MANTLE CELL LYMPHOMA PATIENT JOURNEY

Our client wanted to better understand MCL patients, caregivers and HCPs in the United States to get a better understanding of the therapeutic area and patient experience.

METHODOLOGY
- Patient Journey
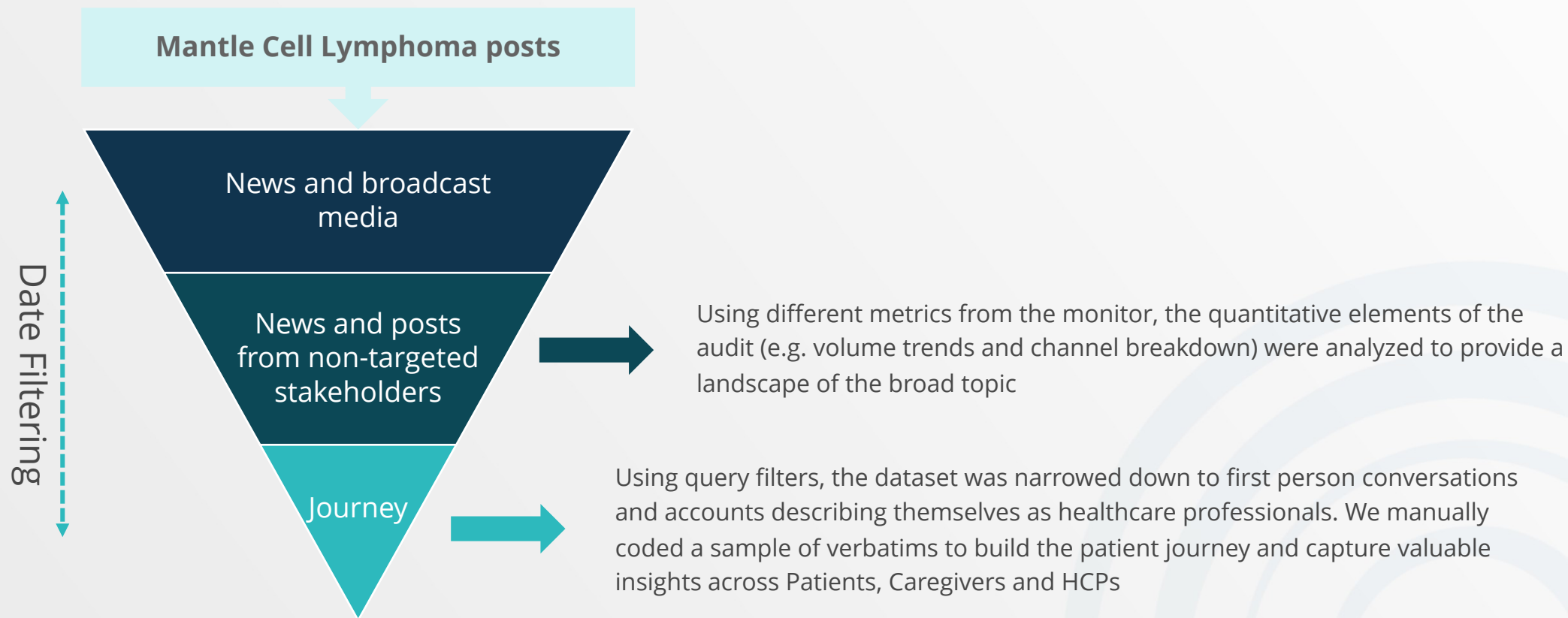- Emotional Analysis

TOOL
- Talkwalker

MARKET

🇺🇸

INDUSTRY
- Pharma

convosphere

ALTHOUGH TWITTER WAS PROMINENT, FORUMS, FACEBOOK AND INSTAGRAM HAD IN-DEPTH STORIES

Mantle Cell Lymphoma posts

Date Filtering

News and broadcast media

News and posts from non-targeted stakeholders

Journey

Using different metrics from the monitor, the quantitative elements of the audit (e.g. volume trends and channel breakdown) were analyzed to provide a landscape of the broad topic

