



# Take My Word For It: Can Patient-Centric Social Listening Enrich Real-World Evidence

**ISPOR EUROPE  
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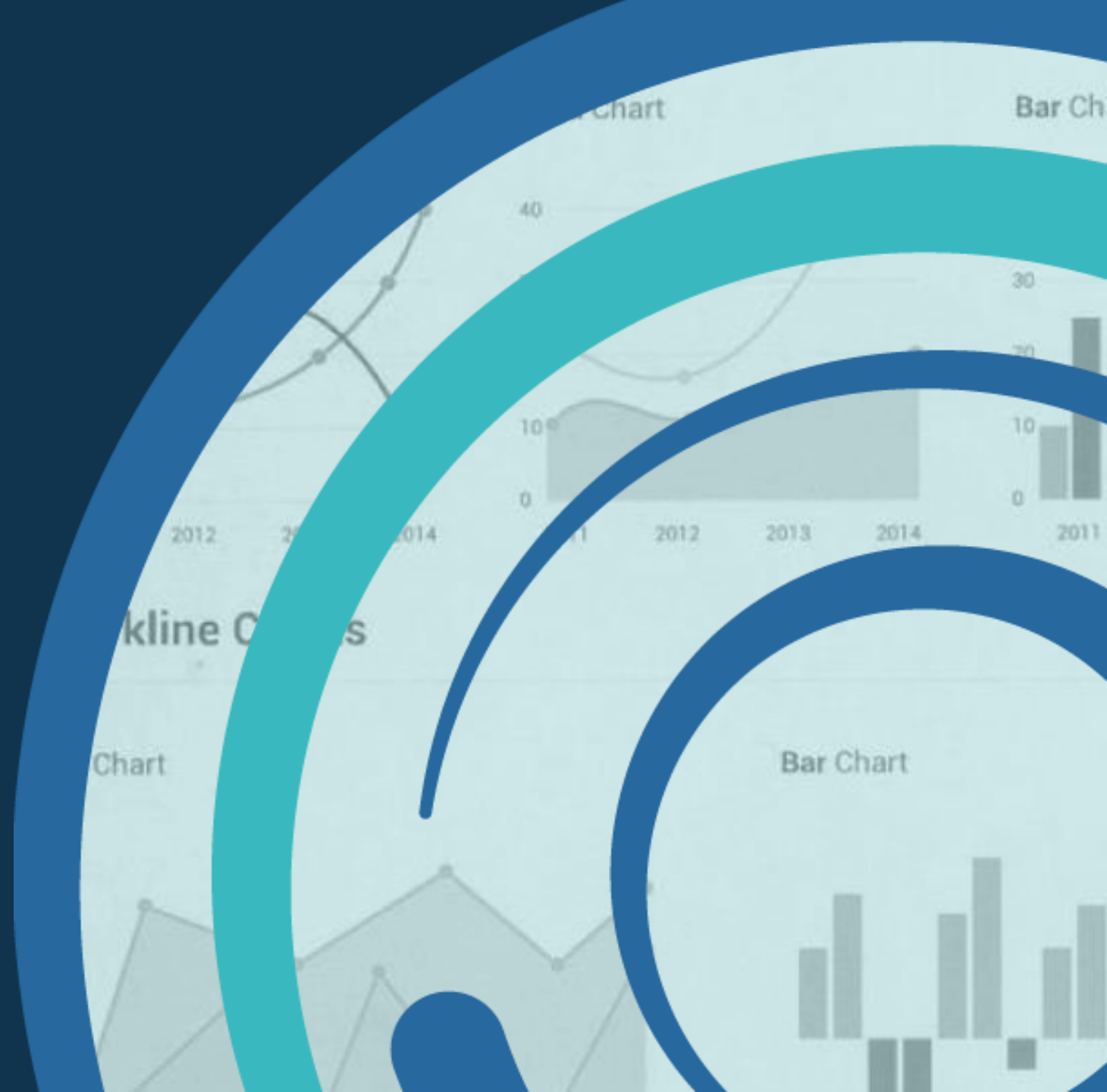
## We will be answering the following questions:

1. What questions can Social Listening (SML) help answer?
2. How are SML studies conducted and where do AI and machine learning fit in?
3. When can SML make the most impact?



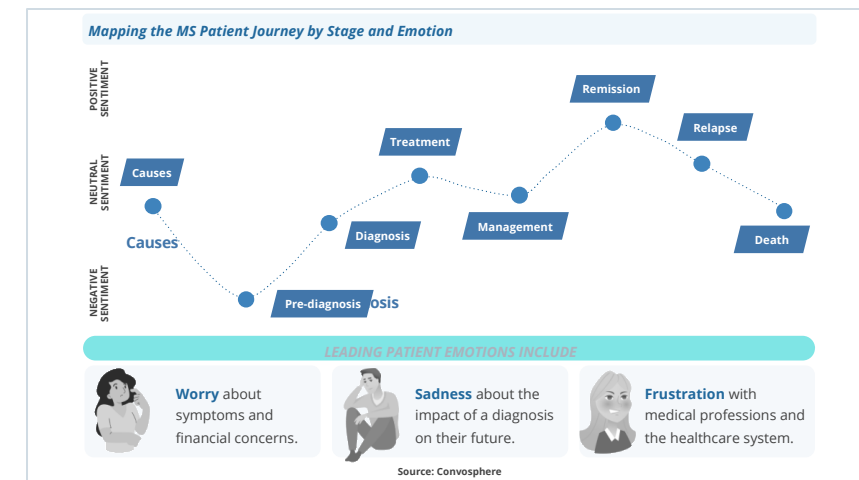
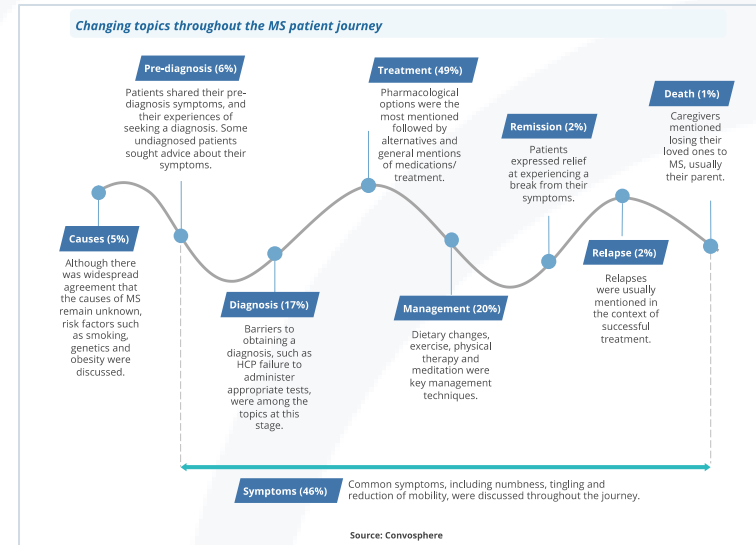


