A Social Media Listening Study to Understand the Unmet Needs and Quality of Life in Adult and Pediatric Amblyopia Patients

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ABSTRACT

Introduction: Amblyopia is an important cause of monocular vision impairment worldwide, and it negatively impacts patients’ quality of life (QoL). Understanding patients’ perspectives may help to optimize treatment outcomes and improve treatment adherence.

Methods: This was a non-interventional, retrospective analysis of social media data available in the public domain posted by patients and caregivers on selected social media channels (Twitter®, forums, blogs, and news) from 12 countries between July 2018 and June 2020.

Results: Approximately 2662 conversations relevant to the research objective were analyzed. The patient journey for adults and children was constructed based on the conversations. Eyeglasses, eye patches, contact lenses, and vision exercises were the common treatment options for amblyopia. Patients also reported vision improvement with emerging technologies such as digital therapeutics. Amblyopia and its treatment had a negative impact on QoL, and increased caregiver burden.

Insurance coverage, long appointment waiting times, and recurring expenses of treatment options were reported as barriers to treatment. Non-compliance, switching between treatment options or technology, or discontinuation of treatment options was found to emanate from various issues including no improvement of the condition, discomfort with the treatment option, bullying, dissatisfaction with healthcare professional (HCP) recommendation, cost of treatment/issues with insurance coverage, side effects, and/or other unspecified reasons. The need for regular eye examinations, better diagnostic tests, awareness of the disease, awareness amongst HCPs about treatment options, and the need for better health insurance coverage policies emerged as unmet needs.

Conclusion: This social media listening study generated insights on patients with amblyopia and their caregivers regarding the patient journey, treatment options, reasons for non-compliance, reasons for switching HCPs, barriers to treatment, and unmet needs. Further qualitative research is required to validate the findings.

Keywords: Amblyopia; Patient journey; Quality of life; Social media listening; Unmet needs

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Key Summary Points

Why carry out this study?
To understand the patient journey and unmet needs in amblyopia using social media surveys.

What was learned from the study?
Patients’ and caregivers’ insights on patient journey, treatment options, lack of compliance, reasons for switching healthcare professionals (HCPs), barriers to treatment, quality of life, and unmet needs were gathered.

A need for regular eye examinations, better diagnostic tests, awareness about the disease, awareness amongst HCPs about treatment options, and the need for better health insurance coverage policies emerged as unmet needs.

INTRODUCTION

Amblyopia is an important cause of monocular vision impairment, which affects 2%–5% of the general population [1, 2]. A meta-analysis study had estimated that by the year 2030, there could be 175.2 million people with amblyopia worldwide, which could increase to 221.9 million by 2040 [3]. Amblyopia typically occurs in infancy or early childhood, during the visual cortical plasticity stage [4]. The exact timing of the visual impairment is unknown, and the critical period may extend from birth to the age of 7–8 years [5–7]. Diagnosis may be made at an older age; however, treatment tends to be less effective in children aged 7 years or older than in those aged less than 7 years [6]. Novel therapies may act on the plasticity window in adults, thereby extending the interval for treatment efficacy [8]. In general, more published literature is available on children with amblyopia than on adults. Despite adequate knowledge of the disease, only limited conventional treatment options are available for amblyopia, with a poor treatment compliance in both adults and children [9–12]. Due to the individual variability in response observed in amblyopia, a personalized treatment approach could be the way forward [13]. In this context, understanding patients’ perspectives and unmet needs could help in improving treatment outcomes, adherence, and compliance [14].

Social media has been used as a tool to gather patients’ perspectives of the disease journey, treatment options, and quality of life (QoL) [15–18]. The internet has helped patients to share information regarding their disease journey, treatment satisfaction, and other factors affecting their lives [15]. Thus, in amblyopia, where treatment options are limited along with poor compliance, social media listening (SML) could provide an opportunity to understand patients’ experiences of the disease beyond what is diagnosed or captured by questionnaires. Such findings can be helpful in improving treatment outcomes, compliance, and adherence. Hence, this study aimed to use SML as a tool to gather insights from patients’ and caregivers’ conversations on the various aspects of amblyopia and its impact on their QoL.

