



Patient Perception and Self-Reported Outcomes with Presbyopia-Correcting Intraocular Lenses (PCIOLs): A Social Media Listening Study

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Received: August 23, 2023 / Accepted: October 19, 2023 / Published online: November 10, 2023
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ABSTRACT

Introduction: Presbyopia-correcting intraocular lens (PCIOL) implantation is a popular treatment option for cataract surgery patients who desire spectacle independence. This study aimed to understand patient perception and outcomes with PCIOLs by analyzing patient social media posts.

Methods: This was a non-interventional retrospective study that used predefined search strings to identify publicly available social media data discussing patient perceptions and outcomes with seven PCIOLs (three trifocal, one multifocal with continuous range of vision, and three extended depth-of-focus [EDOF] PCIOLs). Relevant posts were searched from Reddit,

YouTube, and Facebook and patient forums Patient.info, Medicine.net, Optiker-Forum, and Medizin Forum from September 2020 to October 2022 in four languages (English, German, French, and Spanish).

Results: A total of 2237 posts were included, all in English, with 68% of posts identified on Patient.info. The themes most discussed by patients were quality of vision (69% of total posts), patient experience after PCIOL implantation (30%), patient perception before PCIOL implantation (26%), and visual disturbances (24%). Most discussed PCIOLs were Vivity® (58% of total posts), PanOptix® (38%), Synergy® (26%), and Symphony® (13%). Patient perception of PCIOLs was most frequently influenced by healthcare professionals, online reading, and online videos (31%, 18%, and 15% of posts, respectively). A total of 215 posts (10% of total) discussed glasses use after PCIOL surgery: for EDOF and trifocal/multifocal PCIOLs, 37% and 56% of posts discussing glasses use stated being glasses free, respectively. A total of 537 posts discussed visual disturbances: halos/rings (66%) and starbursts (36%) were the most discussed visual disturbances for all lens types. Being glasses free after PCIOL implantation appeared to be a key driver of patient satisfaction.

Conclusion: Social media provides a rich source of information on patient perception, experience, and overall satisfaction of PCIOLs that can be used to complement and guide the collection

Parts of this work were presented at the ASCRS Annual Scientific Meeting which took place in San Diego, California from 5–8 May 2023.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40123-023-00840-8>.

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of further evidence generated through controlled trials.

PLAIN LANGUAGE SUMMARY

Presbyopia is the gradual loss of near vision as part of the natural aging process, which typically becomes evident around 40 years of age. Presbyopia can lower a person's self-esteem, quality of life, work productivity, and social interactions. Presbyopia can be corrected using a variety of treatments, including surgery. Cataract surgery with a presbyopia-correcting intraocular lens (PCIOL) entails replacing a patient's natural lens with a synthetic lens to improve vision. Social media listening is becoming a popular method to understand how diseases and their treatments affect patients firsthand. The thoughts and opinions expressed by patients on social media are believed to reflect spontaneous patient perspectives and can potentially reflect the patient voice in the real-world setting closer than traditional research. In this study, we examined social media posts from patients with presbyopia to understand their perceptions and experiences with PCIOLs. The main topics discussed by patients were thoughts, questions, and concerns before pursuing PCIOL surgery, and patient experiences after PCIOL surgery. Patients described being happy after PCIOL surgery if their unaided vision improved, including their ability to use electronic devices. Patients were less satisfied if they still needed to wear glasses after surgery or if they experienced disturbances in their vision, particularly if it affected daily activities such as nighttime driving. Social media platforms are a rich source of information on patient perception and experience of PCIOLs; this information can be used to complement and guide the collection of further evidence generated through controlled trials.

Keywords: Cataract surgery; EDOF; Multifocal; Patient experience; Patient forum; Presbyopia-correcting intraocular lens; Presbyopia; Refractive surgery; Social media listening; Trifocal

Key Summary Points

Why carry out this study?

Presbyopia is an age-related vision disorder characterized by a progressive inability to focus on near objects, which can be corrected using surgical approaches such as presbyopia intraocular lens (PCIOL) implantation, a popular treatment option for cataract surgery patients who desire spectacle independence.

Studies have shown the benefits and limitations of PCIOLs, but knowledge of patients' real-world perceptions and experiences with PCIOLs is limited.

Social media posts from patients with presbyopia were examined to better understand their real-world perception of and experience with two categories of PCIOLs, namely trifocal/multifocal and extended depth-of-focus (EDOF) PCIOLs. Insights on patient perception pre-PCIOL surgery and experience post-PCIOL surgery were gathered around themes such as quality of vision, visual disturbances, spectacle independence, activities of daily living, complications, comorbidities, and cost-related topics.

What was learned from this study?

Patients with presbyopia (and potentially cataracts) are active on social media: based on the patient posts identified, the observed spectacle independence rate and visual disturbance profiles were generally consistent with the expected lens profile of each PCIOL category (trifocal/multifocal and EDOF PCIOLs).

Patient dissatisfaction following PCIOL implantation was mostly related to needing glasses after surgery and the presence of visual disturbances.

Social media can provide a rich source of information on patient perception, experience, and overall satisfaction of PCIOLs. Patient-reported outcomes identified via social media provide a real-world perspective that can be used to complement and guide the collection of further evidence generated through controlled trials.

INTRODUCTION

Presbyopia is an age-related vision disorder characterized by a progressive inability to focus on near objects, typically becoming clinically evident in individuals 40 years of age or above [1–4]. Presbyopia affects patients worldwide and has a reported prevalence ranging from 43.8% in Japan (in individuals aged ≥ 40 years) to 88.9% in the USA (age ≥ 45 years) [2]. It has been estimated that presbyopia will affect 2.1 billion people globally in 2030 [5]. Uncorrected presbyopia has a substantial impact on patients' quality of life and ability to perform daily activities, such as writing, reading, threading needles, or using electronic devices including computers and mobile phones [2, 6, 7]. Hence, uncorrected presbyopia has been reported to decrease a person's quality of life by 22% compared to those without presbyopia [2, 6], and reduces patients' self-esteem, work productivity, social interactions, and overall psychosocial well-being [2, 7, 8].