Using query filters, the dataset was narrowed down to first person conversations and accounts describing themselves as healthcare professionals. We manually coded a sample of verbatims to build the patient journey and capture valuable insights across Patients, Caregivers and HCPs
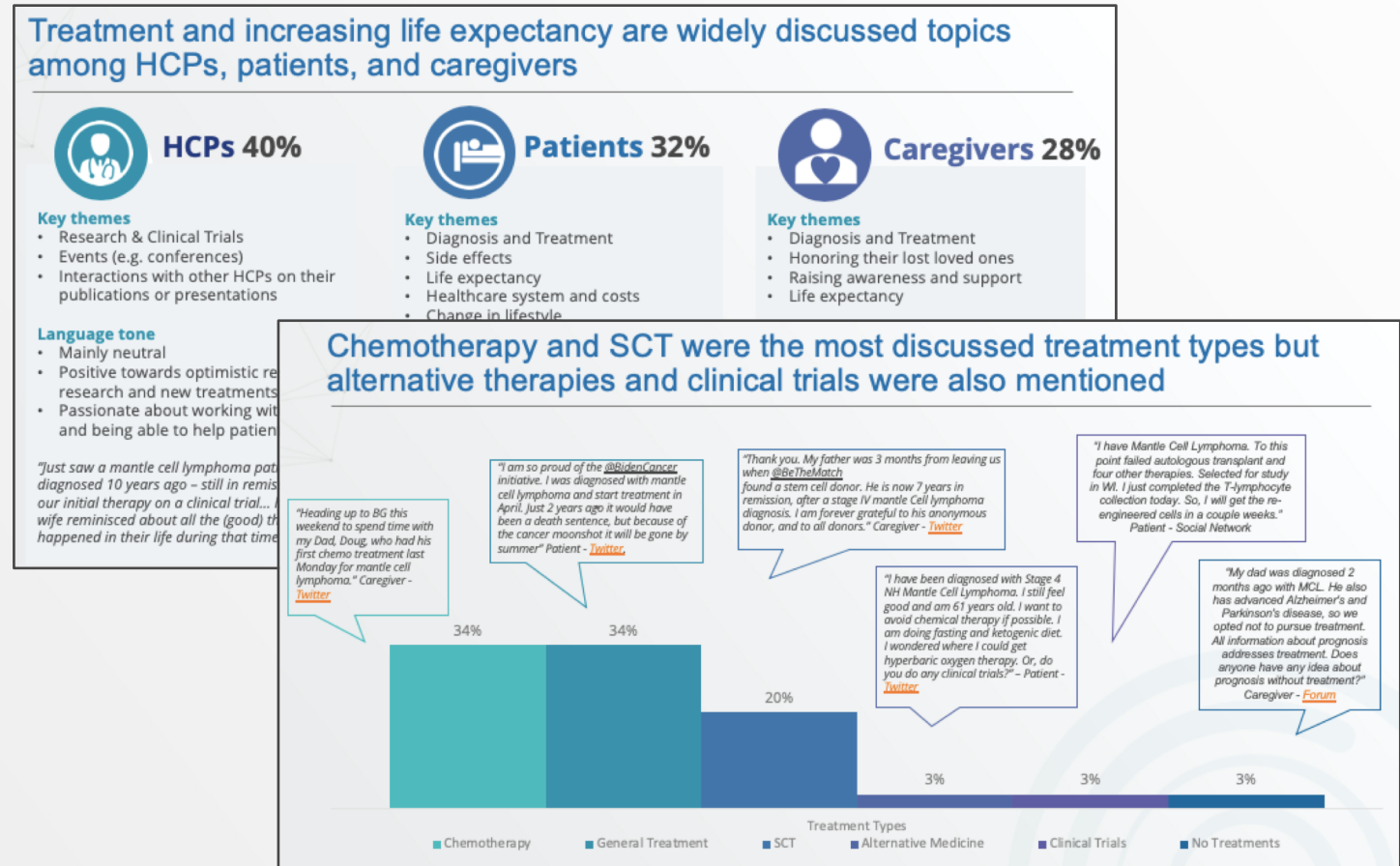
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A GREATER UNDERSTANDING OF STAKEHOLDERS HELPED THE CLIENT DEVELOP A TARGETED APPROACH
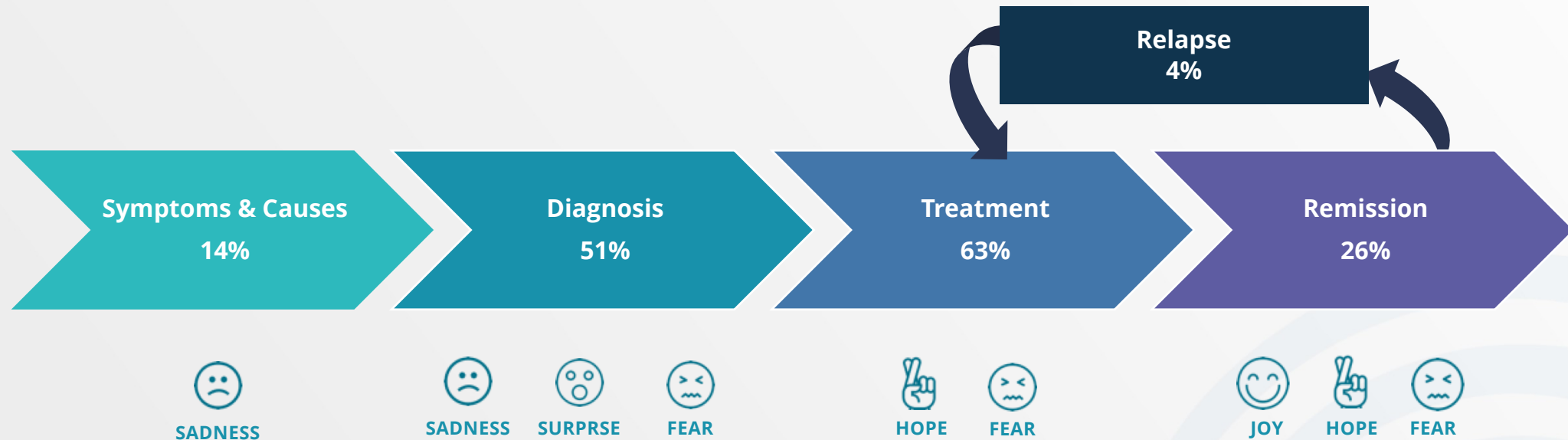
We laid out the key themes and treatments discussed by each of the targeted stakeholders as well as their language and tone, providing the client valuable information on how to approach these groups.

THE DETAILED PATIENT JOURNEY HIGHLIGHTED FINDINGS AND OPPORTUNITIES

Relapse
4%

Symptoms & Causes
14%

Diagnosis
51%

Treatment
63%

Remission
26%

SADNESS

SADNESS   SURPRSE   FEAR

HOPE   FEAR

JOY   HOPE   FEAR

The client received a journey map summarising the findings, opportunities and emotions at each stage.

convosphere

AMYLOIDOSIS PATIENT JOURNEY

A big pharma brand wanted to better understand the AL amyloidosis journey from the patient perspective by mapping out the key steps and milestones in the disease journey.

They wanted to uncover any opportunities by identifying the white space in the current market and ways to make a difference in the lives of patients. Results would also be compared with other studies with physicians, to identify gaps and differences.

