The construction of rare disease discourse on YouTube: highlighting a disparity between policy rhetoric and patient practices around public engagement [version 1; peer review: 1 approved with reservations]

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Abstract

Background: Policy rhetoric around the 6,000-8,000 rare diseases affecting 300 million people worldwide often focuses on public engagement. Meanwhile, medical authorities tend either to treat patients with rare diseases as pre-categorised data sources, proffer to them notions of technological self-care as empowerment, or recruit them as advocacy allies. Conversely, people living with rare diseases often mobilise and engage with one another in self-organised communities via social media to share discussion, information, and resources. How rare disease discourse forms on specific social media platforms, the role of different actors (including medical authorities and algorithms), and its relation to public engagement policy are poorly understood.

Methods: This paper examines data on YouTube video watching/sharing (gathered from YouTube's API via DMI's 'Data Tools for YouTube') through social network analysis (read through a controversy analysis lens).

Results: The paper identifies eight patterns – each revolving around different levels of: focus on rare disease content; engagement between content and viewers, i.e. through likes, dislikes, and surrounding particular videos; permeability of videos between categories; and repetition in viewers watching the same video. Across six of the patterns, the paper finds a rare disease issue-network forming, where discourse is constructed through three distinct communication strategies, each garnering a different form of engagement.

Conclusions: Overall, the paper highlights a disconnect between how rare disease discourse is enacted on YouTube and policy promises of public engagement, with potential spaces for dialogue often closed off by medical authorities. To close, the paper provides recommendations for how policymakers might engage with and facilitate more inclusive forms of social media interaction between specific rare disease related
communities and clinicians to develop more meaningful forms of knowledge exchange.

**Keywords**
Controversy analysis, Issue-mapping, Public engagement, Rare disease, Rare disease day, Social network analysis, YouTube
Introduction

Over 300,000,000 people worldwide live with a rare disease (Yáñez-Muñoz, 2017), defined in America, Europe and many other territories as long-term health conditions affecting fewer than 1 in 20,000 citizens (Côté & Keating, 2012; Mikami, 2019). To understand the experiences of patients with rare diseases, medical authorities (i.e. patient organisations, pharmaceutical companies, policymakers, and researchers) have recently turned to patient engagement/empowerment (Bauer, 2017; EMA, 2020; HM Govt, 2020) following a wider turn to inclusive governance (de Saille, 2015a) that ‘actively involve[es] and support[s] patients in health care and treatment decision making activities’ (Grande et al., 2014, p. 281). The benefits of doing so, as the National Health Service (NHS) England (2017, p. 8) note, are that:

[Patients] can bring unique perspectives and insights into its work, perhaps through their lived experience as a patient/carer or as a member of a community with particular health and care needs. They can challenge thinking, [and] help innovate and improve…

In conceptual terms, ‘[a]longside evidence-based medicine (EBM), “patient-centredness” may represent one of the major transformative trends within health care in recent times’ (Gardner, 2017, p. 240) as a non-patriarchal and inclusive approach. However, beyond policy rhetoric and theory, in practice patients are often: (1) pre-categorised as data sources (Hess, 2015), i.e. for real-world evidence in biomedical research where small disease populations render full clinical trials infeasible (Annemans & Makady, 2020) – their input (via observational data) tabulated as data endpoints in patient registries (Wu et al., 2020); and/or (2) they are recruited as allies for mission-orientated advocacy campaigns over pricing (Mazzucato, 2015) and/or faster drug approvals (Chapman et al., 2020). Bringing together various actors into a single entity to claim legitimisation through numbers offers strengthened voice (Rabeharisoa et al., 2014), opening questions over who sits at the centre/periphery of such alliances. When such entities form around rare diseases, they often ‘have stronger opportunities to democratis[e] research than patient organisations for more common conditions’ (Pinto et al., 2018, p. 124) owing to the smaller size of their patient communities. Thus, questions about how public engagement is carried out around rare diseases, and the (un)evenness of social relations they cohere around become paramount. Elsewhere, medical authorities champion digital resources and technological self-care (Petrakaki et al., 2018), effectively deferring engagement responsibilities onto patients themselves under the guise of patient empowerment.

In contrast to policy rhetoric about public engagement and the ensuing practices of medical authorities, people living with rare diseases (patients) often mobilise and interact with one another by participating in social media community support groups (Ainsworth, 2020; Milne & Ni, 2017; Young & Fujimoto, 2021) to share information or misinformation (Chiang, 2020), resources (Mazanderani et al., 2018), and/or to participate in shared discussion (McKee & Richardson, 2021). Here, social media affords inclusion of ‘unruly’ publics typically held outside the purview of medical authority including activists and actors (de Saille, 2015b). It enables patients to collaborate and interact directly with advocates, clinicians, researchers, technologists and many others to co-construct and exchange knowledge via relatively horizontally structured networks – albeit often steeped within an uneven set of relations (Tempini & Del Savio, 2019). How discourse forms around rare diseases on particular social media platforms and the role of different actors in its construction is not well understood – in part due to a scarcity of literature and research on the topic.