Presbyopia mitigation strategies include wearing corrective spectacles or contact lenses; surgical approaches such as scleral expansion, intraocular lens (IOL) implantation, corneal inlays, or laser refractive surgery; pharmacological therapy; and ciliary muscle electrostimulation [1, 4]. Three main types of presbyopia-correcting IOLs (PCIOLs) exist: multifocal IOLs, extended depth-of-focus (EDOF) IOLs (including diffractive and refractive optical design), and accommodative IOLs [9–11]. Multifocal PCIOLs are designed to allow good vision across a fuller range of distances by providing multiple foci at the same time [12]. On the basis of their

focality, multifocal PCIOLs are further classified as either bifocal (two foci) or trifocal (three foci) [13]. A third type of multifocal PCIOL with continuous range of vision has recently become available [14]. Trifocal PCIOLs have been reported to be associated with good visual acuity across near, intermediate, and distance, and a high degree of spectacle independence; however, they can be linked to a greater risk of visual disturbances [3, 12]. EDOF PCIOLs act to elongate a single focal point or place two foci close together (diffractive EDOF) to extend the vision [9, 12, 13]. By increasing depth of field, EDOF PCIOLs aim to reduce the presence of visual disturbances, but often at the expense of losing visual acuity and quality of vision for near [3, 9].

Over 59% (4.76 billion) of the world population uses social media [15]. Specifically for the age ranges more likely to have presbyopia, 73% and 45% of Americans aged 50–64 and over 65 years of age have been reported to use at least one social media site, respectively [16]. Among the public, social media is a popular tool to search and exchange information on health-related topics, exchange social support in online communities, and track and share health statuses or activities [17, 18]. In 2017, 74.4% of the US adult population used the internet first to search for health-related information [19]. Among patients with cancer, 80% of them used social media to connect with peers [18]. Over 62% of patients seeking dental care will be influenced by written experiences shared by other patients on social networking sites and this will help decide their choice of dentist in 50% of cases [20].

Given the dramatic growth in social media use, social media listening (SML) is increasingly being used to gather insights and information on patient experience across a variety of diseases and treatments [21–23]. Over the last few years, different SML studies have been published investigating the patient experience also in ophthalmologic conditions such as dry eye disease, presbyopia, retinal detachment, or amblyopia [24–28], as well as describing ophthalmology information available on social media platforms like Reddit, Instagram, Facebook, Twitter, or LinkedIn [29–32]. Data from

SML exploring patient experience with presbyopia is limited to two publications which evaluated data acquired up to August 2017 [25, 28]. These studies explored how individuals with presbyopia used social media to describe their experiences and confirmed presbyopia has a substantial impact on an individual's daily life; however, these studies did not report on specific patients' perceptions or outcomes by type of PCIOL [25, 28]. As a growing range of PCIOLs become available, it is expected that patients will increasingly use social media to understand and compare the variety of PCIOLs available and complement information provided by their eye care providers, as well as to connect with their peers and exchange questions, concerns, and their experiences following PCIOL implantation [25, 28, 29]. Understanding patient perspectives on PCIOLs may help generate a real-world understanding of patient expectations, outcomes, and satisfaction that is not typically found in traditional research.

This study aimed to understand patient perception and outcomes with multifocal and EDOF PCIOLs by analyzing patient posts obtained from social media platforms and patient forums.

METHODS

Study Design and Search Strategy

This study was a non-interventional, retrospective analysis of publicly available social media data, 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 platforms and key themes of discussion. Information regarding patients' perceptions and outcomes with PCIOLs was collected from social media posts from September 2020 to October 2022 in four languages (English, German, French, and Spanish). Seven PCIOL brands across two lens categories (trifocal/multifocal PCIOLs and EDOF PCIOLs) were covered in the searches. Among the trifocal/multifocal, three were trifocal multifocal PCIOLs including PanOptix®

(Alcon Laboratories, Inc.; Fort Worth, Texas, USA); FineVision® (Bausch Health Companies, Inc.; West Laval, Quebec, Canada); and AT Lisa® (Carl Zeiss Meditec AG; Jena, Germany); and one was a multifocal PCIOL with continuous range of vision (Synergy® [Johnson & Johnson Services, Inc.; New Brunswick, New Jersey, USA]). The three EDOF PCIOLs included Vivity® (Alcon Laboratories, Inc.; Fort Worth, Texas, USA); Symphony® (Johnson & Johnson Services, Inc.; New Brunswick, New Jersey, USA); and AT Lara® (Carl Zeiss Meditec AG; Jena, Germany). Data were collected only from open-access social media sources, including three social media platforms (Reddit, YouTube, and Facebook public patient groups) and four ophthalmology patient forums. Two of the patient forums included posts in English (Patient.info, Medicine.net) and two included posts in German (Optiker-Forum, Medizin Forum). No relevant public patient forums were identified in French or Spanish languages. A predefined search string was used to identify relevant social media posts across all seven platforms. The search string was defined by searching social media sources for indication-related keywords in English. The search string was further refined on the basis of the clinical expertise of Dr. Dagny Zhu, a board-certified ophthalmologist, and specialist in cornea, cataract, and refractive surgery. The resulting search string contained the names of all PCIOLs of interest (and corresponding manufacturing companies) as well as generic terms to identify presbyopia, cataracts, and PCIOLs. Boolean operators (AND, OR) were used to combine all keywords into a single search string. Once the final search string was defined in English, it was translated into German, French, and Spanish (Table S1 in the supplementary material).

Data Collection and Extraction

For all public forums open to data scraping, the Python package Beautiful Soup and social media platform-specific libraries were used to extract data containing at least one of the search keywords with the associated metadata into Microsoft Excel outputs. Data from the

patient forum Patient.info was collected manually and filtered for the search keywords. The extracted data were deduplicated, anonymized, and cleaned before being stored in a Microsoft Excel-based database. A list of predefined keywords categorized into themes (Table S2 in the supplementary material) was searched in the extracted messages. The themes included patient demographics, quality of vision, spectacle independence, visual disturbances, activities of daily living (ADL), patient perception before PCIOL implantation, patient experience after PCIOL implantation, complications/adverse events following PCIOL implantation, comorbidities, and cost. Activities of daily living refer to the basic actions that an individual completes every day for personal care, mobility, and leisure, which are important for living independently [33]. For this analysis, ADL were classified into tasks requiring near vision for those tasks generally performed at a distance of around 40 cm (reading a book/e-book/fine print, using a cell phone, sewing); intermediate vision for tasks performed at a distance of around 60 cm (cooking, seeing a car dashboard, using a computer/monitor); and distance vision (driving, watching television, reading street signs, playing sports, outdoor activities).

