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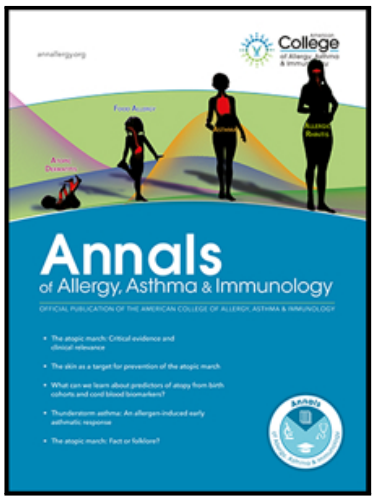

YouTube as a source of (mis)information on allergic rhinitis

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Keywords: YouTube, digital health, patient education, rhinitis, allergy

Abbreviations/Acronyms: None.

Abstract

Background: Allergic rhinitis (AR) is a very common chronic condition that affects nearly one-quarter of the adult population worldwide. The optimal management of AR includes useful information on the several aspects of the condition. Social media and online platforms are increasingly being used to obtain health related information.

Objective: The study aimed to examine and evaluate the popularity and usefulness of YouTube videos on allergic rhinitis.

Methods: Out of 225 screened videos, 86 met the inclusion criteria. A scoring scheme was designed to evaluate and rate the content of the extracted data. Data on views, likes, dislikes, and comments were extracted, and data on source of uploader, duration and content quality were recorded.

Results: 43% of the videos were classified as useful, 36 % as misleading, and 21 % as neither useful nor misleading. Although professional health care providers uploaded two-thirds of the videos, they accounted for only 24.4% of the total videos. Videos uploaded by TV shows and YouTube channels had by far the most user interaction, accounting for 66.9% of the total likes, 66.8 % of the total dislikes, and 54.0 % of the total comments. This source alone accounted for 23.4% of the total views, but for 48% of the total misleading videos.

Conclusion: The usefulness of YouTube videos on allergic rhinitis is varying and less than half of the videos provided useful information. If the proper conditions are met, selected YouTube videos on allergic rhinitis can be used as a source of information for patient education.

Introduction

Allergic rhinitis (AR) affects 25% of the adult population and 40% of children[1], and the prevalence is still increasing[2.] Inflammation of the nasal membranes occurs as a result of allergen exposure, such as pollen or dust, and can cause obstruction of the upper airways. The most common symptoms of AR are sneezing, itchy, red and watery eyes, an itchy, blocked or runny nose, concentration problems and fatigue. Allergic rhinitis is associated with impaired quality of life, reduced productivity at work and an increased risk of developing asthma[3,4]. The treatment of AR consists of both a non-pharmacological approach in which allergens must be avoided and a pharmacological approach aiming to control the symptoms using treatments such as local and systemic antihistamines and steroids[5]. If these treatment options are insufficient or not well-tolerated, the patient might be a candidate for allergen-specific immunotherapy (AIT), which is the only modifiable treatment for AR[6]. Patients often do not turn to healthcare providers, perhaps due to the huge variability in the severity of disease, while others self-medicate with over-the-counter medications, and AR is often left untreated[7]. Thus, there is indeed room for improvement in the management of AR

Patient self-education improves control of the patient's condition and may be associated with less medications to control the disease resulting in less involvement of medical professionals and

hereby less use of resources[8]. Recent studies show self-management education for multiple chronic conditions is insufficiently provided in general practice[9]. This is due to time constraints, logistics, and a lack of resources, all of which can be significant barriers to comprehensive patient education[9, 10]. As a result of inadequate treatment, recent studies show an increase in patients' interest in self-management for their chronic conditions; approximately 76% of internet users go to online platforms and address resources to obtain medical information concerning their chronic condition[11]. One quarter of the internet users have watched a video online about a health or medical problem, indicating that online videos published by both doctors and laymen have been used as educational tools for the treatment and prophylaxis of common chronic conditions in recent years[12].

Since YouTube's inception in 2005, there has been an explosion of videos with a wide range of content, including videos that provide information on health, disease and treatment. The increasing availability of YouTube videos containing information on treatment and procedure for various diseases has piqued the interest among medical professionals[13]. According to studies, 70% of patients with a chronic disease are influenced by information obtained from online sources in the management of their disease. Thus, medical professionals should take into account that their patients most likely will be informed on their chronic condition in the hospital setting.