METHODOLOGY
- Patient Journey
- Emotional Analysis

TOOL
- Talkwalker

MARKET

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INDUSTRY
- Pharma

convosphere

METHODOLOGY

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SOCIAL MONITORING

- Harvest mentions of Amyloidosis using social media listening technology in the United States and EU5.

DATA SAMPLING & CODING

- Manually code a representative sample of Patient, Caregiver and HCP conversations across the dataset to uncover in-depth insights on emotions, topics, perception and behaviors.

REPORT WRITING

- By coding and filtering data into different topics, subtopics and reading through the mentions, we analyzed the qualitative aspects of the conversation to highlight emotions and behavior related to each journey stage.

convosphere

MAPPING THE PATIENT JOURNEY HELPED TO IDENTIFY COUNTRY NUANCES AT EACH STAGE

Our local analysts brainstormed together to highlight the differences and similiarities of the disease journey in different markets and languages.

This allowed the client to better tailor their solutions and strategies to each specific country.

SCT conversation limited to the US and the UK

Chemotherapy was the major treatment option
Chemotherapy was the most common treatment option. CyborD (VCD) (US/France), Daratumumab (UK/France), and Velcade/Endoxan combo (France) were mentioned. No mentions about specific treatments were identified in Germany, Italy and Spain.

*"I suffer from AL amyloidosis and have had a lot of tests done (myelogram, MRI, cardiac puncture, tens, even hundreds of blood tests). **Then chemo treatment over 8 months (Velcade and Andoxan).** A clinical trial (NEO001) for 2 years which was interrupted by the laboratory due to the lack of convincing results overall."– Patient (Facebook), France*

Potentially limited access to Stem Cell Transplant
Stem Cell Transplant was only me... option in the US and UK. While m... the transplant in the US, few were... treatment in the UK.

"Dad wasn't as lucky to live in the USA where stem cell transplants are offered as a treatment" – Caregiver (Twitter), UK

Participation on Clinical Trial
Few clinical trials participation we... US and France, including the NEO... down without good results.

Support groups identified only in the US, UK and France

Online support group and finding peers
Several active Facebook support groups for Amyloidosis were recommended in English and French. German patients had a hard time finding fellow patients and their questions on medical forums were often left unanswered.

"My mother was diagnosed positive for AL amyloidosis (kidneys) and I would like to have some testimonies from people who suffered from this disease...." – Caregiver (Facebook), France

"I would be interested if someone has experience with the disease amyloidosis. As a sufferer of Crohn's disease, I came across several websites on this serious "comorbidity" in terms of CED. What I don't know are, for example, numbers, how often one can expect to have this disease, nor did I find anything from those affected. Does anyone have more information?" – Patient (Forum) Germany

Communities and organizations
Some markets had dedicated organizations, such as Amyloidosis Foundation (US), Myeloma UK (UK), French Association against Amyloidosis (France), providing specialists information and support. No such organization were mentioned in Germany, Italy or Spain.

"Would love to go to the AL Amyloidosis Infoday, but I do watch the recordings made by Myeloma U.K., the charity which generously sponsors the annual event." – Patient (Twitter), UK

Amyloidosis sometimes perceived as "cancer"
Some referred to amyloidosis as "cancer," while others realized it was different, yet rare and incurable. As the disease is often treated similarly to bone marrow cancer, there was some overlap in conversations within the patient and caregiver community.

"My dad died of blood cancer or rather amyloidosis this month. This rare disease needs more research! Tell everyone! AMYLOIDOSE IS SHIT!" – Caregiver (Youtube comment), Germany
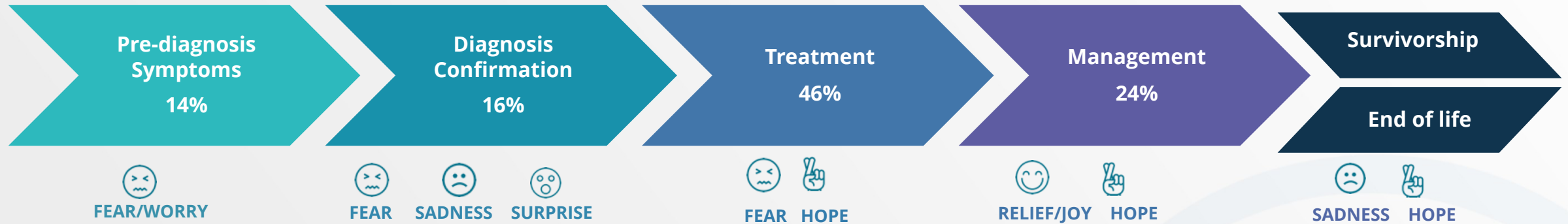
"When I was diagnosed with lymphoma related AL amyloidosis with Waldenstrom's Macroglobulinemia, some folk commented, "At least you haven't got cancer!" My reply was, "no but amyloidosis is a rare incurable life-threatening disease, so just as bad if not worse!" – Patient (Facebook), UK

"Unfortunately, there is no cure for this disease, it is incurable, it is a rare disease that is associated with multiple myeloma (bone marrow cancer). Amyloidosis is not a cancer but it stabilizes with the same treatment as bone marrow cancer." - Patient (Facebook), France

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THE DETAILED PATIENT JOURNEY HIGHLIGHTED FINDINGS AND OPPORTUNITIES

Pre-diagnosis Symptoms 14%	Diagnosis Confirmation 16%	Treatment 46%	Management 24%	Survivorship / End of life
FEAR/WORRY	FEAR SADNESS SURPRISE	FEAR HOPE	RELIEF/JOY HOPE	SADNESS HOPE

The client received a journey map summarising the findings, opportunities and emotions at each stage.