# What questions can Social Listening (SML) help answer?



# What is the value of Social RWD throughout the Clinical Pipeline?

- **Understanding the Patient Journey**
- **Identifying Unmet Needs at each stage of the Patient Journey**
- **Evaluating Real-World Outcomes**
- **Building Enhanced Value Propositions**
- **Accelerated Drug Development and Achieving Market Success**
- **Pharmacovigilance**

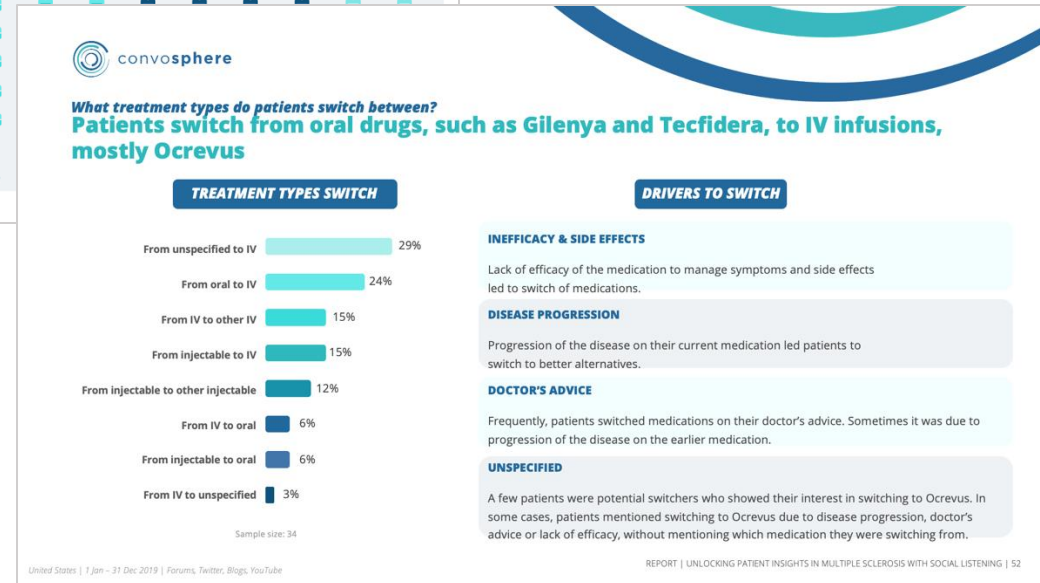
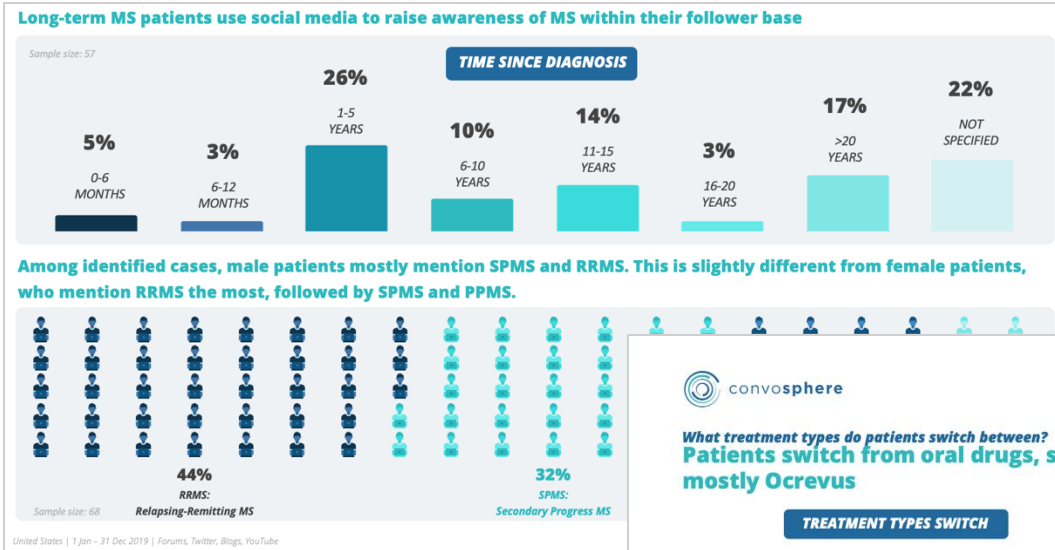


# The Patient Journey can be viewed from a Patient-Centric View

## Patient Pathway



Showcase the disease and treatment pathway from a Patient's POV. Using social we can map out the how patient manage a disease condition and what are the key touch points for them, which might be different from a clinical pathway with varying degree of importance.