METHODS

This was a non-interventional, retrospective analysis of social media data available in the public domain posted on selected social media channels between July 2018 and June 2020. The sources of information were Twitter®, forums, blogs, and news. The conversations posted in English were extracted and analyzed. As there were multiple non-English speaking countries, local language translation was also performed. A set of terms (keywords) were used as the search string to identify social media posts discussing experiences of adult patients, pediatric patients, and caregivers to patients with amblyopia. Keywords were selected on the basis of existing therapy knowledge and desk research and aimed to encompass a broad range of topics relevant to amblyopia. The selected keywords included disease synonyms, symptoms,
diagnosis-related terms, treatment/alternate therapies, risk factors/etiology, complications, healthcare professional (HCP), patient organization names, and competitors. The Salesforce Social Studio and Talkwalker platform covering Twitter®, online forums, and blogs were used to conduct the search.

Data Overview and Screening

The initial data set underwent relevancy check to remove categories such as buy/sell content, animal content, job postings, market research reports, link duplicates etc. Conversations were removed where information on geography, social media channel, or the relevant link to the post were not available. For the data from the USA, stratified sampling was utilized to draw social media posts relevant to the research objective. For data from other countries, conversations were further screened manually to check if they were relevant to the objectives of this study. The patient conversations were identified by features of the writing style, such as “I have an eye condition called amblyopia”, “I am suffering from amblyopia”, “I don’t see 3D”, etc. The caregiver conversations were identified by kinship terminologies such as “like my bro”, “our son”, “my 4-year-old”, “he was diagnosed with anisometropic amblyopia”, etc.”

The initial dataset consisted of 24,044 posts originating from 12 countries: USA, Japan, Spain, UK, Brazil, France, Canada, Germany, Australia, India, Switzerland, and Italy. Following relevancy check, the data set was filtered to 9388 posts. Among these, approximately 2662 posts were relevant to the study objectives (Fig. 1).

Patient Confidentiality

All data utilized and presented in this study were obtained from publicly accessible sources without accessing password-protected information. All personal identifiers were removed from the downloaded data to anonymize the information. The data were categorized for analysis based on channels, stakeholders, and key themes of discussion. Novartis Social Media Council approval was also obtained for conducting this study.

RESULTS

Channels and Audience

In this study, Twitter® emerged as the most commonly used social media channel, accounting for 65% of all posts, followed by internet forums (22%) and blogs (9%). Posts originating from the USA dominated the conversations (ca. 34% of discussions), followed by those from Japan (ca. 13%). The relevant conversations from each country, which matched the assessment criteria and the number of conversations posted by patients and caregivers, are detailed in Fig. 2.

Of the 2662 posts analyzed, the majority (58%) were from patients with amblyopia (44%) and 14% from their caregivers. The remaining posts were from clinics/hospitals, institutes/research organizations, HCPs, and companies. Popular forums included BabyCenter, Reddit, and HealthUnlocked.

Fig. 1 Search strategy and data breakdown
Patient and Caregiver Demographics

Of the total conversations analyzed, 64% were posted by adults (more than 18 years of age) and 36% were posted by children/teenagers (less than 18 years of age). We divided the relevant conversations captured geographically (Fig. 2) into three groups—USA, Canada, and all geographies beyond USA and Canada. Adult patients (more than 18 years of age) contributed to 40% of the total conversations analyzed (including patients and caregivers). Parents contributed to more than 80% of the conversations driven by caregivers. Of the total number of posts (N = 2662), only 1048 provided information on gender; most were female (61%). From the conversations, where patient type could be identified at diagnosis, the majority (94%) of the patients were diagnosed during childhood (less than 18 years of age) and others (6%) were diagnosed at later stages in life. Patients were classified on the basis of type of amblyopia (such as anisometropic, ametropic, astigmatism, unilateral, and refractive amblyopia) and severity of disease (such as progressive, partial, massive, mild, and second-degree amblyopia) (details provided in supplementary Table S1).

Key Discussion Topics

The key discussion topics were treatment (42.6%), followed by QoL (32%) (Fig. 3).