Only posts that mentioned the PCIOL brands in scope and contained information on the predefined search themes and corresponding terms were included. Posts were excluded from the analysis if they were not related to presbyopia, did not specifically mention one of the PCIOL brands in scope, contained buy/sell content, or contained animal content.

Data and Sentiment Analysis

A quantitative analysis was performed on the full dataset by capturing the numbers/percentages of posts collected for each theme per PCIOL category (trifocals/mixed multifocal vs EDOF), social media platform/patient forum, and language. A qualitative analysis was performed by reading through each post to gather key insights shared by patients for each theme and PCIOL category. Each post was analyzed by two independent reviewers.

Sentiment analysis was also done manually. All posts were classified according to four types of sentiment: positive, negative, neutral, or mixed. Posts were classified as having either a positive or negative sentiment when there was an overall positive or negative feel throughout the post, respectively. Mixed sentiment posts were those which displayed a mix of positive and negative sentiments. Posts categorized as having a neutral sentiment were those that displayed no obvious sentiment and most often included questions or generic statements. The sentiment was assigned to each post by theme. If a post discussed multiple themes, the sentiment was analyzed individually for each of the themes mentioned in the post. The sentiment analysis was conducted by two independent reviewers, and any conflict in sentiment assignment was resolved by a third reviewer.

Patient Confidentiality

All data included in this study were obtained from publicly available sources without accessing any password-protected information. All personal identifiers were removed from the data to anonymize the information and comply with General Data Protection Regulation.

RESULTS

Post Distribution and Patient Demographics

A total of 2237 social media posts were eligible for inclusion, of which 1127 were written by unique patients. All relevant posts identified were in English. The largest number of relevant posts was identified on the patient forum Patient.info, followed by YouTube, with 1526 and 595 posts, respectively (Fig. 1). No relevant posts were identified on the German patient forums Optiker or Medizin. The PCIOL brands most discussed were Vivity® (1297 posts), PanOptix® (847 posts), Synergy® (585 posts), and Symfony® (295 posts) (Fig. 2). A total of 650 posts (29% of total posts) mentioned more than one PCIOL brand. Sixteen individual

patients reported having different PCIOL brands implanted in each eye and ten individual patients (across 42 posts) discussed having both an EDOF and a trifocal/multifocal PCIOL implanted. The distribution of posts per theme is shown in Fig. 3.

Where possible, patient demographics including sex, age, and country of origin were identified from social media posts as self-reported by patients. The sex of 431 individuals was available for analysis: 38.5% of patients identified themselves as male and 61.5% as female. Patient-reported age ranged from 18 to 82 years old across 434 patients who directly reported their age in social media posts. The most reported age range was 56–65 years old ($n = 98$ patients, 23% of total), and the second most frequent age range was 66–75 years old ($n = 82$ patients, 19% of total) (Fig. S1 in the supplementary material). A total of 103 patients stated their geographical location: 51% ($n = 53$) of patients reported they were based in North America, particularly in the USA ($n = 35$). The second largest patient group was based in Europe (30% of total patients with location data, $n = 31$), with most reporting to be based in the UK ($n = 20$) (Fig. S2 in the supplementary material).

Patient Perception Before PCIOL Implantation

In total 26% ($n = 578$) of analyzed posts discussed patient perception of PCIOLs before lens

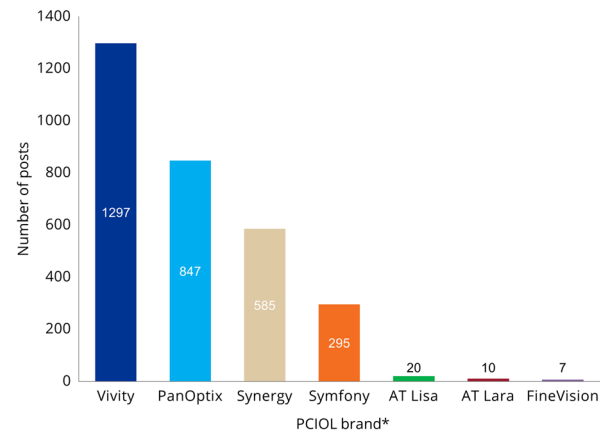


Fig. 2 Total number of social media posts per PCIOL brand. *PCIOL* presbyopia-correcting intraocular lens. *The number of posts per lens may be higher than the total number of posts per platform as a result of some posts citing multiple brands

implantation: of these, 72% ($n = 416$) of posts discussed perception of EDOF PCIOLs and 75% ($n = 436$) discussed trifocal/multifocal PCIOLs. In many incidences, patients discussed their perception of both EDOF and trifocal/multifocal PCIOLs in a single post (274 posts). Patient perception of PCIOLs before surgery was most frequently influenced by healthcare professionals (31% of 578 posts), reading information online (18% of 578 posts), and watching videos online (15% of 578 posts) as shown in Fig. 4.