# Quality of Life impact can be viewed beyond the limitations of survey questions

## QoL Impact

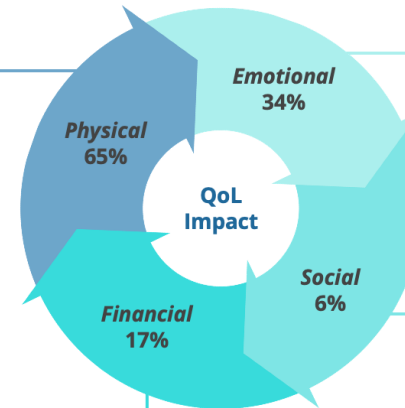
Understand the actual QoL impact of the disease on patients and accordingly map and update survey forms and questionnaires. To provide a 360 view into the impacts and their intensity while not restricting the insights around the survey questions.



### Considering the nature of the disease, physical impact was the most discussed QoL impact

- MS left many patients physically disabled. Patients mentioned using a walker or a wheelchair and how this impacted their mobility.
- Fatigue and tiredness made them weak, they were unable to carry out household tasks properly. These symptoms were sometimes worsened by medication.

- Patients often voiced dissatisfaction with the US healthcare system, and some expressed concern about being unable to afford their medications.
- Patients and caregivers sometimes used social media to raise funds for themselves and the MS community.
- Many elements of MS had financial consequences for patients, not least of which was finding themselves unable to work.



Sample Size = 143

- Patients and caregivers were worried and sad about physical challenges due to the condition. Symptoms also left them emotionally drained, due to the constant pain and the need for support.
- The reality of living with MS caused people to worry about their mental health and that of their loved ones.

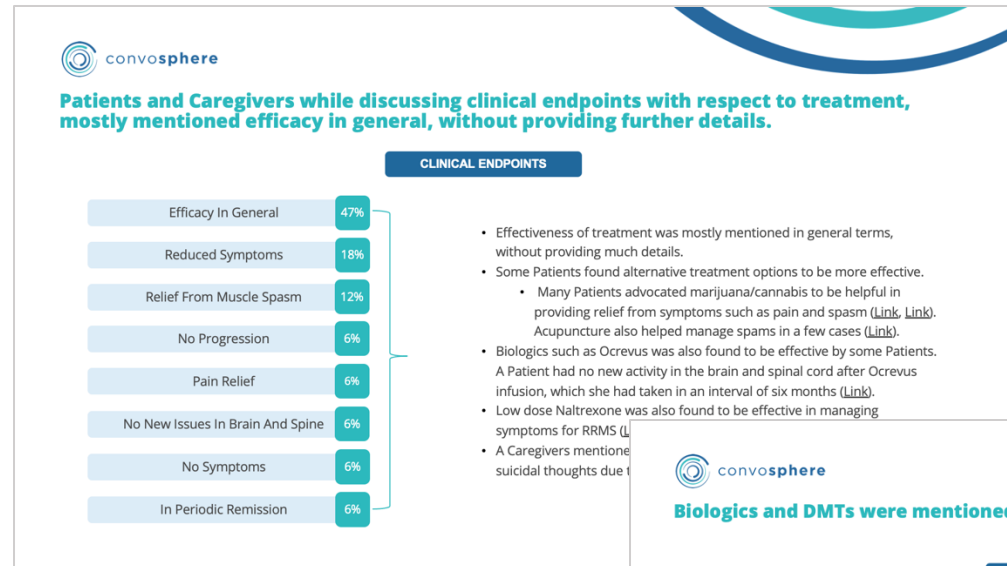
- Some patients had to limit socializing and outdoor activities, due to physical impairment and fatigue.
- Forced to quit their job, some patients spoke of losing out on the social aspects of work.