Patient Journey in Amblyopia

A patient journey diagram for pediatric and adult patients/caregivers was constructed based on the social media conversations collected during the survey period (Fig. 4). For pediatric patients, caregivers played the most important role at different stages of the disease course/journey. Patients presented their symptoms to their ophthalmologists/optometrists, pediatricians, or general physicians. Commonly described symptoms included crossing of eyes, squinting, eyes turning inward or outward, double vision, blurred vision, and poor depth perception. The triggers to arrive at primary touch points were squinting, outward/inward turning of eyes, head tilting, lazy eye when tired, wandering eyes, eye tests at schools, regular family checkups in pediatric patients with worsening of pre-existing ocular conditions, double vision, headache, blurred vision, and eye strain in adults. Pre-diagnosis emotions, such as worry, anxiety, confusion, anticipation, and anger were mentioned in some conversations.
Optometrists and ophthalmologists were the primary point of contact in the majority of cases. If the diagnosis was not confirmed, patients were referred to eye specialists for another opinion. If the diagnosis was confirmed, treatment was initiated with glasses, eye patches, vision exercises or other vision therapies. Eye surgery, as one of the treatment options, was also captured in patients’ responses. However, it is important to note that eye surgery is performed to correct strabismic eyes prior to treating amblyopia in patients who have both conditions. Pediatric patients experienced bullying at schools due to the prescribed treatment options such as eye patching or eyeglasses. Patients generally continued treatment if their condition improved. Most patients visited their HCP every 3–6 months for monitoring. If no improvements were observed, more comfortable/effective treatment options were sought. Adult patients often mentioned the financial burden of prolonged disease treatment/management for many years; access to vision therapies was also a challenge. Once patients accepted their condition, they tried to perform daily activities such as driving, reading, and watching television.

Patients’ and Caregivers’ Perspectives on Treatment Options

Common conventional treatments included eyeglasses, eye patches, eye surgery (prerequisite for patients with strabismus), and contact lenses, as revealed from the conversations captured on social media. Emerging technologies, e.g., digital therapeutics, were also mentioned in some conversations. The overall experience (positive, neutral, or negative) of patients across geographies, as described in social media, regarding available treatments is presented in Table 1.
Eyeglasses
The conversations revealed that eyeglasses were used primarily for management, rather than treatment, of amblyopia. They helped in performing daily activities conveniently and resulted in improved vision when started at an early age. Some patients reported side effects such as headache and dizziness while using eyeglasses; young patients also experienced bullying at school. Patients’ experiences on using eyeglasses were mostly neutral across geographies (Table 1).

Eye Patches
The conversations revealed that eye patches improved vision in many cases, especially in pediatric patients. Patients wore patches while performing eye exercises, gaming, or before undergoing eye surgery due to strabismus correction. Adult patients did not find this treatment option effective and mentioned recurrence of disease after a few years of patching during childhood. The negative sentiment for eye patches was primarily driven by discomfort, headache, double vision, and bullying.

Eye Surgery
The majority of the patients mentioned undergoing multiple eye surgeries for lazy eye — they might refer to the treatment of strabismus rather than the treatment of amblyopia though. Strabismus is a comorbidity frequently associated with amblyopia, which should be corrected before initiating treatment for amblyopia; and
the treatment might be surgical. Caregivers were often scared to opt for eye surgery for their children and resorted to social media platforms to seek guidance on the effectiveness, side effects, and postoperative management.

**Contact Lenses**
Contact lenses were used by teenagers and adults and were effective in improving eyesight and headache relief. However, except in the USA, no positive feedback was captured from other geographies (Table 1). Side effects such as dry eyes, discomfort, double vision, and high cost drove negative sentiments in some cases.

**Vision Exercises**
Adherence to vision exercises improved patients’ condition in many cases, especially in pediatric patients and young adults. Some patients suffered from headaches due to these exercises. Some patients in the USA used social media platforms to spread awareness about the importance of cross and parallel viewing and their experiences with it. Mixed reactions were captured from the conversations of a few patients from Japan, France, Brazil, Australia, Canada, and the UK.

**Pharmacological Treatments**
Among a few available conversations, there were hardly any positive experiences shared by...
the patients on the use of pharmaceutical treatments (Table 1).

**Emerging Technologies: Digital Therapeutics**

Patients with amblyopia have shown improvement in vision (best corrected visual acuity), or stereoacuity, or both using digital therapeutics. These digital therapeutics deliver visual presentation using everyday PCs, tablets, or virtual reality hardware to display software that is, unto itself, a therapeutic medical device. Some adult patients mentioned that they experienced improvements in 3D vision when using a digital therapeutic and expressed their wish to continue therapy for at least 6 months. Patients who do not have access to digital therapeutics often complained about the huge cost, lack of providers, and insurance coverage. Some patients used social media platforms to ask queries about the effectiveness of this therapy.

Digital therapeutic algorithms are often presented as high-end videogames. Some stakeholders used social media platforms to spread awareness about the importance of using digital therapeutics that present amblyopia therapy as games for improving the eyesight in patients with amblyopia.