Further, there is a concern on the liability and usefulness of online videos in terms of educational value. This is due to the structure of YouTube, which is based on global user-generated content,

allowing anyone to share information regardless of the scientific grounds. The original purpose of YouTube was to create a platform for anyone to post and view video content without restrictions. The lack of a peer-reviewed process means that upload of videos is not regulated. Further, the YouTube algorithm also prioritizes videos with a high rate of engagement (views, likes, comments, and dislikes), as such videos uploaded by users with a large number of subscribers are more likely to be displayed to the viewer.

Consequently, the increased number of uploaded videos combined with YouTube's lack of guidelines and strategy to intervene in regulating the content of uploaded material, make it difficult for the user to critically distinguish the information posted on YouTube.

The study aimed to investigate YouTube as a source of information in AR and to assess the usefulness of the videos in patient education.

Methods

Data collection

To include and categorize videos from YouTube for analysis, a selection strategy was conducted. The selection was based on four criteria (1) pre-selected keywords associated with AR, (2) filtered by views, (3) language and (4) relevance.

From June to August 2021, 230 YouTube videos with the terms "Allergic Rhinitis," "Hayfever," and "Allergy" were screened, recoded and analysed in a two-step process. First, time-sensitive data (views, likes, dislikes, and comments) were recorded in a seven-day period. Second, non-time-sensitive data (content categories and usefulness) were recorded. The split of videos was 80 videos with "Allergic Rhinitis," 50 videos with "Hayfever," and 100 videos with "Allergy". The difference in the number of screened videos is due to the varying number of views that the respective terms had.

To avoid individual preferences or recommendations to the specific user, the videos were filtered by views. The number of screened videos was assessed to be adequate because the vast majority of YouTube users do not scroll past the first couple of pages[14]. Also, because no predetermined and generally accepted method of evaluating video content exists, the goal of this study was to resemble methods used in previous articles about YouTube's impact on providing medical information[14].

Videos that were not in English, Swedish, Norwegian, Danish, German, French, or Spanish were excluded from the analysis. The videos had to meet additional requirements, such as (1) being related to AR and (2) being relevant in AR education.

The analyses included 33 videos for ‘Allergic Rhinitis’, 31 for ‘Hayfever’, and 22 for ‘Allergy’.

The 86 videos met the inclusion criteria and were enrolled in the data collection. Following data were obtained for each video: the name and category of uploader, the date of release, the duration, the URL, the language, the date of search, views, likes, dislikes and comments.

Video analyses

The YouTube profile was classified based on characteristics of the main uploader of the video. The uploader was assigned to one of the following groups: 1) specialist (ENT, dermatologists, pulmnologists or allergologists), 2) MD, 3) non-MD healthcare provider, 4) non-medical provider, 5) association, 6) pharmaceutical company, 7) university/hospital or 8) TV-station/YouTube channel. If the video was about a personal case, we registered whether the message was delivered by a celebrity or a layman.

The videos' eligibility and content were determined collaboratively by two authors (CR and HM). Disagreements were settled through consensus among all research participants. The content was classified as (1) *useful:* the video conveys scientifically correct information, (2) *misleading:* the video conveys at least one scientifically unproven detail, or (3) *neither useful nor misleading*: videos that are not misleading but do not provide useful information on epidemiology, symptoms or diagnostics[15]. Thus, we used a prespecified scoring system as an attempt to avoid bias in the evaluation of the videos.

The Cohen's kappa was 0.83 indicating an almost perfect interrater agreement.

Statistics

All variables were visually inspected to determine if they were normally distributed, and if so, handled accordingly in the statistical analyses. When data were not normally distributed, median and interquartile range (IQR) were used. Chi-square test was used to compare proportion between two groups, two-sample t-test and Mann-U-Whitney test was used to compare difference for continuous variables for parametric and non-parametric data, respectively. The statistical software SPSS 28.0 (SPSS Inc., Chicago, IL) was used for the statistical analyses.

Results

The search strategy yielded 229 YouTube videos of which 86 met the inclusion criteria and were included in the analyses (Figure 1).

The 86 videos had 201,457,429 views in total and the median (IQR) number of views was 132,104 (857,167). The median (IQR) likes, dislikes, and comments was 2,048 (7,991), 93 (303), and 181 (1,046), respectively. The median duration was 284 seconds (303) (Table 1).

