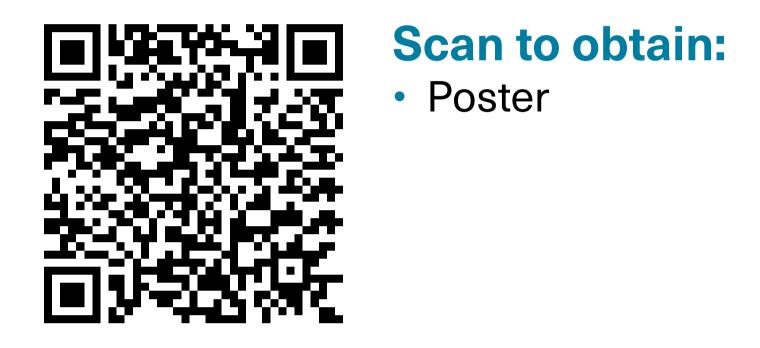Ana Rodrigues, rodriguesana@me.com

Using social listening to understand stakeholder perceptions of the patient journey in lung cancer

Ana Rodrigues,[1] Jyoti Chauhan,[2] Alexandros Sagkriotis,[3] Sathyaraj Aasaithambi,[2] Michele Montrone[4]

[1]Medical Oncology, Instituto Português de Oncologia do Porto Francisco Gentil, EPE, Porto, Portugal; [2]Novartis Healthcare Pvt Ltd (H.A.), Hyderabad, India; [3]Novartis Pharma, Basel, Switzerland; [4]Medical Thoracic Oncology Unit, IRCCS Istituto Tumori "Giovanni Paolo II", Bari, Italy

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KEY FINDINGS & CONCLUSIONS

- Patient interactions with social media evolve over time, from passive observer to active participant, possibly reflecting the emotional and educational journey

- This analysis highlights differences in treatment goals and language used by patients/caregivers and HCPs. Understanding patient treatment goals and adopting patient-friendly language could improve communication and understanding between HCPs and their patients

- This study demonstrates that social listening is a powerful tool that can be used to explore different elements of stakeholder perceptions, providing key insights that are typically not available in published literature or databases