**Patients’ and Caregivers’ Perspectives on QoL**

A total of 629 social media conversations revealed concerns over the disease and its management options impacting QoL negatively worldwide. Among different aspects of life, functional/societal QoL (ca. 30.0%) had the most negative impact, while the rest were comparable (emotional 23.4%, physical 24.5%, and increased caregiver burden 22.3%) (Table 2). The impact of disease management on QoL was also captured geographically (Table S2).

**Impact on Emotional Well-being**

Patients were angry, annoyed, upset, and pessimistic about their condition. Among the conversations captured on emotional well-being, 38.8% of posts from the USA reported a

| Table 1 | Overall perspectives on different treatment options for amblyopia |
|---------|------------------------------------------------------------------|
|         | USA (n) | Canada (n) | All geographies beyond USA and Canada (n) |
|         | Positive | Neutral | Negative | Positive | Neutral | Negative | Positive | Neutral | Negative |
| Conventional treatments | | | | | | | | | |
| Eyeglasses (N = 335) | 19 | 60 | 15 | 6 | 11 | 1 | 47 | 119 | 57 |
| Eye patches (N = 234) | 17 | 87 | 19 | 3 | 12 | 1 | 24 | 55 | 16 |
| Eye surgery (N = 96) | 10 | 46 | 14 | 3 | 2 | 2 | 2 | 12 | 5 |
| Contact lenses (N = 68) | 11 | 13 | 3 | 0 | 4 | 10 | 0 | 17 | 10 |
| Vision exercises/therapies (N = 74) | 7 | 25 | 5 | 4 | 2 | 2 | 8 | 18 | 3 |
| Pharmacological Tx (N = 9) | 0 | 3 | 0 | 0 | 1 | 0 | 0 | 5 | 0 |
| Digital therapeutics (N = 32) | 11 | 8 | 3 | 0 | 1 | 0 | 6 | 2 | 1 |

N total conversation, n conversations regarding different treatment options, Tx treatment
negative emotional impact due to amblyopia, and 2.7% of posts in Canada and 29.3% of posts in geographies beyond the USA and Canada expressed similar concerns. They had low self-esteem due to issues in physical appearance and felt hopeless about any improvement/recovery. With respect to treatment options, they were angry and annoyed because of thick lenses/eye patches. They were upset and angry about not getting treatment on time at a young age or bullying at school. They felt naive about treatment options during adulthood, worried about the outcomes of eye surgeries, and were self-conscious about wearing glasses in public.

**Impact on Physical Aspects**
As evident from the conversations captured from different social media platforms, amblyopia negatively impacted patients’ physical abilities in various ways: while some patients expressed difficulty in playing sports, others reported difficulty in reading, writing, focusing, and watching 3D movies; and experienced headache, lack of hand–eye coordination, and eye pain due to impaired vision. Among the 154 posts across the globe, 22.1% of posts from the USA reported a negative impact, while only 3.9% of posts in Canada and 51.3% of posts in geographies beyond the USA and Canada expressed similar concerns. Patients also reported bumping into things, teary eyes, discomfort, headache, and double vision due to eye patches; dry eyes, discomfort, and double vision due to contact lenses; headache, and dizziness due to eyeglasses; and double vision due to vision therapies.

**Impact on Functional/Societal Aspects**
Overall, functional/social life (ca. 30%) is the most impacted by amblyopia and its various treatments. Patients in the USA (41.5%) were most affected, while those in Canada (5.3%) and the rest of the world (15.4%) were affected less in terms of functional/social well-being. Patients expressed difficulty in choosing career options, driving, and performing well at the workplace and school as a result of amblyopia. They were treated differently by teachers and co-workers, e.g., they were stared at. Hence, they experienced a lack of confidence and anxiety around friends.

**Burden on Caregivers**
Of 140 posts on the increased burden on caregiver, least concern came from Canada (0.7%), moderate from the USA (15.7%), but the majority came from rest of the world (40.7%). Caregivers were worried about results of eye exams, inheritance of disease in children, and delays in HCP appointments. They felt guilty for not identifying symptoms on time and were terrified about the possibility of permanent vision damage. They were also upset about their children being bullied for their condition.