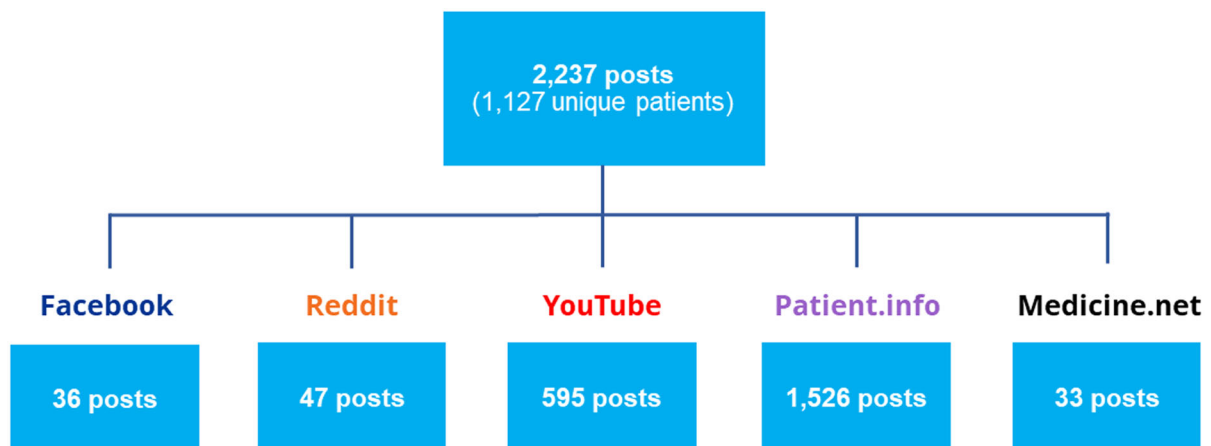


Fig. 1 Post distribution across social media and patient forum platforms

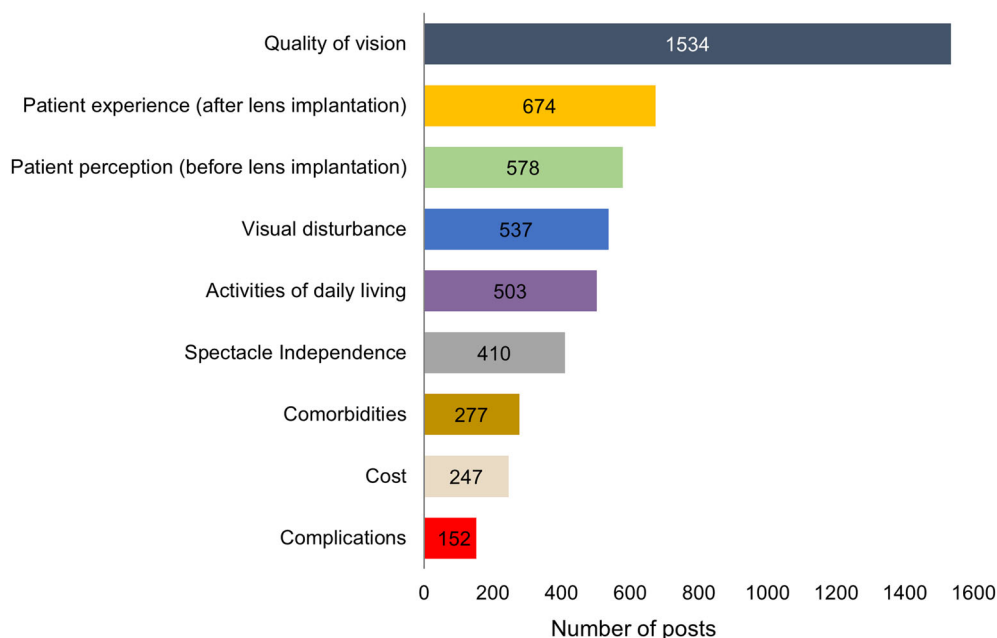


Fig. 3 Number of posts discussing each theme. The sum of the total number of posts across themes will be more than the total number of unique posts ($N = 2237$) as a result of several posts mentioning more than one theme

Patient Experience After PCIOL Implantation

In total 30% ($n = 674$) of total posts discussed patient experience after PCIOL implantation: of these, 53% of posts ($n = 359$) and 54% of posts ($n = 364$) discussed patient experience following EDOF and trifocal/multifocal PCIOL surgery, respectively. Among 359 posts describing patient experience after EDOF PCIOL implantation, 10% of posts described patients having “better” vision/outcomes than before surgery, and 13% of posts explicitly stated that patients were happy/satisfied with their PCIOL. Meanwhile, 8% of posts discussed that patients were unhappy with their EDOF PCIOL, with 5% of posts claiming vision was worse after surgery and 1% of posts highlighting discomfort after implantation. Out of 364 posts discussing patient experience after trifocal/multifocal PCIOL implantation, 7% and 9% of posts described improved patient outcomes after surgery, and that patients were happy with their outcomes, respectively. For trifocal/multifocal PCIOLs, patients explicitly described being unhappy with their post-surgery outcomes in

9% of posts, and 5% of posts described worsening vision after surgery.

Spectacle Independence

A total of 18% ($n = 410$) of analyzed posts discussed the use of glasses either before or after surgery. Among these, 52% ($n = 215$) discussed glasses use after PCIOL surgery: 57% ($n = 122$) and 40% ($n = 87$) of posts discussed glasses use after EDOF and trifocal/multifocal PCIOL surgery, respectively (6 out of the 215 posts were excluded from further analysis as it was unclear whether patients needed glasses or were glasses free after surgery). Of 122 posts discussing glasses use after EDOF PCIOL surgery, 63% and 37% of posts reported needing glasses versus being glasses free, respectively. Among 87 posts discussing glasses use after trifocal/multifocal PCIOL surgery, 44% and 56% of posts reported needing glasses versus being glasses free, respectively (Fig. 5). Eighty-six posts specified the range of vision that needed correction with glasses post-surgery (Fig. 6): among these, 87% of posts described needing glasses for close vision, 8% for intermediate vision, and 5% for

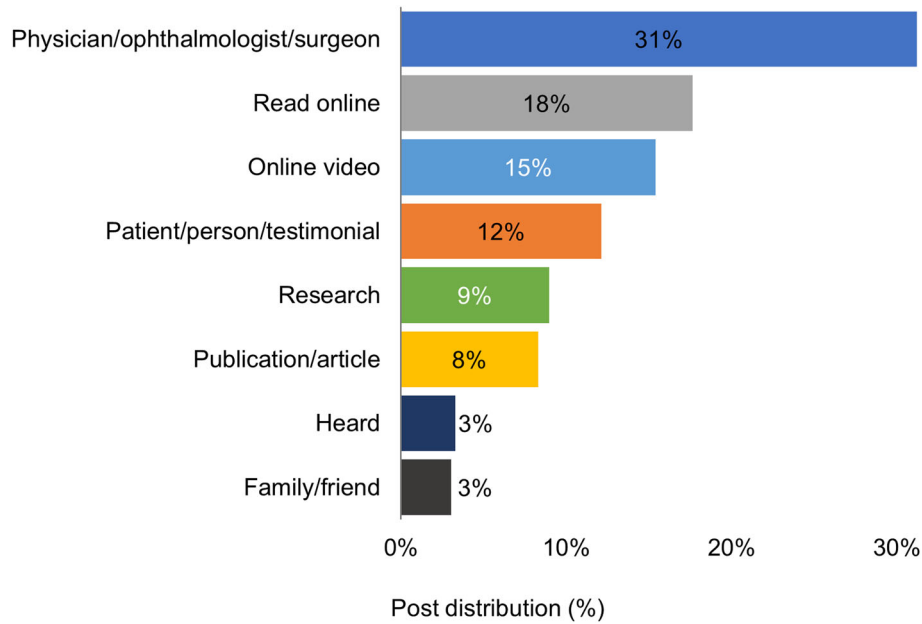


Fig. 4 Distribution of patient information sources before PCIOL surgery. *PCIOL* presbyopia-correcting intraocular lens

distance vision following EDOF PCIOL implantation; whereas 57% described needing glasses for close vision, 22% for intermediate vision, and 22% for distance vision after trifocal/multifocal PCIOL implantation.