# SML can help us understand real-world outcomes beyond the clinical endpoints

## Clinical End Points

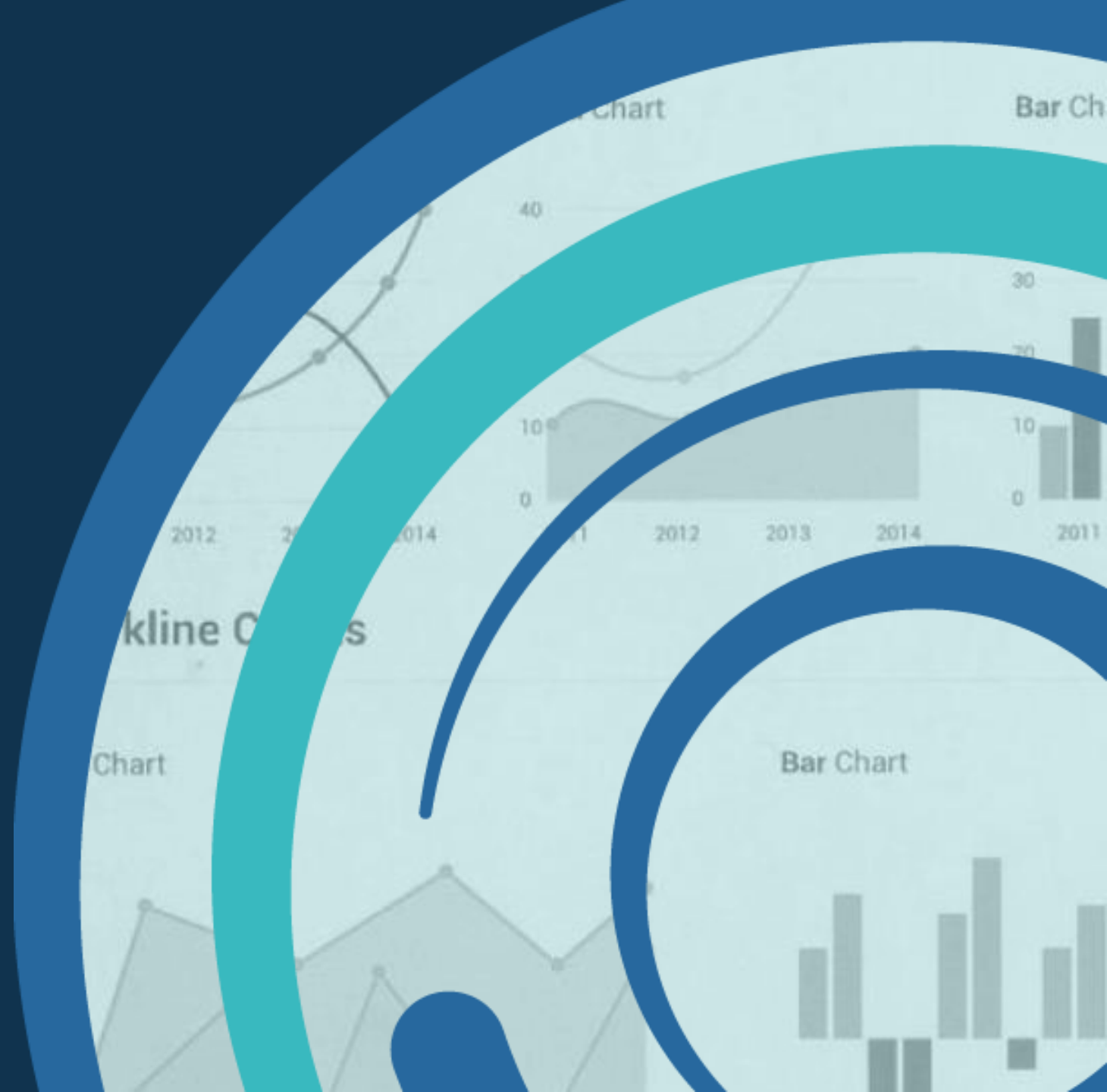


Social media data helps understand the actual treatment endpoints that patients consider the most significant and help interpret the clinical endpoints in a more real-world setting, which can be in turn utilized to develop surveys and analysis clinical data better.