Regarding treatment options, caregivers were worried about changes in physical appearance due to eye patches, upset about treatment expense, and worried about the outcomes of eye surgeries (that may be required in patients having strabismus as a comorbidity). They struggled to make children adhere to eye patches/glasses. They reported that regular visits for vision therapies impacted them functionally.
Barriers to Treatment

The main barriers to treatment noted from the conversations were insurance issues, long waiting times for HCP appointments, and recurring expenses for treatment across all geographies (Table S3). In addition, they also mentioned that eye surgeries (patients with strabismus) and vision therapies imposed a huge financial burden on patients and caregivers. Vision therapies were not covered by insurance in many cases, and costs are variable across geographies depending upon the number of sessions. From the responses received, we found that the cost is around $2000–10,000 per patient in Canada and $3000 in the USA. Eyeglasses can cost up to ¥60,500 in Japan.

Reasons for Lack of Compliance, Switch, or Discontinuation of Treatment Options

Some of the reasons for lack of compliance, switch, or discontinuation of treatment options identified from the conversations were having no improvement in condition, discomfort with the treatment options, bullying, dissatisfaction with the HCP recommendations, cost of treatment/issues with insurance coverage, side effects, and any other unspecified issues (Table S3).

Reasons for Switching HCPs

Caregivers/patients primarily switched HCPs as a result of referrals provided by pediatricians and ophthalmologists; in some cases, caregivers themselves looked for ophthalmologists’ referrals for confirmation on diagnosis and treatment (Table S3).

Unmet Needs of Patients

The following unmet needs in the disease journey were captured from the conversations: the need for regular eye examinations, better diagnostic tests, and greater awareness regarding disease symptoms to avoid delay in diagnosis. In addition, the need for awareness amongst HCPs regarding treatment options for adults, transparency in communication about the diagnostic procedures and results, better consultation services, and availability of more eye specialists to reduce appointment waiting times were also indicated. As a result of the lack of disease management options for adults and the need for comfortable and affordable options, the need for better coverage policies emerged as the primary concern with respect to treatment.

DISCUSSION

Value of Findings

The results from this study generated important insights from both adult and pediatric patients with amblyopia and their caregivers across the globe on various aspects of the condition. Around 2662 conversations from social media were analyzed. Our analysis revealed that although conventional treatments, including eye patches, glasses, vision exercises, surgery, and contact lenses, continued to be the most popular treatment options, improvement in vision using emerging technologies was also mentioned. Symptoms and treatment options revealed by the posts were consistent with the current literature [10, 19, 20]. The main reasons for switch and lack of compliance to treatment options included worsening of vision, discomfort, bullying, and huge financial burden/insurance issues. Patients mainly switched HCPs as a result of a referral by other HCPs and the need for a second opinion on diagnosis or prescribed treatment.

Unmet Needs in Patients with Amblyopia and Caregivers

Patients and caregivers utilized social media channels to gather information and share their perspectives during all stages of their disease journey, from initial presentation of symptoms to a HCP to management and follow-up. The need for greater awareness regarding the symptoms of amblyopia amongst patients and
caregivers, and treatment options amongst HCPs was highlighted as an important unmet need.

Many studies have observed the lack of public knowledge about amblyopia, more so in rural areas [21–25]. Early detection and timely treatment are key factors that would prevent vision loss due to amblyopia [22, 26]. Regular eye examinations at schools could help in timely diagnosis and treatment initiation [21, 23]. The American Academy of Pediatrics recommends amblyopia screening as a part of regular health checkups, with the use of instrument-based vision screening techniques for preverbal children [27]. In the pediatric population, developing easier diagnostic procedures could improve the rate of diagnosis, as some existing eye tests (such as the Landolt ring chart) are considered complicated. Our study revealed long waiting times for doctor’s appointments, unavailability of eye specialists, and inadequate consultation services as limiting factors. The results suggested the need for greater awareness among HCPs regarding treatment options and encouraged a transparent dialogue with patients and caregivers about diagnostic procedures and results. Clear and effective communication between the HCPs and the patients was also suggested as an important factor affecting treatment adherence [14].

Also, reliable treatment options for amblyopia, especially in adults, are lacking. Conventional treatment options, such as refractive correction and patching, are found to be more beneficial in children and, hence, were not undertaken as treatment by older children and adults [28]. There is no single recommended treatment option for amblyopia, as the treatment approach varies among patients [13]. Therefore, awareness of emerging treatment options, such as vision therapies and virtual reality technologies, and understanding their benefits, could aid in choosing the right treatment option for the patient, which in turn could reduce switching technology, prevent disease recurrence, and reduce the financial and societal burden. Lack of better coverage policies for vision therapies and eye surgeries often limits accessibility to treatment. Increasing the number of vision therapy providers could help patients and caregivers to undergo treatment at nearby locations rather than travelling long distances.