Based on the posts identified, patient satisfaction associated with spectacle independence post-surgery appeared to be influenced by patient expectations around the use of glasses before lens implantation. Of 215 posts discussing use of glasses after PCIOL implantation, 19% ($n = 41$) discussed being unhappy with their PCIOLs as a result of glasses still being required for some tasks, or if the use of glasses had increased after surgery. On the contrary, 14% ($n = 31$) of posts that discussed patients needing glasses after PCIOL surgery were of positive or neutral sentiment; these patients reported being happy if they did not have to wear glasses as often/for fewer tasks than before the surgery or were not bothered about needing to still wear glasses. In addition, 10% of posts (41/410) in the overall spectacle independence theme included discussions stating these patients were aware that glasses may still be required after surgery.

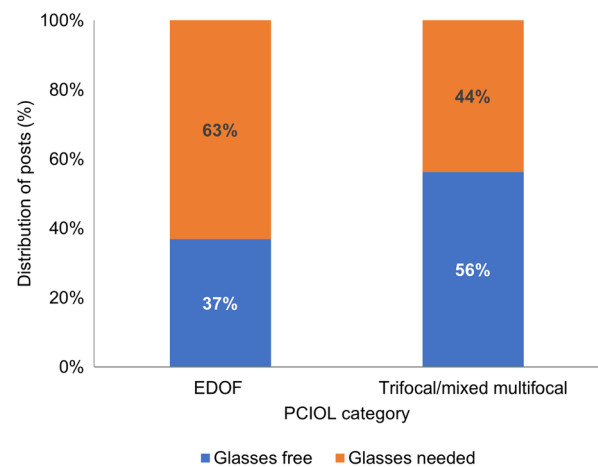


Fig. 5 Distribution of posts discussing glasses use after PCIOL surgery per lens category. *EDOF* extended depth-of-focus; *PCIOL* presbyopia-correcting intraocular lens

Visual Disturbances

In total 24% ($n = 537$) of analyzed posts discussed visual disturbances. The visual disturbances discussed in patient posts were grouped into seven categories, namely halos/"rings", starbursts, glare/"glow", "shadow/ghost", "disturbance", double vision, and floaters. The words captured in quotation marks are not

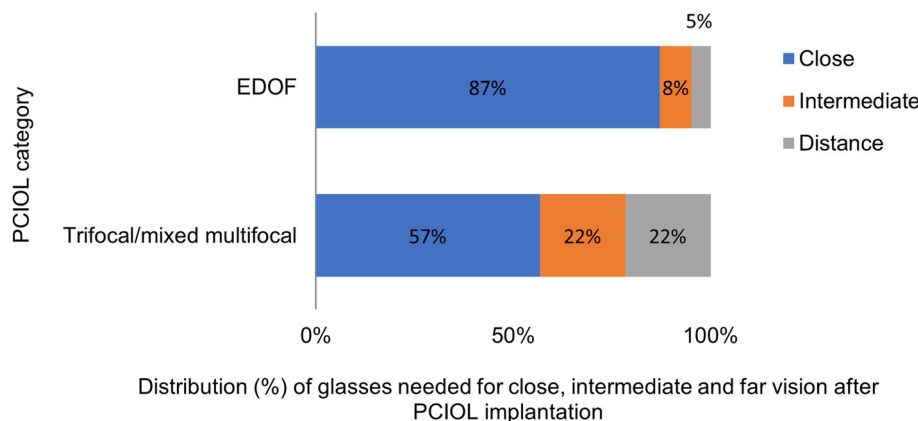


Fig. 6 Distribution of posts discussing the range of vision requiring correction with glasses after PCIOL surgery per lens category. *EDOF* extended depth-of-focus; *PCIOL* presbyopia-correcting intraocular lens. The total number of close, intermediate, and far counts may be greater than

the total number of posts discussing spectacle use as a result of more than one range of vision being identified in a single post

technical visual disturbance terms but were specifically used by some patients in social media posts. Visual disturbances were discussed in 383 posts for trifocal/multifocal PCIOLs (71% of all posts discussing visual disturbances) and 340 posts (63%) for EDOF PCIOLs. Patients often discussed visual disturbances for both EDOF and trifocal/multifocal PCIOLs in a single post (186 posts).

Overall, 50% (268/537) of visual disturbance-related posts discussed the presence of visual disturbances after PCIOL surgery, and the remaining 50% of posts (269/537) discussed patient perception of visual disturbances pre-surgery. Dysphotopsias, which encompassed the terms halos/"rings" (66% of 537 posts describing visual disturbances), starburst (36%), and glare/"glow" (20%), were the most discussed visual disturbances. Halos/"rings" and starbursts were discussed more often for trifocal/multifocal (68% and 45% of 472 posts, respectively) than EDOF (62% and 39% of 378 posts, respectively) PCIOLs. The distribution of posts discussing visual disturbances per type of visual disturbance and PCIOL category is summarized in Fig. 7.

Of the posts which discussed the presence of visual disturbances after PCIOL surgery, 55% (147/268) were of negative sentiment, often seen in patients who had expectations of

minimal visual disturbances following surgery. Similarly, patients expressed strong satisfaction if they experienced no visual disturbances after lens implantation. All posts of patients who reported not experiencing any visual disturbances after PCIOL surgery ($n = 29$) were of positive sentiment. Three posts were identified in which patients reported experiencing mild visual disturbances but who were not bothered by them.