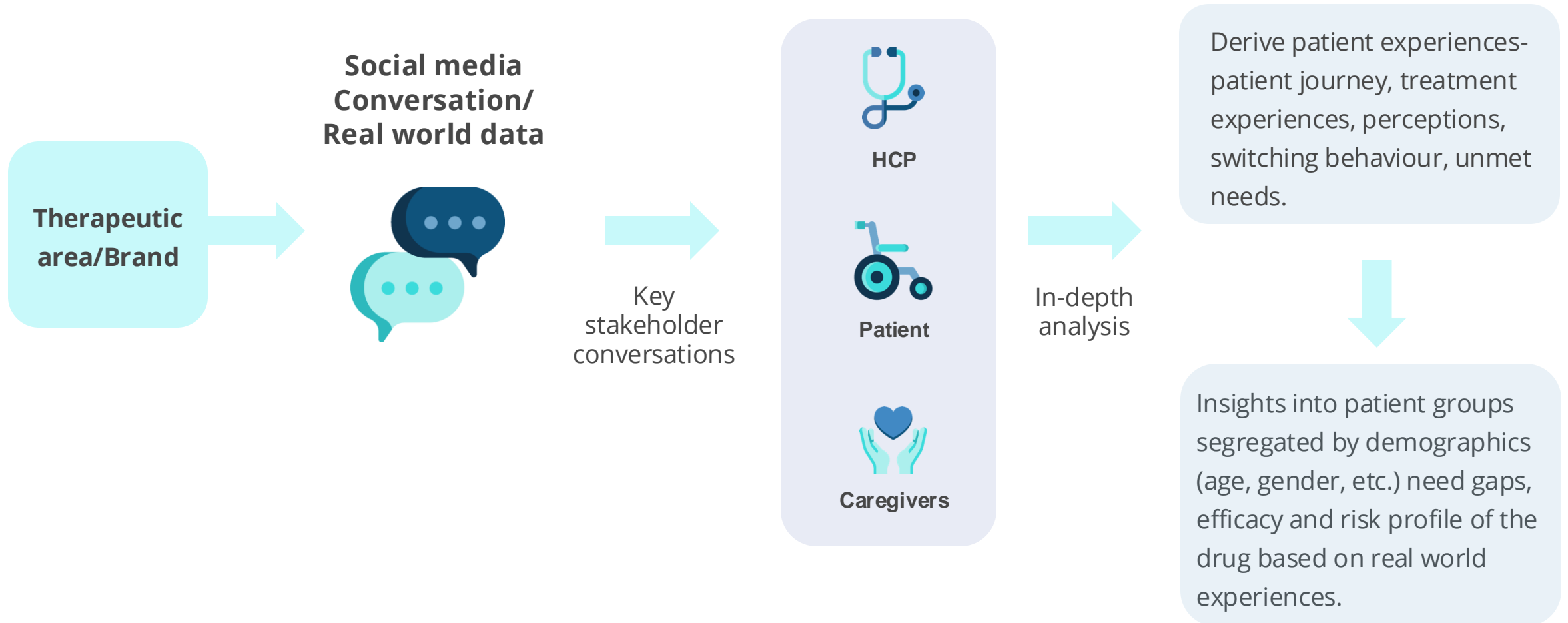


# How are SML studies conducted and where do AI and machine learning fit in?

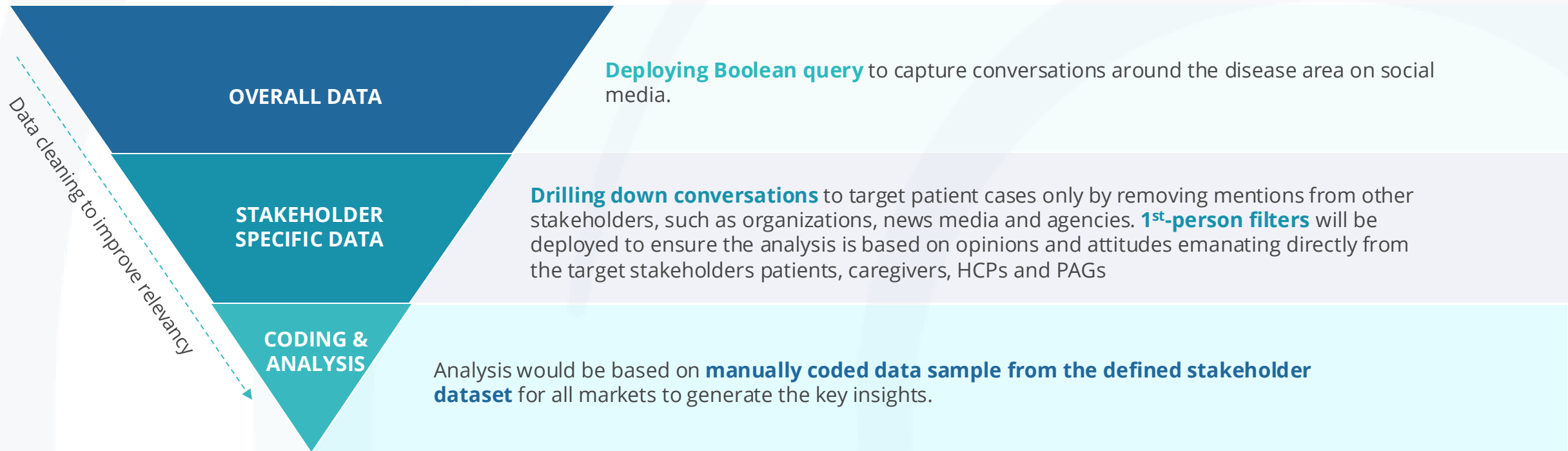




## RWE from social data - Process

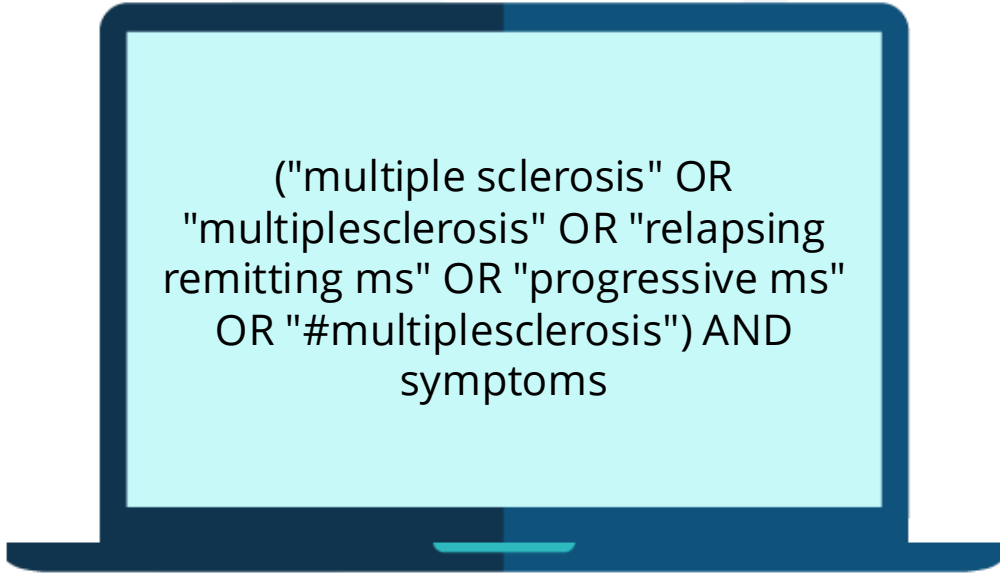


# Methodology - Data collection & cleaning






## Query development

Build comprehensive search queries based on Boolean logic and relevant business questions



("multiple sclerosis" OR  
"multiplesclerosis" OR "relapsing  
remitting ms" OR "progressive ms"  
OR "#multiplesclerosis") AND  
symptoms

-  *Conducting desk research would be useful to identify relevant key terms associated with the therapeutic area*
-  *Variation of terms and abbreviations associated with the therapeutic area should be considered*
-  *Search queries should be comprehensive to collect the accurate and relevant data*

# Patient-Centric posts are identified through human analysis, machine learning and AI



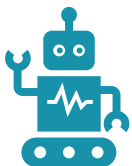
**AI module:** Utilize AI in the data aggregator tool to identify relevant conversations as well as exclude irrelevant noise.



**Keywords based data filtering:** Deployed keywords indicating 1st person conversations and/or patient journey stages to identify potential patient-centric posts.