Only 17.5% of the videos were uploaded by a specialist, MD or a healthcare provider, whereas the uploader of 39.5% of the videos was a TV-show or a YouTube channel. Uploads from universities and governmental institutions comprised only 7% of the videos and both associations

and companies uploaded each 9.3% of the videos, while 17.4% were uploaded by non-healthcare providers (Table 2).

Videos uploaded by universities/hospitals had the highest median (IQR) views: 973,695 (4,478,825), while a single video from a non-MD healthcare provider had the lowest views: 66,676. When we compared all of the median views from different sources with the overall median views, videos published by universities/hospitals had a higher median value (973,695) than the general median views (132,104). Videos uploaded by specialists, non-MD HCPs and HCPs had lower median views than the overall median value of views. Characteristics of the videos are shown in Table 1 and Table 2.

Videos produced by TV shows/YouTube channels received the most user interaction in terms of likes, dislikes, and comments. Videos uploaded by TV shows/YouTube channels received 66.9 % of all the likes, 66.8 % of all the dislikes, and 54.0 % of all the comments. They also accounted for 23.4% of the total views, making TV shows/YouTube channels the second most popular source in terms of views. Videos uploaded from companies received the highest number of views, accounting for 59.9 % of the views and thus being the most viewed source. Even though universities/hospitals received the highest median of views, they only accounted for 6.5% of the total views, 2.0% of the likes, 2.2% of the comments but 12.5% of the dislikes, making it the second most disliked category of sources (Table 3).

Of the 86 included videos, 37 (43%) were classified as useful, 31 (36%) as misleading and 18 (21%) as neither useful nor misleading (Table 4).

When comparing video characteristics by usefulness category, we found that the median views was numerically, but not statistically lower in the misleading group compared with the useful group, 112,327 (IQR=704,921) versus 145,664 (IQR=641,628), respectively. However, the videos in the misleading group had a higher median number of likes compared with the useful videos, 2,197 (IQR=6,292) versus 1,356 (IQR=12,980), respectively, but the difference was not statistically significant (Table 4).

Not only were videos by TV shows/YouTube channels the most common source of uploaders, they also accounted for 48% of all misleading videos. In comparison, professional sources (non-MD, MD, specialists, or hospitals) accounted for only 9.7% of the misleading videos. Only 32% of the videos uploaded by TV shows/YouTube channels were classified as useful. On the contrary, all videos uploaded by associations were categorized as useful. The one video uploaded by a non-MD healthcare provider was also useful, whereas 80% of the videos uploaded by the non-HCP source were classified as misleading (Table 5).

Discussion

To the best of our knowledge, this is the first study for evaluate the usefulness of YouTube videos as a source of information in allergic rhinitis. We found that the vast majority of uploads

came from non-medical sources (TV shows/YouTubers, companies, and non-HCP), but these sources also had a higher number of misleading videos than those uploaded by medical professionals or associations, who primarily uploaded useful videos. The number of total views suggests that YouTube is a highly used source of information, but less than half of the videos were categorized as useful. More than one-third of the videos were classified as misleading. However, misleading content generated a higher user interaction in terms of likes and comments than videos with a useful content. No statistically significant difference was found in the number of views between useful and misleading videos, which might indicate that misleading videos are just as popular as useful videos. This study shows that the popularity does not correlate with the usefulness of the videos, as only around one-third of the videos from the two most popular sources of information were classified as useful. Previous research showed that the heterogeneity of the uploaders varies depending on the disease studied[15-18]. Regardless of the variety in the uploading sources, a main issue is that the viewers may be unable to distinguish between scientifically based information from misinformation. This could be explained by the even popularity of videos with useful and misleading content[19, 20].

Social media has become a part of our everyday life. Platforms like Facebook, Instagram, and YouTube are increasingly supplementing traditional sources of information. Approximately 76% of internet users address online resources to obtain medical information concerning their chronic condition[16]. YouTube, in particular, has grown in popularity as a source of health information[21-22]. The findings of this study add to previous research as the majority of the YouTube videos did not provide accurate information[17, 23-24]. We found that less than half (43%) the videos in this study were classified as useful. The usefulness of YouTube videos seems to vary depending on

the specific disease of interest. A systemic review found that proportion of useful videos varied across of a number of diseases[25]. For rare conditions such as rhabdomyosarcoma and soft-tissue sarcoma, only 16% of the videos were useful, whereas the proportion was increasingly higher in rheumatoid arthritis and urine incontinence, 30% and 45%, respectively[25].