INTRODUCTION

- Social media platforms are being increasingly used by stakeholders to generate, access, and share health-related information[1,2]
- Analysis of data from different stakeholder groups, including patients, caregivers, and healthcare professionals (HCPs), can provide unique insights into stakeholder perceptions, preferences, and knowledge levels
- Lung cancer is one of the most common cancer types, affecting >2 million patients globally[3]
- This observational study used a social listening approach to analyse social media trends and gain insights into stakeholder perceptions in lung cancer
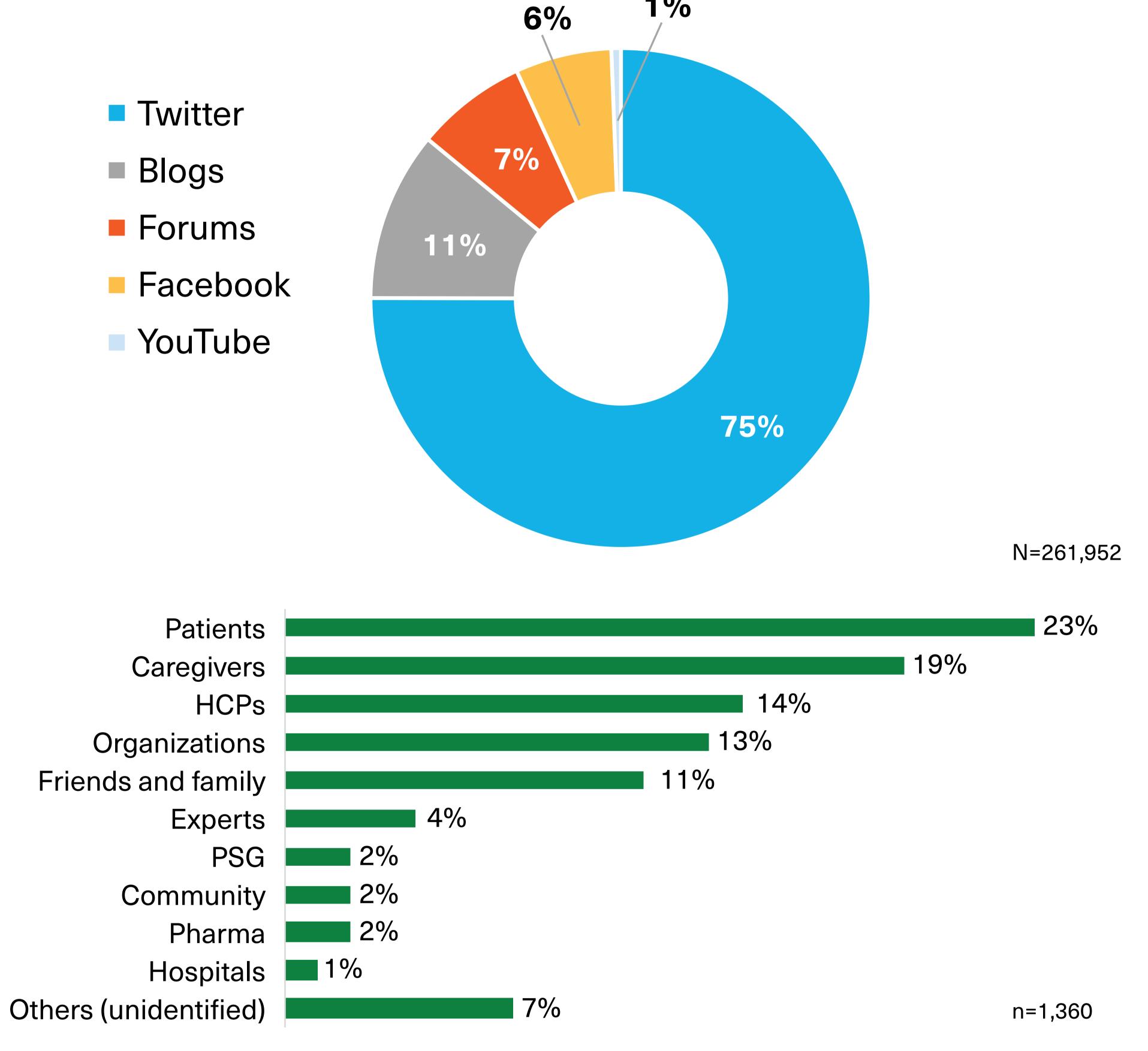
METHODS

- Data were collected retrospectively (June 2019 to May 2020) across 14 European countries (UK, Spain, France, Switzerland, Belgium, Germany, Austria, Netherlands, Italy, Nordic countries, and Portugal) from open-access blogs, forums, and social networking sites (including Twitter, public Facebook, and YouTube). SocialStudio and Talkwalker were used for UK and non-UK data collection, respectively

- A three-tier technique was used to identify relevant data, with random sampling procedures generating the final dataset for analysis. Conversations containing lung cancer and non-small cell lung cancer (NSCLC)-specific terms were extracted using social media aggregator tools. The information was filtered to a contextualised dataset by automated relevancy algorithms and manual review

- The final dataset was analysed for insights and themes relating to stakeholder perceptions of multiple aspects of the NSCLC experience

RESULTS

- Overall, lung cancer had 242,000 mentions, with Twitter being the primary channel
- Of 1360 conversations analysed, 23% were generated by patients, 19% by caregivers, and 14% by HCPs (**Figure 1**)