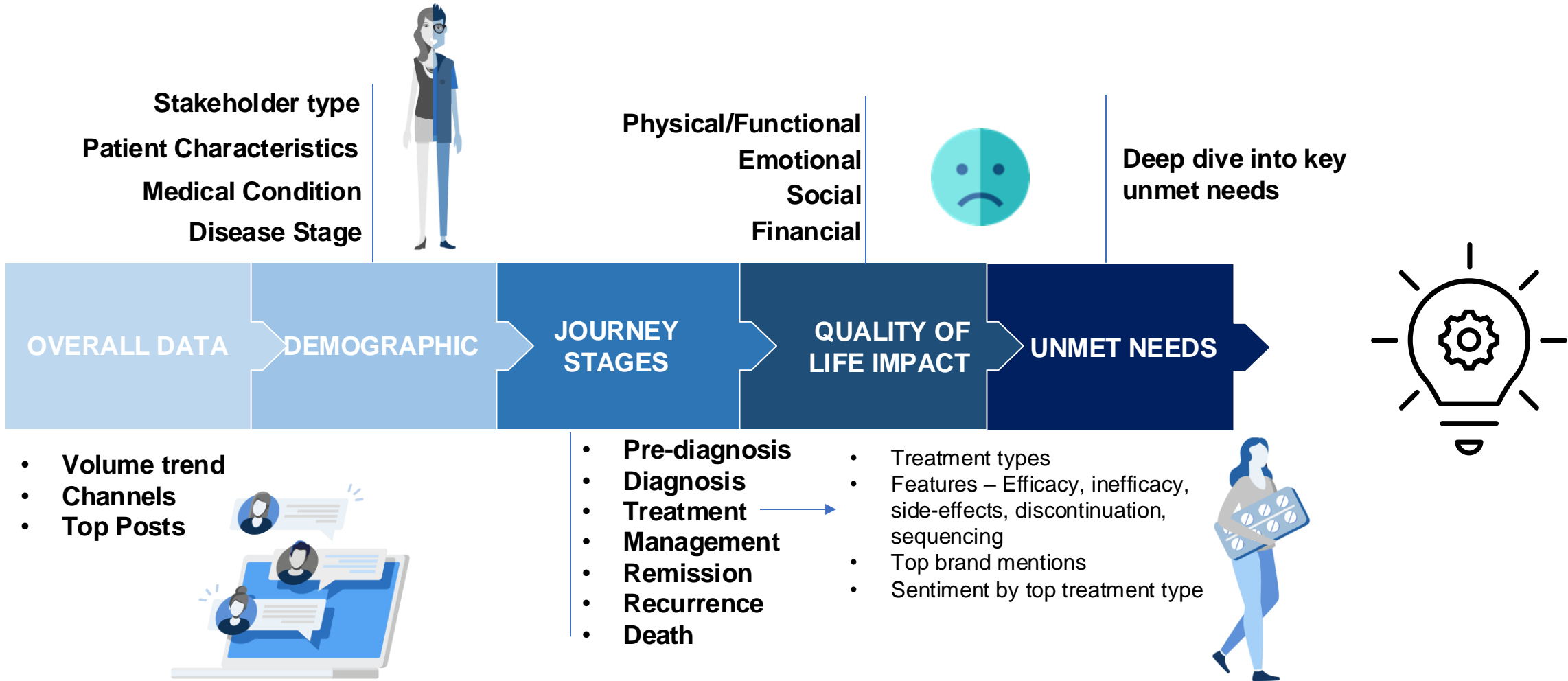


**Manual review:** Manually review a large sample of the data to identify relevant patient-centric conversations based on how they are describing the condition and talking about the disease.