In our study, we found that most of the videos were uploaded by non-professionals sources and less than the half of the videos were useful. These findings are in line with other studies suggesting that the fewer the professional uploading sources, the lower the quality and usefulness of the videos[26-28].

Studies like ours show that the quality of videos on YouTube is limited by the platform's applied structures; missing peer-review system, built-in algorithms and the existence of ads. It has been suggested that non-professional sources often are more popular for people without a medical background because their videos are more patient-friendly than videos from professional sources[26]. This implies that the quality is often secondary to the viewers, resulting in the spread of misinformation[26, 29].

Furthermore, YouTube's algorithms prioritize videos with the highest user interaction, which can lead to a vicious circle in which unpopular videos are not prioritized. As a result, YouTube's algorithms could possibly promote false information[29]. YouTube is aware of the issue; during the COVID-19 pandemic, the online platform chose to delete one million videos that contained misleading information about the COVID-19 and vaccines over the last year. YouTube has stated

that they aim to increase the availability of videos containing reliable information and prevent the spread of misinformation[30]. Since YouTube is a free online video sharing and social media platform, any user can upload videos and in the absence of a peer-reviewed process, there is an increased risk of misinformation.

It is important to note, however, that under the right conditions, YouTube can be a useful source of self-education for patients and health-care providers if the videos are produced with the appropriate amount of information and accuracy. YouTube is a social media sharing platform, but it is now evident that both private and professional sources use the platform to inform, instruct and teach on various subjects. One solution to increase the educational value could be that videos with health-related content undergo a peer-reviewed process or verification process by health care professionals. Another solution could be that videos are provided with a label indicating the source of the uploader, e.g. ("Uploaded by verified health-care professional"). Two-thirds of the professional videos (from specialists, MDs, non-MD HCP, and hospitals/universities) were found to be useful. This suggests that there is still room for improvement in the use of YouTube as an educational tool for health information. Improvement of the educational value of health related videos enables the possibility for including online material in patients self-management of allergic rhinoconjunctivitis.

The study has several limitations. YouTube is a dynamic platform, with content changing daily. As a result, it is a snapshot of the current tendency. Furthermore, videos in English, Danish, Norwegian, Swedish, German, French, and Spanish were screened for inclusion in the study.

Many videos, for example, in Hindi, were excluded. Therefore, we cannot extrapolate our findings to videos in other languages which could give us biased results.

Although all the videos were assessed by two authors and that a high interrater agreement was found, the assessment of the content of the videos was based on the authors' subjectivity. However, we had carefully prespecified the scoring scheme as used in other similar studies[14].

A specific and validated method to evaluate the usefulness of YouTube videos has yet to be developed.

It is assumable that advertisements uploaded by companies play a significant role in the number of views. Companies may have paid for advertisements on other websites that direct viewers to YouTube, resulting in views that reflect both viewers who unconsciously sought self-education (by clicking an ad) and viewers who deliberately searched for information on YouTube. Non-profit specialists and other non-profit health care providers are obviously less eager and have fewer financial resources to gain publicity and popularity than medical companies[31]. It makes no difference if the views are partially paid for if we want to measure actual popularity based on the number of views as a sign of which videos are watched the most. If we use the number of views to determine which type of video is more popular, paid views will distort the picture of which type of video is the most appealing in the eyes of the viewers. As a result, the measure may turn out to be a false popularity measure in this case. Finally, we might have missed videos that could

be hidden under other terms such as ‘runny nose’ and ‘sneezing’, although we used both professional and laymen terms for the disease (i.e. allergic rhinitis and hay fever).

In conclusion, YouTube videos on allergic rhinitis are popular in terms of views, likes and comments. The quality varies and does not correlate with popularity of the video. Associations tend to be the most reliable source of information, whereas TV shows/YouTube channels are responsible for most misleading videos. Non-professionals are more inclined to publish the most popular videos, but they are characterized by providing misleading information with less than half of the videos classified as useful. Non-professional sources, such as TV shows account for more than 80% of total views. Initiatives aiming to highlight useful rather the misleading YouTube videos on allergic rhinitis are warranted.