Impact on Activities of Daily Living (ADL)

In total 23% ($n = 503$) of analyzed posts discussed themes related to ADL. Of these, 55% ($n = 279$) of posts discussed ADL after PCIOL implantation, including driving ($n = 101$ posts [36%]), computer/monitor use ($n = 98$ posts [35%]), reading ($n = 89$ posts [32%]), and mobile phone use ($n = 80$ posts [29%]). Among posts discussing ADL, 26% ($n = 132$) specified whether patients saw an improvement, worsening, or no change in the performance of these activities following lens implantation. Compared to before surgery, improvements in the ability to perform near vision or intermediate vision ADL after surgery (43% and 31% of 132 posts, respectively) were reported more commonly than improvements in distance vision ADL (14% of 132 posts). Among posts that

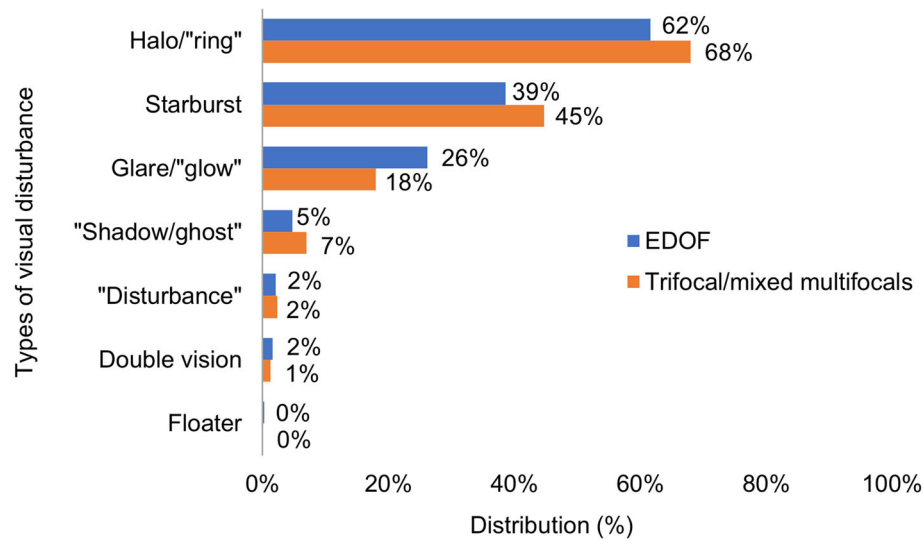


Fig. 7 Distribution of posts discussing visual disturbances per PCIOL category. *EDOF* extended depth-of-focus; *PCIOL* presbyopia-correcting intraocular lens. The words

captured in quotation marks are not technical visual disturbance terms but were described by some patients in social media posts

reported worsening of vision post-surgery and how this impacted ADL, worsening in distance vision was most often reported ($n = 44$, 33% of posts), as opposed to worsening in intermediate ($n = 9$, 7% of posts) or near vision ($n = 13$, 10% of posts) (Fig. 8). Worsening of distance vision post-PCIOL surgery was discussed more regularly in the context of trifocal/multifocal PCIOLs ($n = 28$, 64% of 44 posts) than EDOF PCIOLs ($n = 16$, 36% of 44 posts). Among posts discussing ADL after PCIOL implantation, 22% (60/279 posts) reported a reduced ability to drive at night due to visual disturbances around light sources or difficulty in seeing the car dashboard.

Patient sentiment around ADL appeared to have a similar distribution for trifocal/multifocal PCIOLs and EDOF PCIOLs (data not shown). Sixty-seven of 279 posts (24%) discussing ADL post-PCIOL implantation had a positive sentiment. Of these, 67% (45/67) were from patients showing satisfaction because of improvements in their ability to use electronic devices, such as mobile phones, Kindles, computers, or television.

Quality of Vision

This was the theme most discussed by patients on social media with a total of 1534 posts (69% of total posts). Overall, the posts examined did not report obvious differences regarding quality of vision between EDOF and trifocal/multifocal PCIOLs, and the distribution of post sentiment was also similar between the two lens categories. Of 578 posts discussing patient perception of PCIOLs before implantation, 75 posts (13%) discussed patient concerns about possible changes in vision quality in dim light. Following PCIOL surgery, 43 posts (6%) reported patients being unhappy with their vision in dim light. In addition, 45 posts (7%) discussed reduced contrast sensitivity after PCIOL surgery, particularly at night and in dim light conditions: of these, 30 posts (67%) were associated with EDOF PCIOLs, and 15 posts (33%) with trifocal/multifocal PCIOLs.

Complications/Adverse Events After PCIOL Implantation

This was the least discussed theme: 7% ($n = 152$) of total posts discussed post-surgical complications or adverse events. Among these,

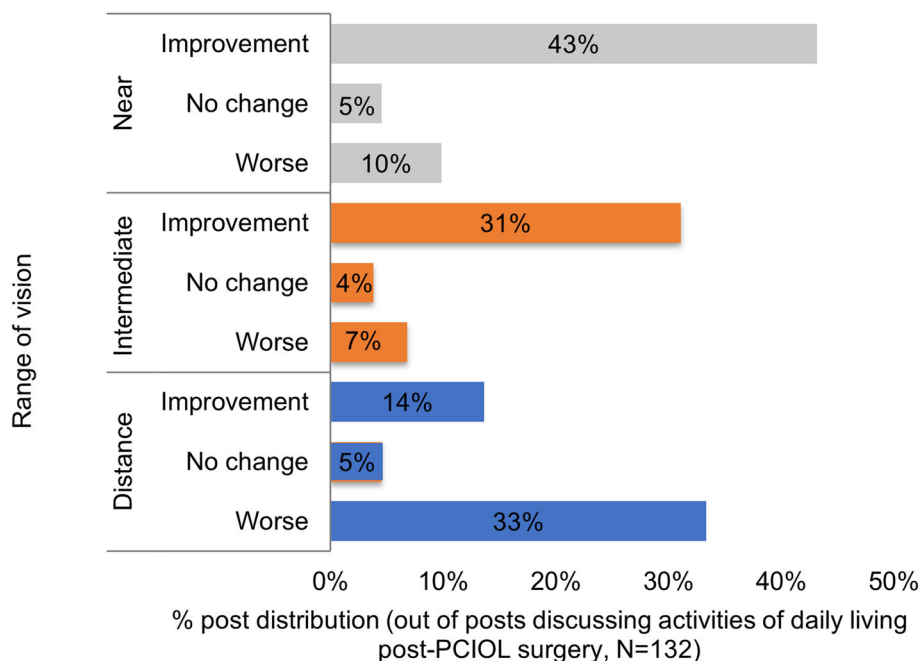


Fig. 8 Distribution of posts indicating improvement, no change, or worsening of near, intermediate or distance vision after PCIOL surgery. *PCIOL* presbyopia-correcting intraocular lens