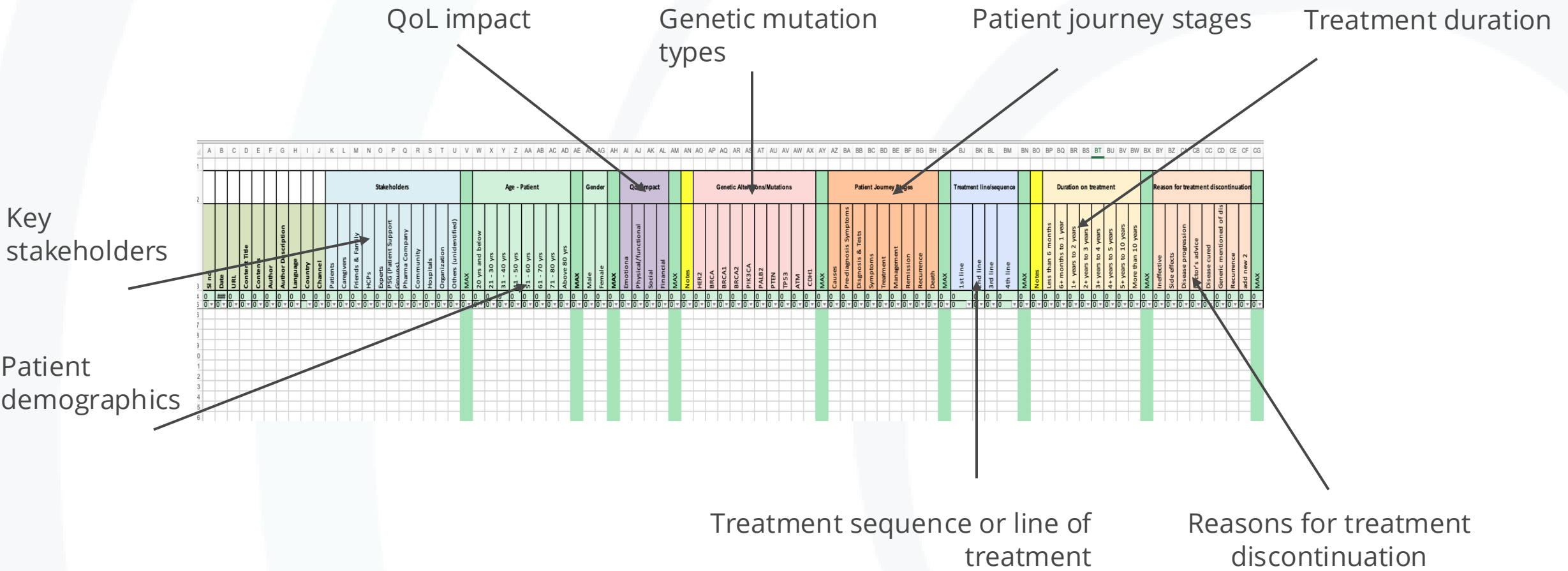


**Machine Learning & AI:** Use human-coded posts for machine learning and AI to conduct analysis on large datasets.

# RWE data analysis framework – Broad Level



# Manual coding ensures accuracy and can also be used to train machine learning



# Patient-Centric insights are developed from the findings

The coded data is reviewed by a team of analysts to derive quantitative and qualitative insights to highlight patients' journey and experiences with the condition and map the outputs from an RWE perspective.

## Social Data

15 years ago this month I was diagnosed with #MultipleSclerosis. It was one of the darkest moments of my life, but like every storm, the winds eventually calmed down and it cleared the way for a more rewarding path than the one I was on before the illness came into my life.

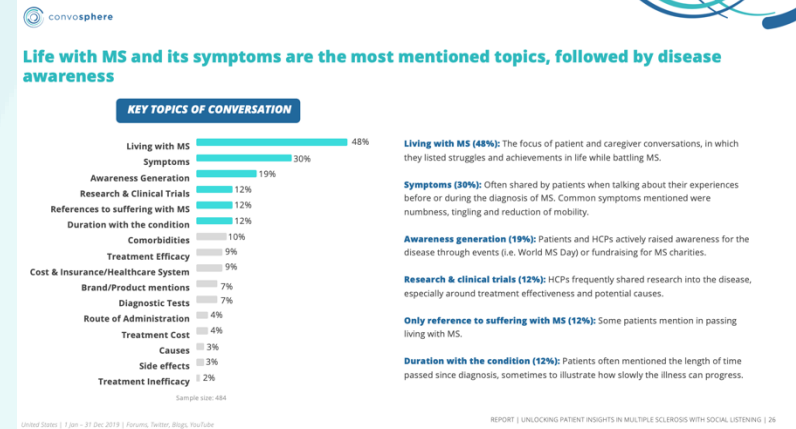


## Data Coding & Analysis

Keywords	Frequency	Quality of Life Impact									
		Physical	Emotional	Social	Financial	Health	Work	Family	Relationships	Self-Care	Overall
MS	150	High	High	High	High	High	High	High	High	High	High
Symptoms	120	High	High	High	High	High	High	High	High	High	High
Living with MS	100	High	High	High	High	High	High	High	High	High	High
Research & Clinical Trials	80	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium
Duration with the condition	60	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium	Medium
Awareness Generation	40	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Cost & Insurance/Healthcare System	30	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Brand/Product mentions	20	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Diagnostic Tests	15	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Route of Administration	10	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Treatment Cost	8	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Cause	5	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Side effects	4	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Treatment inefficacy	2	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low



## Build Insights



## The use of AI must undergo critical evaluation before implementation

### Use AI to increase efficiency

- Support initial desk research
- Support Project Setup
- Improve accuracy of dataset
- Manage large datasets