Figure 1. Channel and audience overview of analysed data

- Twitter
- Blogs
- Forums
- Facebook
- YouTube

1% YouTube, 6% Facebook, 7% Forums, 11% Blogs, 75% Twitter

N=261,952

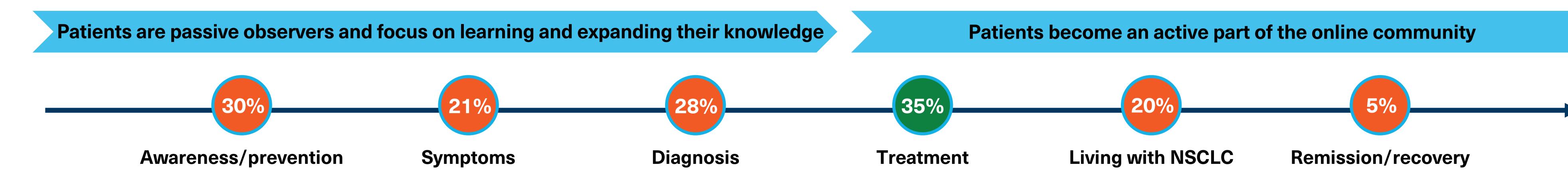| Stakeholder	%
Patients	23%
Caregivers	19%
HCPs	14%
Organizations	13%
Friends and family	11%
Experts	4%
PSG	2%
Community	2%
Pharma	2%
Hospitals	1%
Others (unidentified)	7%

n=1,360

HCP, healthcare professional; PSG, patient support groups.

- Most patients were 51 to 70 years old (~50%) and 91% (n=550) had late-stage cancer, 11% had early-stage cancer, and 8% had stage III cancer. Terminology varied, resulting in overlap of figures
- General mentions of lung cancer were common across all stakeholders; the term "NSCLC" was mostly used by specialist news or HCPs
- Across regions, awareness generation around causes of lung cancer and importance of early detection was prominent

Patient journey stages and treatment types

- During the early stages of the patient journey, patients/caregivers were more likely to passively observe online forums, as they tried to increase their disease knowledge
- As their journey progressed, patients/caregivers more actively participated by answering questions and sharing experiences online
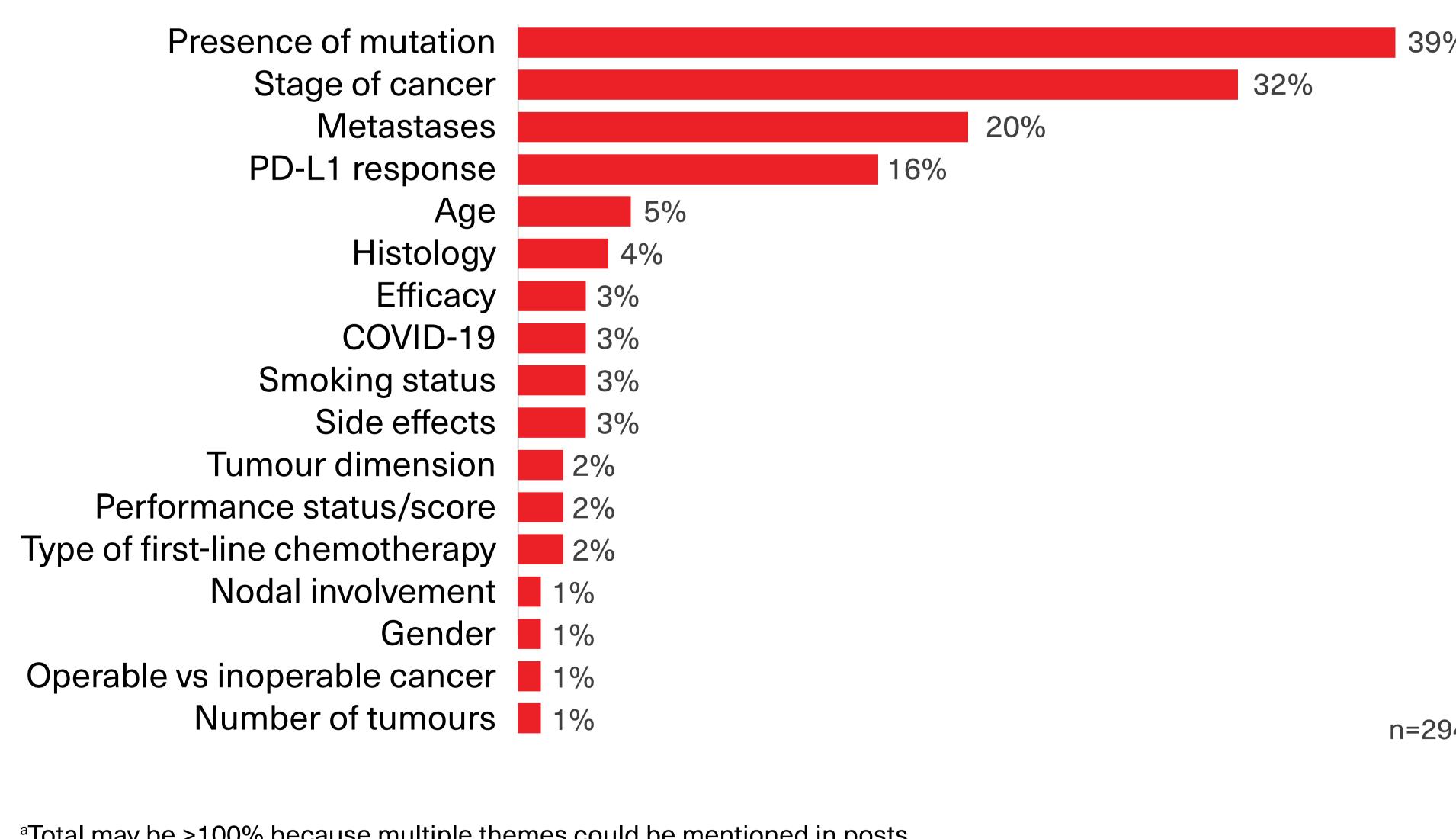
Figure 2. Patient journey analysis: overall segments