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THERAPEUTIC AREA OVERVIEW - LUPUS

A client in the pharmaceutical industry lacked an understanding of the key topics and the language used in lupus conversations. The goal was to obtain an overview of the therapeutic area as well as identifying stakeholder challenges and unmet needs for each disease stage.

METHODOLOGY
- Social listening of the therapeutic area
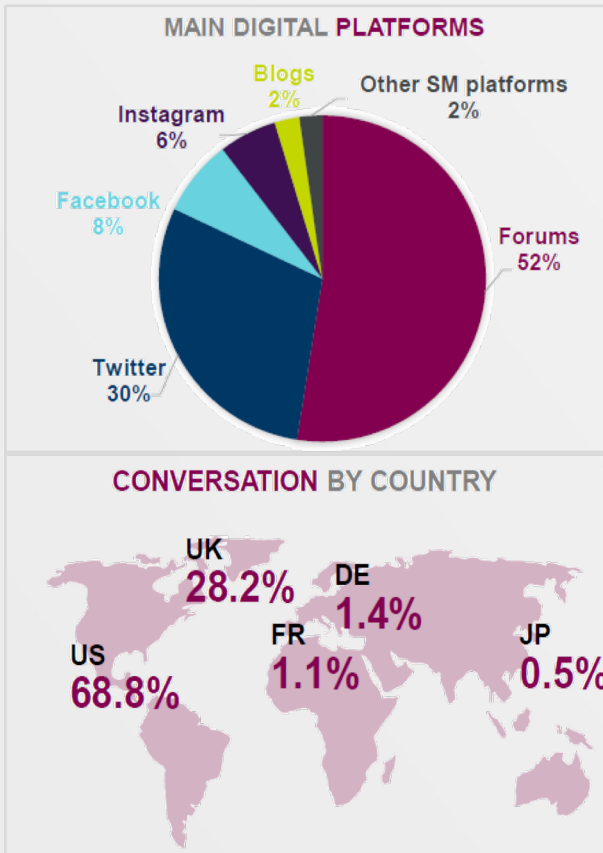
TOOL
- Synthesio

MARKET

INDUSTRY
- Pharma

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OUR SOLUTION

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MAIN DIGITAL PLATFORMS

- Forums 52%
- Twitter 30%
- Facebook 8%
- Instagram 6%
- Blogs 2%
- Other SM platforms 2%

CONVERSATION BY COUNTRY

- UK 28.2%
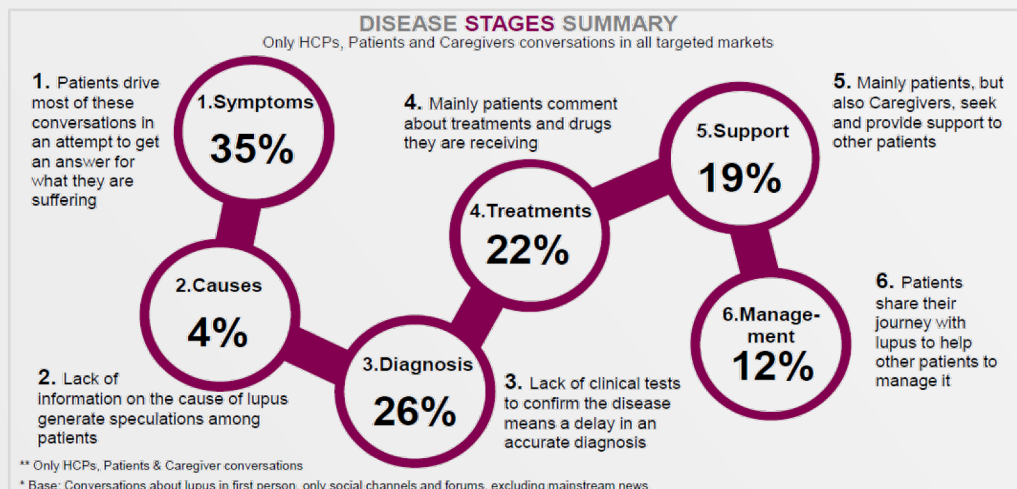- DE 1.4%
- FR 1.1%
- JP 0.5%
- US 68.8%

Social listening study around Lupus Therapeutic Area:

▪ We conducted social listening in four languages and five countries to identify the key topics by disease stage in each market and identify stakeholders SOV across different countries. By analyzing these conversations, we were able to understand patient support systems and caregiver themes.

▪ Scanning across news, forums, Twitter and other social media provided us with a quantitative measure of the themes. We also looked for an indication of relative numbers by topic and segments, which we used to search insights to complement our findings.

▪ A qualitative deep-dive allowed us to understand the stakeholders' conversations and establish the context of the posts, segment sentiments and unmet needs, as well as identifying top influencers by market.

▪ The findings and analysis were presented in one report along with an easily digestible infographic with key findings.

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KEY FINDINGS & BUSINESS IMPACT

Disease Stage Summary

DISEASE **STAGES** SUMMARY
Only HCPs, Patients and Caregivers conversations in all targeted markets

1. Patients drive most of these conversations in an attempt to get an answer for what they are suffering

1.Symptoms 35%

4. Mainly patients comment about treatments and drugs they are receiving

5. Mainly patients, but also Caregivers, seek and provide support to other patients

5.Support 19%

4.Treatments 22%

2.Causes 4%

6. Patients share their journey with lupus to help other patients to manage it

6.Manage-ment 12%

2. Lack of information on the cause of lupus generate speculations among patients

3.Diagnosis 26%

3. Lack of clinical tests to confirm the disease means a delay in an accurate diagnosis

** Only HCPs, Patients & Caregiver conversations
* Base: Conversations about lupus in first person, only social channels and forums, excluding mainstream news

- In general, there was a lack of awareness regarding this disease. Although special lupus awareness days had an impact on online conversations, the general public as well as lupus patients, didn't have a clear understanding of the disease, its symptoms, treatments and the effects on sufferers.

