



Understanding Consumer Awareness and Perceptions about Gene Therapy for Hemophilia among EU5 Countries

CLIENT

**Leading Multinational
Biopharmaceutical
Company**

INDUSTRY

Life Sciences



STUDY OBJECTIVE

The objective of the study was to understand how much consumers already know about Gene Therapy (GT) for Hemophilia in order to inform the messaging and positioning strategy for their new drug in the EU5 markets (France, Germany, Italy, Spain, United Kingdom).



DATA SOURCES

Social media including Twitter, Reddit, consumer and industry forums, and comments under relevant articles

RESEARCH PROCESS



- C5i ran an initial market scan to understand the various treatments available for Hemophilia and why Gene Therapy (GT) is revolutionary.
- An extensive query was prepared in the 5 languages of the EU5 countries that not only included the various ways gene therapy is referred to but also included current gene therapy drugs and their manufacturer names.
- The following analyses were performed on the data:
 - Sentiment/tone of the comments
 - Advantages/disadvantages of GT for Hemophilia
 - Questions/concerns around GT for Hemophilia
 - Likelihood to use if offered
 - Patients' source of information
 - Overall conversation themes
 - Analysis of tweets by influencers: a KOL and a patient

EXAMPLES OF KEY INSIGHTS



- Consumer sentiment was mostly negative due to concerns about safety and efficacy of Gene Therapy for Hemophilia.
- Most conversations were centered on topics discussed in conferences or as reactions to press releases and news articles about latest developments in Gene Therapy for Hemophilia.
- Major concerns revolved around the effect of COVID-19 vaccines (perceived to be Gene Therapy-based) on Hemophilia patients and about the reliability, cost, durability, safety and reported side effects from clinical trials. Other concerns were about side effects from steroids administered in Gene Therapy, increased risk of Thrombosis, variations in factor levels in patients, etc.
- Very few people expressed interest in undergoing Gene Therapy for Hemophilia, if offered.

OUTCOME

- The study revealed to the client that patients had a lot of concerns regarding Gene Therapy for Hemophilia.
- It also helped the client understand the precise nature and areas of concern in terms of safety, reliability, and side affects, thereby providing critical insights for messaging and positioning their product in ways that would reduce resistance and increase acceptance of their product.

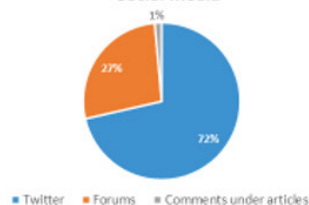
SAMPLE DASHBOARD SCREENSHOTS

3/4TH OF THE CONVERSATIONS RELATED TO GENE THERAPY FOR HAEMOPHILIA WERE FROM TWITTER;
MOST WERE FROM UK AND GERMANY

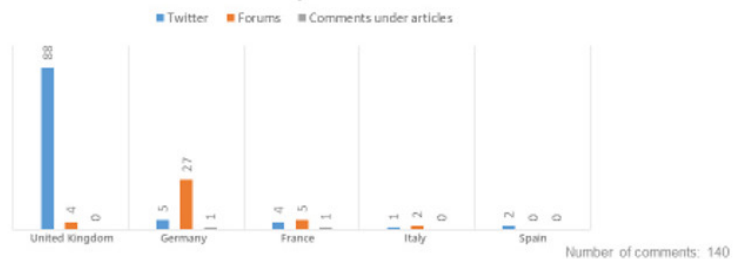
Overall conversations in EU5 related to Gene Therapy for Haemophilia



Source of conversations in EU5 on Social media



Information by EU5 countries



Source: Course5's internal social media analytics solution; Data source: Twitter, forums, comments under articles; Timeline: 1st August, 2020 to 10th November, 2021

MAJOR DISADVANTAGES EXPRESSED WERE ABOUT SIDE EFFECTS AND EFFICACY OF GENE THERAPY FOR HAEMOPHILIA; A FEW SAID THE THERAPY IS A MEDICAL REVOLUTION

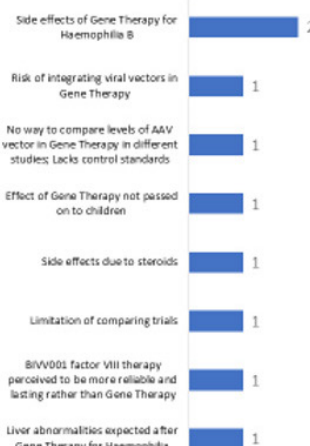
Perceived Advantages/Disadvantages



Advantages



Disadvantages



Verbatim

Disadvantages

"In a sense, UniQure shares the fate of bluebird bio. QURE is (also) not sure whether the gene therapy triggered the case of liver cancer. After the FDA discontinued uniQure's hemophilia B gene therapy in December due to a liver cancer case, the company is still not sure whether the event is treatment related or not."

"Glenn Pierce explained at the webinar that the risk of integration after #hemophilia gene therapy is 100%. So far this has not resulted in adverse events but long term follow up of all recipients of gene therapy will be required."

"The problem with all the studies discussing antibodies to the AAV vector in gene therapy in #hemophilia is that there is no gold standard assay and no control standards to compare levels between studies. #ISTH2021"

"If you have gene therapy for haemophilia the effect is not passed on to your children"

Advantages

"Also, like, gene therapy is lifesaving!!! my hemophiliac partner is on the waitlist for gene therapy, and it'll mean he can travel further away from major hospitals, risking death from bleeding, nothing wrong with gene therapy, it's amazing"

Source: Course5's internal social media analytics solution; Data source: Twitter, forums, comments under articles; Timeline: 1st August, 2020 to 10th November, 2021

Number of comments: 140

ABOUT US

C5i is a pure-play AI & Analytics provider that combines the power of human perspective with AI technology to deliver trustworthy intelligence. The company drives value through a comprehensive solution set, integrating multifunctional teams that have technical and business domain expertise with a robust suite of products, solutions, and accelerators tailored for various horizontal and industry-specific use cases. At the core, C5i's focus is to deliver business impact at speed and scale by driving adoption of AI-assisted decision-making.

C5i caters to some of the world's largest enterprises, including many Fortune 500 companies. The company's clients span Technology, Media, and Telecom (TMT), Pharma & Lifesciences, CPG, Retail, Banking, and other sectors. C5i has been recognized by leading industry analysts like Gartner and Forrester for its Analytics and AI capabilities and proprietary AI-based platforms.



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