104 posts (68%) and 66 posts (43%) were in the context of trifocal/multifocal and EDOF PCIOLs, respectively. Some posts discussed post-surgical complications for both lens categories. Most discussions in this theme evolved around additional interventions after PCIOL implantation, namely laser enhancement (38% and 30% of EDOF and trifocal/multifocal PCIOL posts in this theme, respectively); followed by discussions on lens explantation/exchange (27% and 34% of EDOF and trifocal/multifocal PCIOL posts, respectively); and floaters (26% and 14% of EDOF and trifocal/multifocal PCIOL posts, respectively). The distribution of posts discussing complications/adverse events after PCIOL implantation, per PCIOL category is highlighted in Fig. S3 (supplementary materials). Patients appeared to discuss lens explantation or laser vision correction only if they experienced poor vision after PCIOL surgery. Only two posts indicated that patients went ahead with explantation surgery, both of which wanted to exchange trifocal/multifocal PCIOLs.

Comorbidities

In total 12% ($n = 277$) of total posts discussed comorbidity-related themes. Myopia and astigmatism were the most mentioned pre-existing conditions and were discussed in the context of EDOF (91% of 169 posts discussed both comorbidities and EDOF PCIOLs) and trifocal/multifocal PCIOLs (91% of 173 posts discussed both comorbidities and trifocal/multifocal PCIOLs). A small number of patients reported improvement in their astigmatism ($n = 8$) following PCIOL implantation, whereas others reported no change ($n = 4$). No posts reported worsening of pre-existing astigmatism after surgery.

Cost

In total 11% ($n = 247$) of total posts discussed cost-related themes, making it the second least discussed topic. Of these, 13% of posts ($n = 32$) described PCIOLs as “expensive” or having a “premium” price. As a result of the cost, some patients indicated they expected high-quality

vision after PCIOL surgery. Overall, 16% ($n = 40$) of cost-related posts were of negative sentiment if high-quality vision was not achieved after PCIOL implantation. Ten posts (4% of cost-related posts) reported PCIOLs were not worth the money if patients were still required to wear glasses after surgery, whereas three posts were from patients who were willing to make the investment provided they experienced an improvement in vision.

DISCUSSION

This research sought to gather and understand patient perception and outcomes with PCIOLs by analyzing 2237 patient posts obtained from social media platforms and patient forums. The results illustrate that social media is regularly used by patients with presbyopia (and potentially cataracts) to share their questions and concerns surrounding lens choice before pursuing PCIOL surgery, as well as to share their experiences following PCIOL implantation. The data acquired in this study identified insights discussed by patients with presbyopia around key themes such as quality of vision, visual disturbances, spectacle independence, or ADL, among others.

Most relevant posts were identified on the US patient forum Patient.info (68% of total analyzed posts), followed by comments on YouTube videos (27% of total analyzed posts). A limited number of posts were identified on Facebook, Reddit, and the patient forum Medicine.net, with only 5% of total posts identified across these three platforms combined. This suggests that a larger or more active community of patients with presbyopia is present on the patient forum Patient.info. Moreover, among those patients who indicated their country of origin, the USA and the UK appeared to be overrepresented, whereas no relevant posts were identified in any of the other languages evaluated (French, Spanish, or German). These findings suggest there may be cultural differences in expressing opinions online. It is also possible that ophthalmology patient forums may not be as common or used less often outside of the USA and UK, as the 20 health forums reported to

have the most traffic and followers are all in English [34].

Among 434 patients who self-disclosed their age, common age ranges were 56–65 years (23%), followed by 66–75 years (19%). This is consistent with a high prevalence of presbyopia across these age ranges [1–4] and is also the population most likely to undergo cataract surgery for the first time [35]. Interestingly, among patients stating their age, up to 19% of them were between the ages of 36 and 45, and 13% between 26 and 35 years old. This group may include refractive lens exchange patients as well as those patients who developed premature presbyopia, which has been linked to extensive smartphone or computer usage [36]. In addition, this age group may be more active on social media owing to their familiarity and regular use of these platforms [37], and therefore, may be overrepresented in this channel. Furthermore, a small number of patients (5%) were identified to be between 18 and 25 years old. Although individuals of this age are unlikely to experience presbyopia, in some incidences, individuals discussed their perception of PCIOLs based on the lived experience of friends or family members.

The online posts analyzed in this study most often discussed quality of vision, patient experience following PCIOL implantation, patient perception before PCIOL implantation, and visual disturbances. Other commonly discussed topics were ADL and spectacle independence. Patients posting on social media before PCIOL surgery wished to understand potential outcomes post-surgery and how much they should expect their vision to improve. Following PCIOL implantation, patients typically discussed how their vision had changed, if any visual disturbances were present, or what the impact of their new lens was on their ability to perform ADL and/or their need for glasses. A previous SML study on presbyopia focused on the lived experience of individuals with this condition by evaluating their symptoms and the impact of presbyopia on patient quality of life [25]. This study also included 54 posts from patients who discussed surgery, with only five posts reporting IOL use [25]. Our study offers a wider overview of patient perception and

experience before and after PCIOL implantation for two of the PCIOL categories most used, trifocal/multifocal and EDOF PCIOLs [38].

Among the posts identified, no clear differences related to self-reported quality of vision could be drawn for the two PCIOL categories in scope. The observed visual disturbance profiles and spectacle independence rate were consistent with the expected lens profile for each PCIOL category. Regarding visual disturbances, dysphotopsias (including halos/rings, starbursts, and glare) were the predominant visual disturbance reported by patients for both PCIOL categories. The percentage of posts discussing visual disturbances was higher for trifocal/multifocal (71%) versus EDOF (63%) PCIOLs among a total of 537 posts discussing this theme. This is consistent with the expected lens profile for trifocal/multifocal PCIOLs, which may be more prone to dysphotopsias compared with EDOF PCIOLs [3, 9, 12]. Of note, 186 social media posts discussed visual disturbances for both EDOF and trifocal/multifocal PCIOLs in a single post, of which most posts (153/186, 82%) were patient perceptions of visual disturbances pre-surgery. The remaining 33 posts were written by patients with both EDOF and trifocal/multifocal PCIOLs implanted, discussing their experiences of visual disturbances post-surgery.

