b>	Combination	27%	13.8%*
	Erlotinib	28.7%	36.9%
	Afatinib	13.3%	20.6%
	Gefitinib	0.00%	10.9%*
	<b>Osimertinib</b>	<b>34.6%</b>	<b>17.8%*</b>
	Chemotherapy	19.2%	9.6%*
	<b>Immunotherapy</b>	<b>4.8%</b>	<b>0.00%</b>
	Radiation (Palliative)	19.7%	10.9%



		US	Ex-US
<b>Brain metastasis present</b>	Yes	64%	49%
<b>Type of treatment for brain metastasis</b>	<b>Whole brain radiation</b>	<b>14.7%</b>	<b>33.3%*</b>
	SRS	60.3%	50.0%*
	Surgery	14.7%	8.3%
	Controlled by TKI**	48.5%	33.3%*

\* - significantly different from US respondents at p < 0.05 by Chi-square

\*\* - Did not receive surgery or radiation

\* - significantly different from US respondents at p < 0.05 by Chi-square

\*\*\* - Combination = TKI + chemo or TKI + angiogenesis inhibitor//Excludes radiation

# CONCLUSIONS

- Project PRIORITY participants match characteristics of the EGFR-positive lung cancer community
- Considerable differences exist between treatment experiences of US and ex-US participants
- Additional analysis ongoing:
  - Risk factors including familial history of lung cancer
  - Treatment sequencing and side-effect management
  - Difference by demographics (gender and patient/caregiver)

Patient-reported data is a powerful source of real-world data and can complement clinician-reported data and electronic health records data to identify treatment patterns

# IN MEMORY



**Anita Figueras**  
Co-founder, EGFR Resisters



**Teri Kennedy**  
Co-founder, EGFR Resisters