The recommended treatment option also needs to be comfortable for the patients to enhance treatment adherence and improve the QoL of the patients. Often, children who use patches are bullied at school, which has a negative impact on their mental well-being. Preschool vision screening as early as possible could lessen the likelihood of bullying [29]. Evidence supports that patching is associated with peer victimization and some children also reported feelings of stigmatization resulting in negative psychosocial outcomes [30, 31]. Patients also experience emotional and physical impact with increased burden on caregivers; this is supported by the findings from a systematic review [32]. The randomized control trials by the Pediatric Eye Disease Investigator Group demonstrated that following a period of treatment with eyeglasses, 2 h patching combined with 1 h near visual activities modestly improved moderate to severe amblyopia in children aged 3–7 years [33]. The 2 h patching at home is encouraging in terms of emotional well-being as children do not have to wear eye patch to school. Moreover, increasing the daily patching dose to 6 h, after initial 2 h patching treatment, led to more improvement in visual acuity after 10 weeks [34]. However, a recent systematic and network meta-analysis found that the efficacy is comparable for most treatment options such as refractive correction (eyeglasses alone), patching of 2 h per day (patch 2 h), patch 6 h, patch 12 h, patch 2 h + near activities, patch 2 h + distant activities, atropine (Atr) daily, Atr weekly, Atr weekly + plano lens over the sound eye, optical penalization, and binocular therapy [35]. In addition to more efficacious treatment modalities, holistic treatment approaches with support from society (family, friends, caregivers, schools, teachers, etc.), and HCPs may further help in improving treatment compliance, adherence, and optimize treatment outcomes in patients with amblyopia.
Study Limitations and Strengths

Only publicly available information on digital platforms has been accessed and used for this research; all personal identifiers were anonymized in the current study. Obtaining individual formal consent from patients and caregivers to use their data is not feasible, but as social media posts are in the public domain, it is implied that these can be used for research; however, there is some guidance available to protect the privacy of individuals [36]. More clarity is required for conducting research using data available in the public domain [37, 38]. Limited by the design of the study, it was assumed that the information provided by patients on the social media was authentic. The quality of insights gathered from the analysis of digital conversations was dependent on the richness of patient conversations, i.e., the details shared by patients about their health condition, treatment, medication, disease management challenges, QoL, etc. As social media data are unstructured in nature, a relevance check was first performed to ensure suitability and alignment of available information with the objectives of our study before reporting findings. The unstructured nature of the data led to variations in sample size related to each research objective. During the sampling process, the nature of available digital content was found to vary across platforms primarily as a result of format (e.g., Twitter® vs. other internet forums). To overcome this, the most appropriate platform was first determined to derive in-depth consultative insights prior to presenting the results. Local language data were translated using Google translator, which could have accounted for some variations while drawing conclusions, since these were not validated by any language expert.

The literature related to SML studies is very sparse, especially in the field of ophthalmology [17] probably because of the lack of the depth of data collected from public domain [39, 40]. This is one of the first SML studies conducted to understand the unmet needs of pediatric and adult patients with amblyopia and their caregivers. This methodology gathered patients’ perspectives on various aspects of amblyopia, which provided ecological validity to other qualitative findings in the literature. However, the findings from this study should be supplemented with qualitative and quantitative research for any further validations.

CONCLUSIONS

Based on the insights generated from patients with amblyopia and their caregivers, this social media listening study reveals that disease awareness, effective treatment options, affordability, and access to treatment are the areas of concern that require further investigation in order to reduce the disease burden and to improve quality of life of patients with amblyopia. Moreover, this SML study was functional to the identification of key health-related QoL domains which would be further investigated with the creation of a novel QoL questionnaires. Such questionnaires may have the potential to be included in label claims for possible novel treatments in amblyopia (such as software as a medical device).

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Compliance with Ethics Guidelines. All data utilized and presented in this study were obtained from publicly accessible sources without accessing password-protected information. All personal identifiers were removed from the downloaded data to anonymize the information. The data were categorized for analysis based on channels, stakeholders, and key themes of discussion. Novartis Social Media Council approval was also obtained for conducting this study.

Data Availability. Novartis is committed to sharing access to patient-level data and supporting clinical documents from eligible studies with qualified external researchers. The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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