

# Ready for a Revolution?

## Uniting to Improve Understanding of Gene Therapy

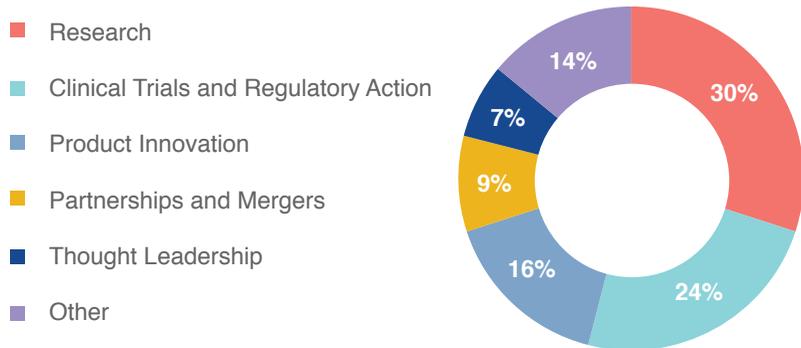
**Gene therapy** is one of the most promising investigational therapies for genetic disease, but its complexity poses significant communication and education challenges.

After decades of research, a **revolution** is taking place.



**4x** Increase in volume of social media conversations about gene therapy from 2012 to 2016

Clinical and regulatory updates from industry drive traditional media reports.



Based on an audit of 4,931 stories published between August 2015 and August 2016

### Patients and Caregivers:

**65%** of patients and caregivers surveyed rate their knowledge of gene therapy at or below 5 out of 10. They want to know more about:

- 32%** Efficacy
- 29%** Mechanisms
- 25%** Research

### Preferred information sources:

- 62%** Patient advocacy organizations
- 41%** Physicians

Based on interviews with industry and academic experts, **physicians will need:**

- Dedicated coursework and curricula
- Access to continuing education
- Clear, accessible information for patients

### Roadmap for Gene Therapy Education

Establish a **common nomenclature**

Foster **realistic expectations** about gene therapy

Secure **alignment** among all stakeholders

Encourage **dialogue** among and between audiences

Engage audiences through **multiple media**

Provide **basic education** about genetics that follows health literacy best practices

Information included in this infographic comes from "Enhancing Awareness and Understanding of Gene Therapy among Rare Disease Communities: A Research Driven Roadmap." To read the full report, please visit [www.smithsolve.com/ready-for-a-revolution](http://www.smithsolve.com/ready-for-a-revolution). To get in touch, send us an email at: [news@rarecollective.org](mailto:news@rarecollective.org)

<sup>1)</sup> Alliance for Regenerative Medicine. 2017 cell & gene therapies: state of the industry briefing. Presented at 35th Annual J.P. Morgan Healthcare Conference, San Francisco, CA, January 9, 2017.

### Gene Therapy Myths:

- It will cure you forever
- It can be passed on to your children
- It alters your DNA
- All gene therapies are the same