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Table 1. Basic characteristics of included videos

Video Characteristic	Total	Median	IQR
Views	201,457,429	132,104	857,167
Comment	71,011	181	1,046
Likes	1,119,212	2,048	7,991
Dislikes	29,431	93	303
Duration	8h, 48min, 29sec	284	294
Time from upload [days]		1,342	1,475

Table 2. Video characteristics by source

Source	Frequency n (%)	Views Median (IQR)	Comments Median (IQR)	Likes Median (IQR)	Dislikes Median (IQR)
Specialist	8 (9.2)	120,325 (368,727)	31 (712)	317 (6,047)	31 (208)
MD	6 (6.9)	715,491 (1,046,777)	1,863 (5,483)	12,661 (39,234)	347 (450)
Non-MD HCP	1 (1.1)	66,676	281	1316	52
Non-HCP	15 (17.2)	87,393 (76,475)	152 (404)	1,622 (2,760)	81 (99)
Associations	8 (9.2)	187,195 (639,804)	749 (1,402)	1,266 (14,550)	104 (169)
Company	8 (9.2)	699,191 (17,684,712)	75 (326)	281 (3,756)	18 (179)
University/Hospital	6 (6.9)	973,695 (4,748,825)	61 (405)	5,970 (7,585)	305 (1,623)
TV Show/ YouTube channel	34 (39.5)	153,657 (1,076,434)	235 (1,615)	2,073 (14,140)	104 (916)

The number of videos varies across the four various interaction variables as some videos had disabled the like, dislikes, and comment option.

Table 3. Video characteristics according to usefulness category
Table 4. Interaction indices according to source

Source	Views	Likes	Dislikes	Comments
	N (% of total)	**N (% of total)**	**N (% of total)**	**N (% of total)**
	(min-max)	(min-max)	(min-max)	(min-max)
Specialist	**1,966,839 (0.97)**	**23,393 (2.1)**	**1,016 (3,4)**	**1,757**
	(36,807 – 752,942)	(12 – 16,122)	(6 – 642)	(6 – 1,757)
MD	**3,836,418 (1.9)**	**1,119,212 (10.3)**	**1,704 (5.8)**	**17,709 (25.5)**
	(49,004 – 1,266,354)	2,339 – 42,741	19 – 497	225 – 6387
Non-MD HCP	**66,676 (0.03)**	**1,316 (0.1)**	**59 (0.2)**	**281 (0.4)**
	(66,676 – 66,676)	1,316 – 1,316	59 -59	281 – 281
Non-HCP	**2,763,139 (1.4)**	**165,228 (14.8)**	**2,173 (7.4)**	**5,089 (7.2)**
	(37,492 – 1,516,166)	187 – 138,597	7 – 1007	18 – 2061
Associations	**11,909,492 (5.9)**	**33,933 (3.0)**	**697 (2.4)**	**6,433 (9.1)**
	(47563 – 5,036,641)	503 – 15,140	18 – 211	85 – 1614
Company	**120,668,446 (59.9)**	**8,618 (0.8)**	**429 (1.5)**	**816 (1.1)**
	(32,014 – 93,753,961)	171 – 7,503	13 – 343	18 – 615
University or hospital	**13,125,592 (6.5)**	**22,827 (2.0)**	**3,695 (12.5)**	**1,530 (2.2)**
	48,445 – 6,722,455	201 – 8,765	10-2201	0 – 1258
TV show or YouTube channel	**47,120,827 (23.4)**	**748,556 (66.9)**	**19,658 (66.8)**	**38,396 (54)**
	36,696 – 10,882,094	124 – 340,270	11 – 4,756	12-7606

Video characteristics	Useful n=37 (43%)	Misleading n=31 (36%)	Neither n=18 (21%)	P-value (useful vs. misleading)
Views Median (IQR)	145,664 (641,628)	112,327 (704,921)	145,890 (5,112,826)	NS
Comments Median (IQR)	231 (1,247)	230 (567)	103 (1,146)	NS
Likes Median (IQR)	1,356 (12,980)	2,197 (6,292)	521 (5,846)	NS
Dislikes Median (IQR)	104 (303)	88 (269)	42 (1,188)	NS

Mann-U-Whitney test was used to compare the median of each video characteristic for 'useful' versus 'misleading'. P-value < 0.0.5 was considered statistically significant. The number of videos included in the analyses for 'comment', 'likes', and 'dislikes' were lower than the actual number of videos as some videos had disables these functions.