- The restricted awareness of Lupus means it's often referred to as the "unknown disease" and there is a clear need for more funds and research. A lack of accurate and timely diagnostics tests has led to delayed diagnosis or misdiagnosis for many patients.

- The financial strain of having to pay for treatment following diagnosis was one of the key difficulties identified among patients' conversation.

- We provided the client with a rich understanding of the how, where and what of the topics prevalent in the stakeholders' conversation around lupus to help the client develop relevant and timely content which engages patients, caregivers and HCPs. This also provided a first step to develop a closer relationship with KOIs.

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THERAPEUTIC AREA OVERVIEW - LSCD

Our client wanted to know how customers interact with social media and how they could optimise content for the most effective engagement and influence.

METHODOLOGY
- Social listening of the therapeutic area

TOOL
- Talkwalker
- Synthesio

MARKET

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INDUSTRY
- Pharma

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OUR SOLUTION

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- **Social listening study around LSCD Therapeutic Area**:

  - To understand key conversation topics by stakeholders and analyse shifts in conversation volume over time and to understand the month-on-month comparison of the topics to determine any shift in perception levels.

- **Relevant Properties Benchmark of User Engagement on Content:**

  - Using social listening tools, we also looked at the top 2 online profiles per market (as identified by the Therapy Area Overview and desk research on Twitter or Facebook).

  - Provided insights into what type of content is shared, when it is shared (day of week, time of day), frequency and audience engagement (likes, comments, re-shares and engagement).

- We provided insights and recommendations based on the consolidated analysis of what we heard through the conversation analysis and what we saw relevant targets were doing through the analysis of their behaviour online.
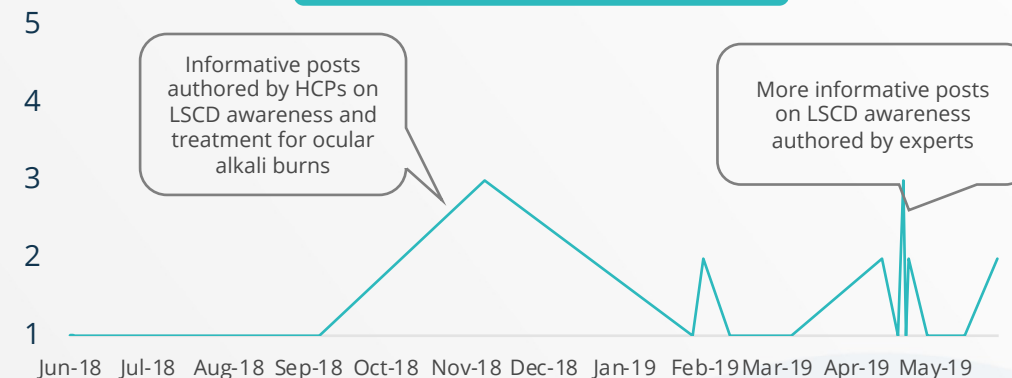
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KEY FINDINGS & BUSINESS IMPACT

LSCD Key Topics Breakdown

Top 2 topics

Research & Trials: 31%
Treeatment Effectiveness: 26%
Comorbidities: 17%
Treatment - Surgery: 9%
Awareness: 9%
Treatment - Medicine: 6%
Causes: 3%

Overall Volume Trend Analysis

Informative posts authored by HCPs on LSCD awareness and treatment for ocular alkali burns

More informative posts on LSCD awareness authored by experts

Jun-18, Jul-18, Aug-18, Sep-18, Oct-18, Nov-18, Dec-18, Jan-19, Feb-19, Mar-19, Apr-19, May-19
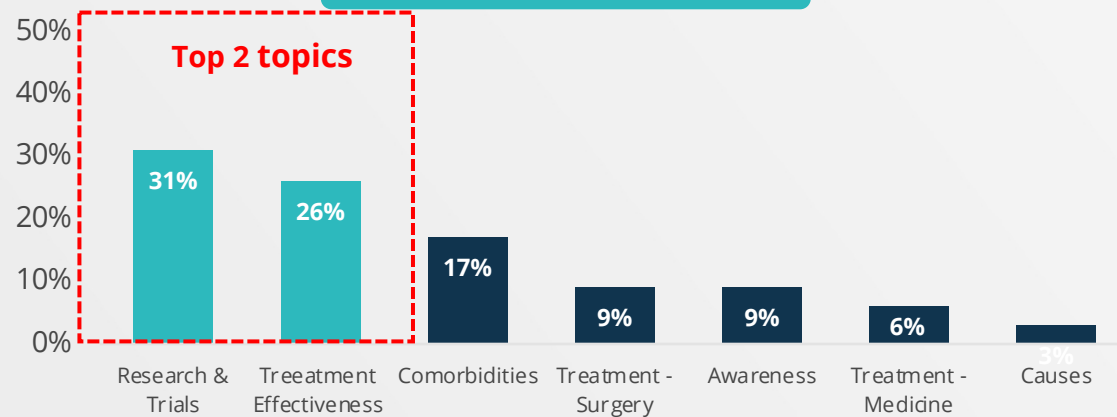
- Overall, social media conversation around LSCD was rare. No patients or caregivers were identified talking about this topic online.

- Although the level of LSCD conversation on social media was low, LSCD awareness and scientific/research informative content performed well.

- There was an opportunity to engage stakeholders with treatment innovation, as HCPs and Experts represented 12% and 88% respectively of the stakeholder conversations.

- The top two pages were Organizations for awareness generation. We analyzed the profile activity of the page, identified examples of top performing content, weakest posts, days of the week driving maximum engagement etc.