Patients are passive observers and focus on learning and expanding their knowledge → Patients become an active part of the online community

Awareness/prevention	Symptoms	Diagnosis	Treatment	Living with NSCLC	Remission/recovery
30%	21%	28%	35%	20%	5%

NSCLC, non-small cell lung cancer.

- Treatment was the most discussed stage of the patient journey, followed by awareness/prevention and diagnosis (**Figure 2**)

Therapy

- The most discussed treatments were chemotherapy (49%) and immunotherapy (46%); both were often discussed in the context of first-line therapy
- While HCPs explicitly referred to lines of therapy, patients/caregivers often used terms relating to treatment pattern, rather than referring to "lines of therapy"
- Three of the top 5 mentioned molecules were biologics; pembrolizumab was the most mentioned molecule, followed by osimertinib and nivolumab
- Mutations were a key factor in treatment decisions (39%) (**Figure 3**); the most discussed mutations were *EGFR* (54%), *ALK* (23%), *ROS1* (8%), *KRAS* (5%), and *MET* (5%)

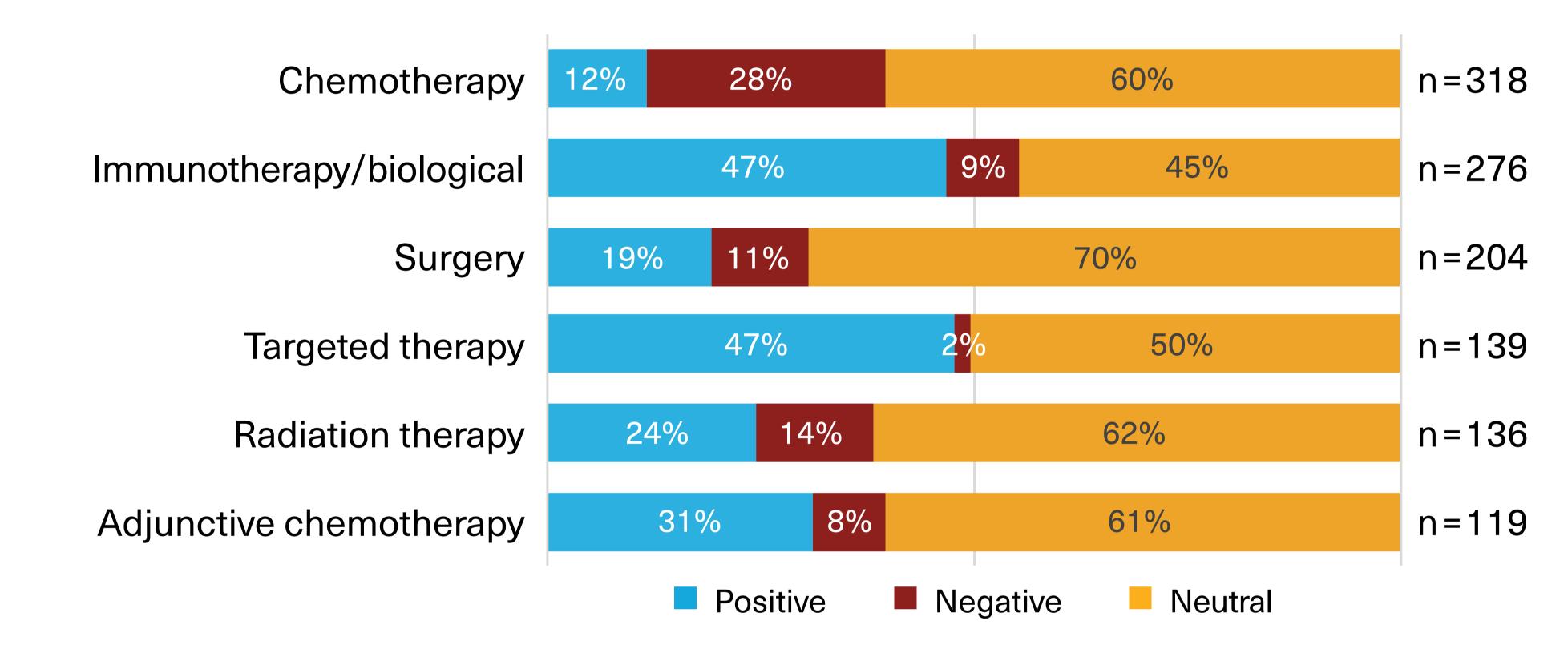**Figure 3. Key factors in driving treatment decisions[a]**