Table 5. Usefulness category by source

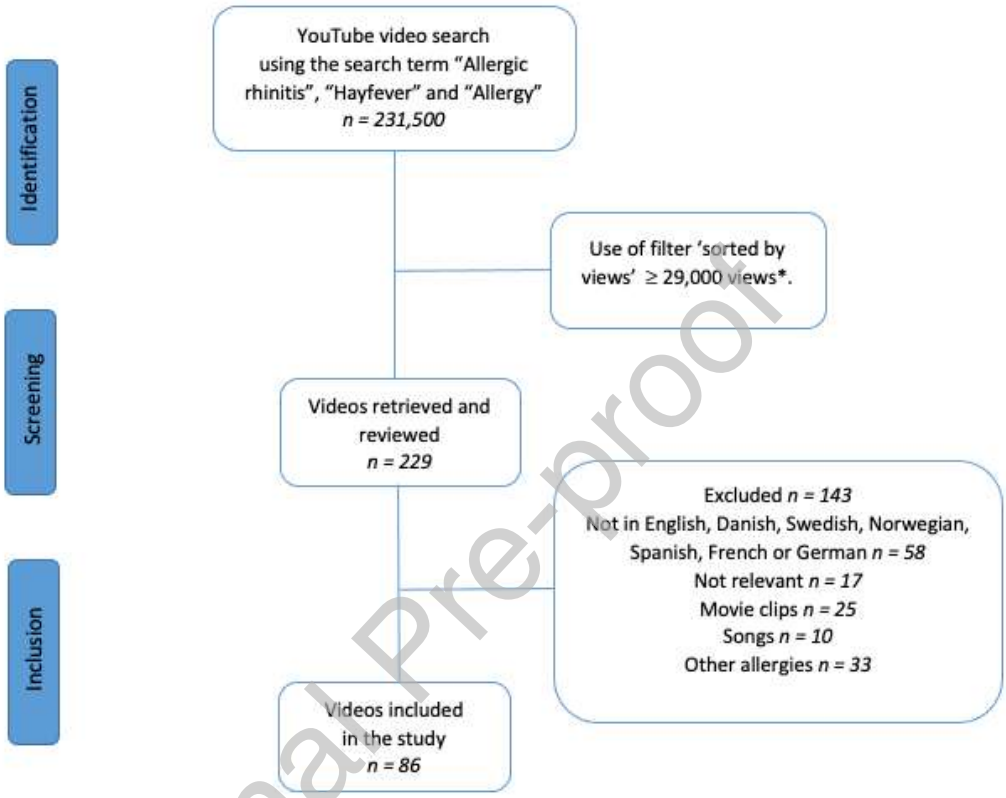
Source	Useful	Misleading	Neither
	n (%*)	n (%*)	n (%*)
Specialist	5 (13.5)	0	3 (16.7)
MD	4 (10.8)	2 (6.5)	0
Non-MD HCP	1 (2.7)	0	0
Non-HCP	1 (2.7)	12 (38.7)	2 (11.1)
Associations	8 (21.6)	0	0
Company	3 (8.1)	1 (3.2)	4 (22.2)
University or hospital	4 (10.8)	1 (3.2)	1 (5.6)
TV show or YouTube channel	11 (29.7)	15 (48.4)	8 (44.4)
Total	**37**	**31**	**18**

* Percentage of the respective source

Table 6. Examples of content classified according to the 3 categories

	Uploading category	Content
Useful		
	Association	Briefly explains pathophysiology in AR correctly informs on saline douching as a treatment option
	Specialist	An animated video that correctly describes the underlying immunological mechanisms and symptoms in AR
Neither		
	Specialist	A video of a nasal endoscopy but without any speak or graphics
	TV show	A clip from BBC featuring a patient with multiple allergies sharing her experiences
Misleading		
	Non-medical provider	Gives specific instructions to make your own natural remedy to get cure your hay fever
	Non-medical	Informs that one can get relief via pressure in certain place in the face and breathing exercises

Figure 1. Flow chart showing video search and selection.



*Based on studies that emphasized that users do not scroll past the first couple of pages on YouTube[14].