- We provided the client a rich understanding of the conversations around LSCD. Detailed analysis of the top profiles helped the client to develop ideas to curate similar content to that which had resonated well with stakeholders and garnered good engagement.

convosphere

THERAPEUTIC AREA OVERVIEW - LSD

Our client wanted to know how do customers interact with social media and how they could optimise content to most effectively engage and influence them.

METHODOLOGY
- Social listening of the therapeutic area

TOOL
- Talkwalker
- Synthesio

MARKET

🇬🇧

INDUSTRY
- Pharma

convosphere

OUR SOLUTION

- **Social listening study around LSD Therapeutic Area**:

  - To understand key conversation topics by stakeholders and analyse shifts in conversation volume over time and to understand the month-on-month comparison of the topics to determine shift in perception levels.

- **Relevant Properties Benchmark of User Engagement on Content:**

  - Using social listening tools, we also looked at the top 2 online profiles per market (as identified by the Therapy Area Overview and desk research on Twitter or Facebook).

  - Provided insights into what type of content is shared, when it is shared (day of week, time of day), frequency and audience engagement (likes, comments, re-shares and engagement).

- We provided insights and recommendations based on the consolidated analysis of what we heard and what we saw relevant targets were doing through the analysis of their behaviour online.
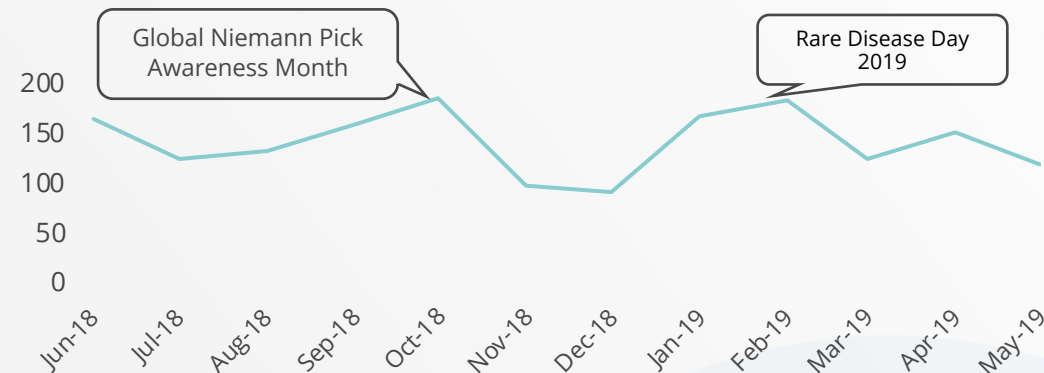
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KEY FINDINGS & BUSINESS IMPACT

LSD Key Topics Breakdown

Top 3 topics

- Awareness: 39%
- Research & Trials: 31%
- Treatments: 18%
- Diagnosis: 17%
- Causes: 16%
- Symptoms & Comorbidities: 14%
- Living with the Condition: 13%

Overall Volume Trend Analysis

Global Niemann Pick Awareness Month

Rare Disease Day 2019
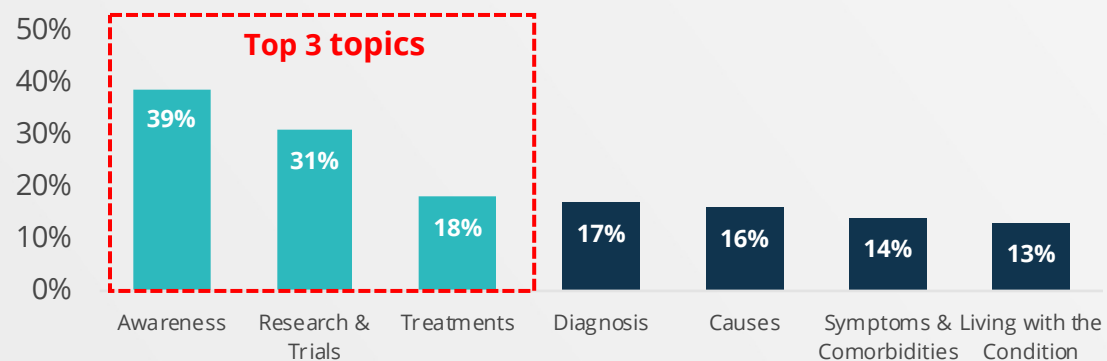
- Overall, social media conversation around LSD was low in volume. Patients or caregivers rarely participated in conversation. This could be attributed to the fact that engagement and level of activity around rare diseases is low on social media.

- We identified the top two pages and analyzed the profile activity of the page. We identified when and what were they posting when engagement levels were high.

- We provided the client with a rich understanding of the conversations around LSD. Detailed analysis of the top profiles helped the client to develop ideas to curate similar content to that which had resonated well with stakeholders and had garnered good engagement.

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TREATMENT OPTION ANALYSIS - MS

Our client wanted to understand the patient and caregiver's perceptions around treatment options for MS, such as mode of administration , preference towards oral or injectables, around biologics as medications, concerns around side-effects, unmet needs and pain points.