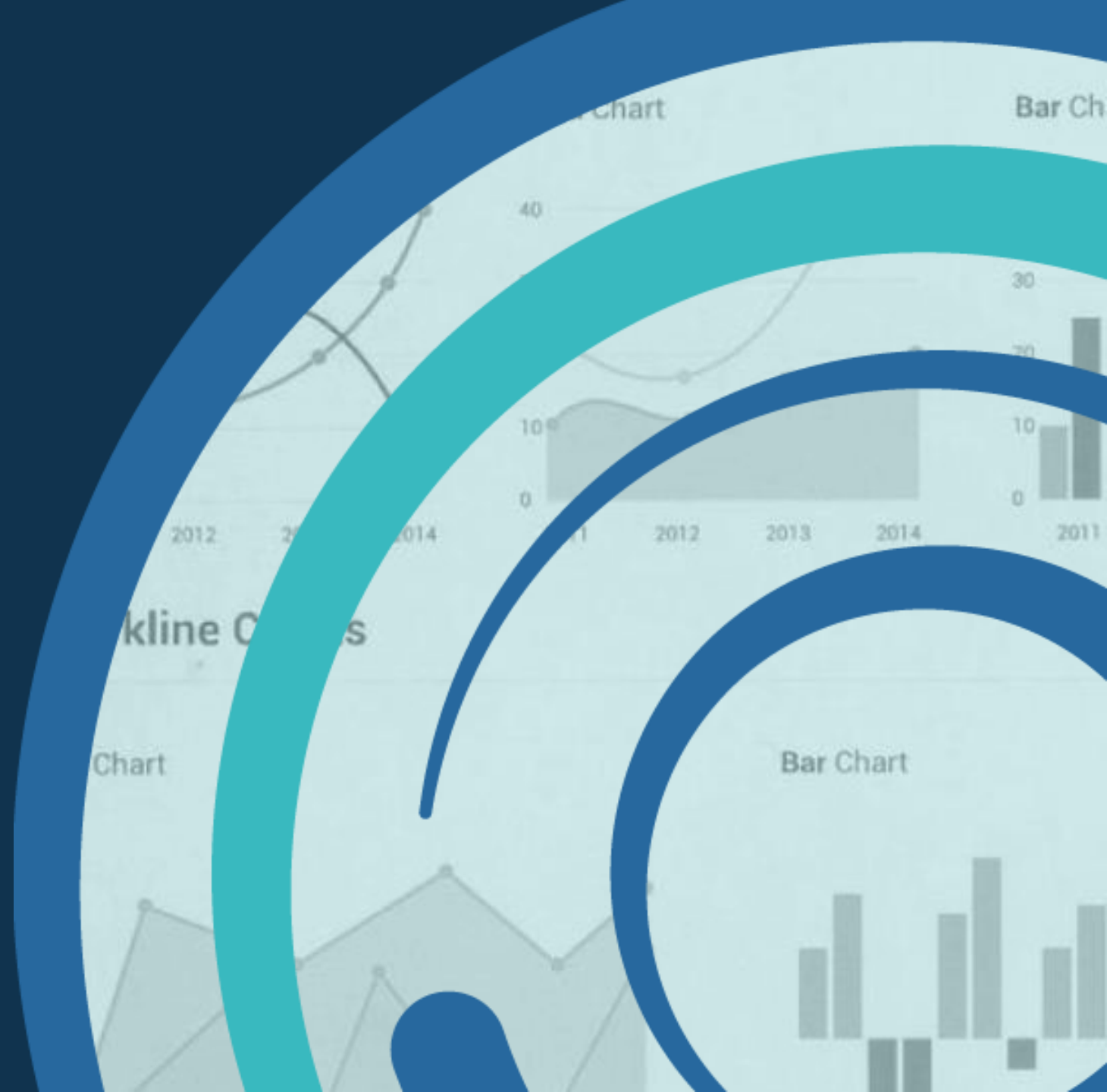
### Beware of the risks AI can present

- Lacks context
- Access limitations
- Can hallucinate
- Lacks TA, business or cultural nuance
- Needs human oversight & logic
- Unknown biases

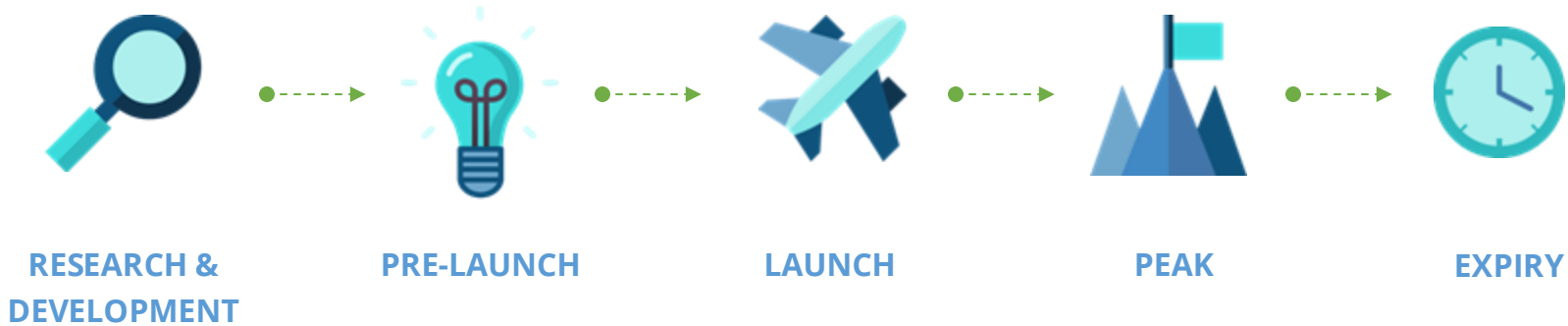




# When can SML make the most impact?



# SML can be used at any stage of the pharma lifecycle



- Understand therapeutic areas
- Identify stakeholders
- Identify key channels
- Identify unmet needs
- Map KOLs online
- Identify & Profile KOLs
- RWE

- Identify key messaging
- Understand key topics and themes
- Uncover unmet needs by segment
- Identify opportunities to engage KOLs and KOIs
- Measure launch impact

- Identify adherence issues
- Refine and measure messaging
- Refine and measure campaigns
- Understand brand choice drivers by segment

# SML for RWE can contextualise, connect and augment other data for a truly patient-centric view

Hospital/doctor's visit

Patient registries

Insurance claim reports

Connected devices

Prescription data

Observational studies

Primary/secondary patient level data

How patients describe their interaction with their HCPs?

What (%) of patient's adherent to treatment and what is the time to treatment discontinuation?

What were the pain points of patients with respect to medication – cost and insurance?

Who are the active online segment in the disease area ?

What are the treatment approaches/pathways being followed by patients?

What influences patient's decisions at each stage and how can brands intervene?

What are the patient characteristics based on mutation types and method used for the evaluation?

Social media conversations by key stakeholders, focused on patients (Patients, Caregivers, HCPs etc.)

*"I'm sorry I don't have any experience with this. I've had a break from Twitter. I'm struggling with a chronic condition and was in hospital on and off from September to end of December with every virus, bacteria and infection known."*

*"Hello, I am XXX, 54 years old. I was diagnosed with breast cancer, which immediately metastasized her2+, RH+ last April. Right carcinoma with axillary nodes, hepatic lesions, nodules and pleuropulmonary micronodules with effusion ..."*