Factor	%
Presence of mutation	39%
Stage of cancer	32%
Metastases	20%
PD-L1 response	16%
Age	5%
Histology	4%
Efficacy	3%
COVID-19	3%
Smoking status	3%
Side effects	3%
Tumour dimension	2%
Performance status/score	2%
Type of first-line chemotherapy	2%
Nodal involvement	1%
Gender	1%
Operable vs inoperable cancer	1%
Number of tumours	1%

n=294

[a]Total may be >100% because multiple themes could be mentioned in posts.
PD-L1, programmed death-ligand 1.

Treatment perception

- Chemotherapy had the highest share of negative perceptions (**Figure 4**), owing to perception of long-term side effects

Figure 4. Key treatment types by sentiment[a]

Treatment	Positive	Negative	Neutral	
Chemotherapy	12%	28%	60%	n=318
Immunotherapy/biological	47%	9%	45%	n=276
Surgery	19%	11%	70%	n=204
Targeted therapy	47%	2%	50%	n=139
Radiation therapy	24%	14%	62%	n=136
Adjunctive chemotherapy	31%	8%	61%	n=119

Positive / Negative / Neutral

[a]Adjunctive chemotherapy included several combinations and the most frequent were with immunotherapy (45%), radiation therapy (30%), and surgery (12%).

- Immunotherapy and targeted therapy were more positively perceived due to perceptions of longer survival and limited side effects

Clinical endpoints

- Survivability (47%) and overall survival (30%) were the most mentioned clinical endpoints across stakeholders
- HCPs mostly used technical terms, whereas patients and caregivers used colloquial terms, such as "getting rid of cancer"
- For patients/caregivers, efficacy was of greatest importance, and patients looked for reduction in tumour size, symptom relief, improved quality of life, and prolonged survival
- Discussed reasons for treatment discontinuation were exhaustion of treatment options and intolerable side effects

Limitations

- Data collection was limited to those made publicly available, and information provided by social media users was interpreted as being authentic
- Available content varied in sample size and by social media platform
- The most appropriate platform to derive in-depth insights per key performance indicator was determined objectively
- Quality of insights gathered depended on the richness and detail of patient conversations

Acknowledgements

Disclosures

References

1. Data on file: 210419_ESMO_Social listening_KO call_v1_ 2. Taylor J, Pagliari C. *NPJ Digit Med*. 2019;2:51. 3. World Health Organization. *Cancer*. 2021. Available at: https://www.who.int/en/news-room/fact-sheets/detail/cancer (accessed July 2021).