METHODOLOGY
- Social listening of the therapeutic area - Multiple Sclerosis with a focus on treatment

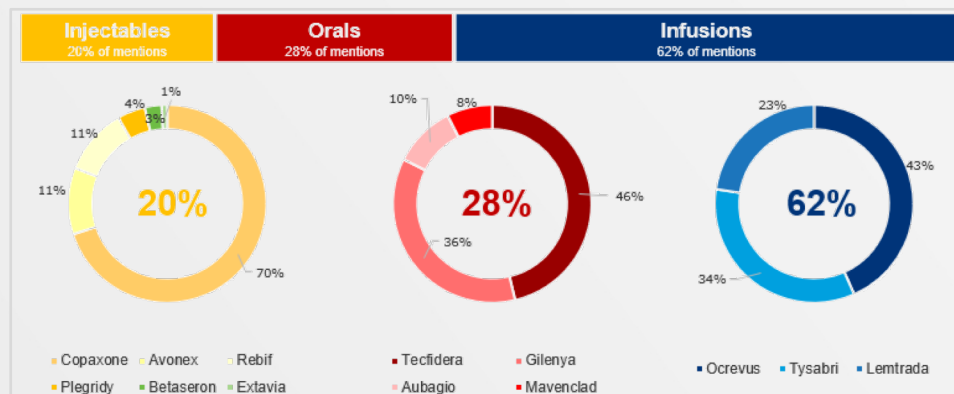**TOOL**
- Talkwalker

MARKET

INDUSTRY
- Pharma

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OUR SOLUTION

- **Social listening around the therapeutic area with a focus on treatment options**:

  - Analyzed social media conversation around MS, focusing mostly on conversations by patients and caregivers.

  - Deep dived into patients and caregivers behaviour through social listening to understand their sentiment, unmet needs, perceptions around treatment options, such as oral vs. injectables medications, around biologics, side-effects of the medications and their behavior towards switching medications.

  - Identified the needs of patients, their preferences, pain points and the drivers and barriers to adoption, towards different medication forms (injectables, orals and infusions) and various biologic brands.

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KEY FINDINGS & BUSINESS IMPACT

Treatment Types Discussed By Patients In The US

Injectables 20% of mentions	Orals 28% of mentions	Infusions 62% of mentions

Injectables

20%

1%
4%
3%
11%
11%
70%

- Copaxone
- Avonex
- Rebif
- Plegridy
- Betaseron
- Extavia

Orals

28%

10%
8%
46%
36%

- Tecfidera
- Gilenya
- Aubagio
- Mavenclad

Infusions

62%

23%
43%
34%

- Ocrevus
- Tysabri
- Lemtrada

Treatment Types Discussed By Patients In Germany

Injectables	Orals	Infusions

Injectables

32%

1%
16%
12%
71%

- Copaxone
- Avonex
- Rebif
- Extavia

Orals

49%

8%
7%
39%
46%

- Aubagio
- Tecfidera
- Gilenya
- Mavenclad

Infusions

19%

20%
28%
52%

- Ocrevus
- Tysabri
- Lemtrada

- While infusions were a more discussed form of treatment for MS in the US among patients, in Germany it was orals and injectables.

- Both in the US and in Germany patients felt that injectables were tolerable but not efficacious over time and relapse and long-term efficacy became an issue. However, injectables were the initial treatment received by most patients in the US.

- Orals were easy to consume but patients experienced side effects.

- The behaviour of switching medications was mostly due to the desire to find a more suitable and effective option, fear of developing JCV and the risk of PML, or uncertainty regarding which treatment to choose.

- This detailed analysis helped the client with specific answers to their questions on patient's preferences towards medications forms, drivers of switching behavior for certain medications, including biologics, unmet needs of patients taking orals, issues related to the cost of medications etc.

- We provided the client with a rich understanding of the drivers and barriers to adoption of various treatment forms and brands to help the client develop relevant content which would resonate well with patients and caregivers and help in better positioning of their product for MS.

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THERAPEUTIC AREA OVERVIEW - IPF

Our client wanted to wanted to gain better understanding of the therapeutic area of IPF. Being a rare disease it was difficult gain to stakeholder view and insights into the category. The current data available was unstructured and unmanaged, making it hard to derive specific insights and outcomes

METHODOLOGY
- Social listening of TA - IPF (Idiopathic Pulmonary Fibrosis)

TOOL
- Synthesio
- Crimson Hexagon

MARKET

INDUSTRY
- Pharma

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OUR SOLUTION

- **Social listening study around IPF Therapeutic Area**:

  - Disease specific queries were created, and data was collected from social media aggregator tools.

  - A proprietary tagging and coding technique was used to identify top stories, key stakeholder groups and key drivers of conversations.

  - Areas of interest and behavioural aspects were analysed to understand stakeholder level nuisances.

  - An influencer identification exercise was carried out to understand key influencers, their area of interest and influence in the TA.

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KEY FINDINGS & BUSINESS IMPACT

Social mentions of Pulmonary Fibrosis/IPF
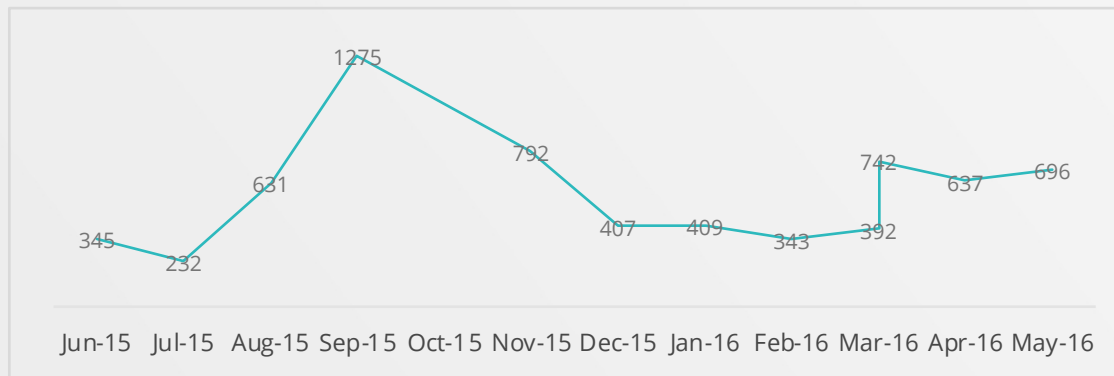
Key Stakeholder Groups
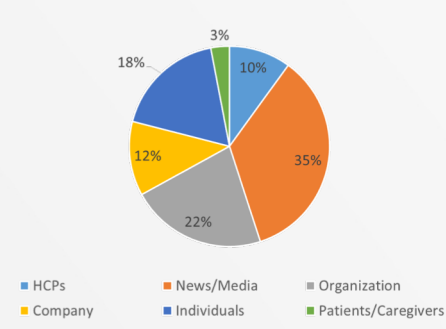
Sentiment
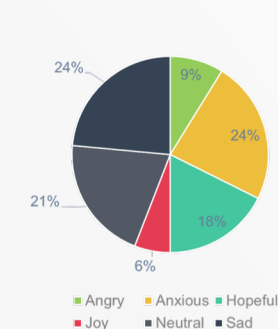
Key Topics of Conversation

- The most prolific themes were around raising awareness and financial support for treatment.