Regarding spectacle independence after PCIOL implantation, social media posts identified suggested lower spectacle independence across patients with EDOF versus trifocal/multifocal PCIOLs (37% versus 56% of posts discussing glasses use after surgery stated being glasses free, respectively). Lower spectacle independence with EDOF compared to trifocal/multifocal lenses was expected, as a result of previous studies showing statistically better near vision with trifocal lenses compared to EDOF PCIOLs [39, 40]. However, a previous meta-analysis (examining 13 studies and a total of 513 patients) found that spectacle independence rate after trifocal PCIOL surgery was as high as 92% (95% credible interval 86.8–95.9%) [41], a value considerably higher than the number of identified patient posts describing spectacle independence after surgery in this study. It is possible that not all patients documented their spectacle independence after

PCIOL surgery when posting online; in fact, of 674 posts describing patient experience after PCIOL surgery, only 209 (31%) directly stated whether patients required glasses after surgery.

Being glasses free following PCIOL implantation appeared to be a key driver of patient satisfaction; whereas requiring glasses after PCIOL surgery was associated with strong patient dissatisfaction, especially in patients who had expectations of being glasses free post-surgery. The improved ability to use electronic devices and experiencing no visual disturbances following lens implantation also correlated with higher patient satisfaction.

In this study, healthcare professionals were the main source of information influencing patient perception of PCIOLs before surgery, followed closely by online content. These data confirm how the internet and social media are commonly sought after as sources of health-related information among the public [19, 25, 29, 42, 43].

Social media platforms contain a breadth of ophthalmic information that continues to grow rapidly [24–32, 42]. However, to our knowledge, this is the first study to examine the perception of patients with presbyopia and the outcomes of PCIOLs on social media. This study identifies key patient concerns and questions pre-PCIOL surgery, and their first-hand experiences post-surgery. Based on the posts analyzed, patient satisfaction post-surgery appeared highly dependent on outcomes meeting patient expectations. Therefore, managing patient expectations, particularly surrounding spectacle independence and visual disturbances post-surgery, seems key to minimizing patient dissatisfaction.

This study highlights the value of SML for identifying patient-reported perceptions and lived experiences with PCIOLs. The utilization of social media not only provides a new platform for real-world understanding of patient experience and satisfaction but also provides a digital venue for ophthalmologists to engage with patients faster and potentially reach larger audiences than was possible using traditional methods [29]. Furthermore, population health experts have identified that social media could be valuable for improving community

engagement and could be used to enhance patient-centered care [44].

It must be acknowledged that information derived from SML has limitations, as it could be prone to bias, such as demographic bias, keyword bias, and platform bias [45]. In addition, data acquired through SML reflects patients' opinions and thus it is subjective and not acquired in a blinded or controlled manner. Also, those posting comments are probably not representative of all individuals with implanted PCIOLs; patients with negative experiences may be more prone to sharing their opinions on social media than those with positive experiences, which can skew the collected data towards greater negative outcomes and sentiment. Moreover, most social media posts do not report how much time has passed since the surgery; hence, symptoms reported might be temporary and normal within the recovery period. Alternatively, patients who are delighted with the success of their procedure may be more inclined to post their experience than those with mixed outcomes, skewing data towards positive sentiment. There is also a possibility that interested parties may exert pressure on patients to post favorable comments on specific lenses, introducing bias. An additional limitation is that all posts identified were in English, which may add a geographical bias. Plus, individuals aged 55 years and over have been reported as less receptive to using social media for healthcare-related purposes than younger age groups, which highlights an unavoidable age bias [37], inherent to all studies that are focused on presbyopia. Strengths of this study include a large sample size with close to 2300 posts examined across two PCIOL categories. Also, the use of a predefined search string, themes, and keywords provided a comprehensive overview of patients' perceptions and experiences around a variety of topics, which can help inform clinicians on key subjects which seem to be most discussed by patients in relation to PCIOLs.

CONCLUSION

Social media platforms and patient forums are a rich source of information on patient perception and experience of PCIOLs. Being glasses free, experiencing no visual disturbances, and the improved ability to use electronic devices appeared to be the main drivers of patient satisfaction following PCIOL implantation. Managing patient expectations, especially around topics such as spectacle independence and visual disturbances post-surgery, is important to minimize the impact of suboptimal outcomes following PCIOL implantation. Patient opinions and experiences extracted from social media provide real-world insights that can be used to complement and guide the collection of further evidence generated through controlled trials.

ACKNOWLEDGEMENTS

Medical Writing, Editorial, and Other Assistance The authors would like to thank Rachana Patel, Cameron Scott, Filippas Maniatis, and Federico Ghinelli (Valid Insight, Macclesfield, UK) for providing technical support. This assistance was funded by Alcon Vision LLC, Fort Worth, Texas, USA.

Author Contributions. Dagny Zhu, Mukesh Dhariwal, Jun Zhang, and Paula Martin contributed to the study conception and design. Data collection and analysis were performed by Annabel Smith and Paula Martin. All authors contributed to data interpretation. The first draft of the manuscript was co-written by all authors and all authors commented on draft versions of the manuscript. All authors read and approved the final manuscript. All authors agreed to be accountable for all aspects of the work and take responsibility for the integrity of the work as a whole.

Funding. Sponsorship for this study and Rapid Service Fee were funded by Alcon Vision LLC, Fort Worth, Texas, USA.

Data Availability. The data sets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Conflict of Interest. Dr. Dagny Zhu has received consulting fees from Alcon to advise on this research study. Dr. Dagny Zhu has served on advisory boards and received speaking honoraria for Alcon and Johnson & Johnson. Mukesh Dhariwal and Jun Zhang are employees of Alcon Vision LLC. Annabel Smith is an employee at Valid Insight; this company received professional consulting fees from Alcon to conduct the research. Paula Martin was an employee at Valid Insight at the time of writing; Paula Martin is now an employee at Novartis. No authors received financial compensation for their contribution on the manuscript.

Ethical Approval. 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 and comply with General Data Protection Regulation. The data were categorized for analysis based on platforms and key themes of discussion.

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