- Unlike other diseases, patients and caregivers make up the minority of online content, at 3% of the total volume, and HCPs 10%.

- A lack of clarity on the treatment options for IPF, and the lack of palliative care were identified as the key business opportunity areas.

- The client was able to direct their marketing efforts towards sharing IPF awareness content online, primarily on Facebook and Twitter, resulting in increased user engagement and category leadership.

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DISEASE PERCEPTION ANALYSIS - RSV

Our client wanted to wanted to have an overview of perceptions around RSV. They wanted to better understand HCPs and parental awareness and attitudes around RSV and its prevention.

METHODOLOGY
- Disease perception: RSV (Respiratory Syncytial Virus)

TOOL
- Talkwalker

MARKET

INDUSTRY
- Pharma

OUR SOLUTION

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- **Analyzing perceptions around RSV**:

  - Disease specific relevant key words were deployed to harvest conversations related to the topic across relevant social channels in the target markets on social media aggregator tools.

  - Used queries to filter out the data to a relevant sample from HCPs and parents/caregivers, by using a range of pronouns to identify first person conversation and biography keywords to identify healthcare professionals.

  - Analyzed the shift in conversations and awareness levels on a monthly basis, identified key channels, key themes and topics of conversations, posts with the highest engagement, attitude towards prevention of RSV, perception and emotions around the condition. Detailed analysis done for each of the stakeholders –parents, caregivers and HCPs.

  - Identified 10 digital influencers within the RSV conversations with examples of posts shared by them.

  - Performed a Google trend analysis based on how people were searching online for RSV.
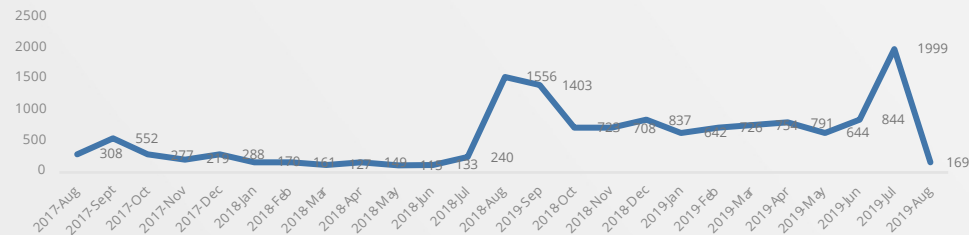
convosphere

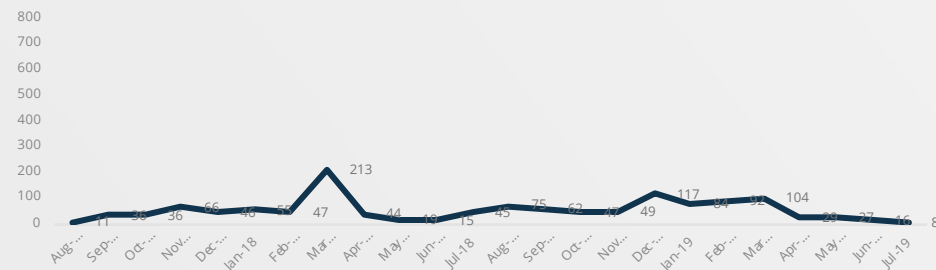# KEY FINDINGS & BUSINESS IMPACT

Conversation Volumes In The Past 2 Years
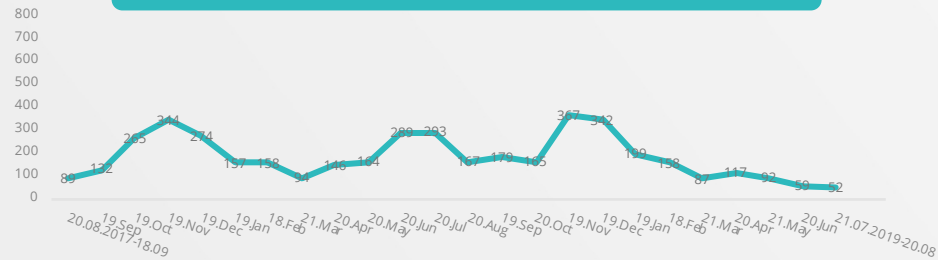
- In Spain, the conversations were less around RSV, rather bronchiolitis. Parents with ill children went online to ask for advice, share their experiences or provide emotional support. There was a correlation between awareness of severity and hospitalisation. Parents whose babies had been hospitalised talked about bronchiolitis in more serious terms. On Google people mostly searched for symptoms and related diseases.

- In Japan, most of the conversations were by parents sharing their experience of their children contracting RSV.

- In Italy, parents mostly talked about symptoms, signs and prevention of bronchiolitis.

- The study helped the client to understand the change in awareness levels and the respective drivers, attitude and perceptions of parents/caregivers and HCPs as well as the preventive measures adopted by them. This provided ideas for future awareness and prevention related campaigns targeted at parents/caregivers and HCPs.

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