This paper draws on social network and controversy analyses to examine data on a selection of YouTube videos relevant to ‘rare disease’ - and those watched immediately before or after. It includes videos users have purposively selected and ones recommended by YouTube’s ‘related videos’ feature. It addresses questions about: (1) what groups form around rare disease related videos on YouTube - and whether there are any discernible patterns; (2) to what extent YouTube’s algorithmic recommendations are formulative of those groups; and (3) what discourses circulate within and between them - and within what sets of relations.

The social media platform specifics of YouTube

Social media communication about health conditions often involves communities forming around influential actors and/or content (Vicari, 2017; Vicari & Cappai, 2016). The affordances of specific social media platforms shape communication within/between those communities (Struck et al., 2018) offering variable data. Twitter offers publicly open and conversational interaction through 280-character limited posts and private messaging (Bruns, 2012; Twitter, 2021). Data on pre-set fields via an application programming interface (API), enables examination of connections between users and hashtags (Giglietto & Lee, 2017). Facebook users can confine posts of up to 63,208 characters (Bossetta, 2018) to a page, group, pre-approved list of friends, or make it publicly open (Facebook, 2021). Meanwhile, tools like CrowdTangle (Shiftman, 2021) interface with Facebook’s API to return various data on those posts. Nuance between different social media platforms’ affordances spawns unique communication etiquettes too. Users are ‘more uncivil and impolite and less deliberative among strangers on Twitter...than on Facebook’ (Oz et al., 2018, p. 3414), raising questions about the specificity of YouTube regarding the types of interaction and data it affords.

As a highly popular video-sharing platform (Covington et al., 2016), YouTube is steeped in cultural participation (Burgess & Green, 2009; Carpennier, 2014; Pires et al., 2021) with users uploading content, sharing others’, and/or simply watching videos. It is often engaged within a medical context for information and/or education about particular health conditions (Struck et al., 2018). However, despite being second only to Facebook in popularity - with 2.3 billion active users worldwide as of January 2021 (Statista, 2021) - there has been little research about how rare disease discourse is generated on
Understanding YouTube’s ‘related videos’ feature and algorithm

When users search/watch YouTube videos, they receive recommendations on what to watch next via the platform’s ‘related videos’ feature - powered by its recommendation system algorithm. The latter offers a ‘codified step-by-step processes implemented by YouTube to afford or restrict visibility’ (Bishop, 2019, p. 2589) of videos to particular users. The structure of this proprietary feature is not publicly documented (Airolidi et al., 2016), however, in its technical development Covington et al. (2016) recall facing several challenges. The size and scale of YouTube’s data rendered some types of algorithms unfeasibly slow. Meanwhile, the speed and frequency of content uploaded to YouTube meant traditional predictive models would be unable to keep pace, posing problems in balancing new and old content. Covington et al. note ‘[h]istorical user behavior on YouTube is inherently difficult to predict due to sparsity and a variety of unobservable external factors’ (2016, p. 191), making it difficult to recommend videos reliably from past user activity alone. Turning to deep learning and Google’s ‘TensorFlow’ library, they adopted an approach whereby ‘algorithms no longer explicitly specify a decision model, but draw on user feedback to inductively generate such a model’ (Rieder et al., 2018, p. 53). Here, the recommendations users encounter as ‘related videos’ on YouTube are iteratively and continually updated based on their own ‘personal activity (watched, favourited, liked videos) as seeds and expanding the set of videos by traversing a co-visititation-based graph of videos’ (Davidson et al., 2010, p. 294). This draws on web browser and/or Google account histories, alongside aggregated viewing histories of other users, i.e., what was watched after a particular video, weighted by number of users (Yang et al., 2017). As such, YouTube’s related videos feature offers users predictive recommendations that mirror their own past choices (personal and collective).

Framework: Issue-mapping, controversy analysis, and YouTube videos as actors

As a theoretical lens, the paper uses Marres & Moats’ (2015) ‘issue-networks’ - borne from controversy analysis. The former involved mapping hyperlinks between climate change websites to examine how different ‘publics engage with debates about technologies...to analyse interactions between the problems and social dynamics shaping [particular] technological controversies’ (Waller & Gugganig, 2021, p. 589). Using social network analysis (SNA), Marres and Rogers mapped ‘networks composed of heterogeneous self[s] of entities (actors, documents, slogans, imagery) that have [been] configured into [a] hyperlink-network around a common problematic’ (2005, pp. 6–7). This involved ‘identifying and tracing the associations between actors involved with an issue, and to render them both in narrative and visual form’ (Rogers et al., 2015, pp. 9–10). Marres & Moats (2015) later suggested this might resolve a balance between science and technology studies’ focus on historical developments of artefacts and media studies’ focus on content and reception, labelling their approach ‘controversy analysis’. Here, they combined: the radically constructivist notion of generalised symmetry in actor-network theory (ANT), which treats all actors (human and non-human) as equal and all claims to knowledge as equally valid (Moats, 2019); and social construction of technology (SCOT) studies’ focus on the positions of different actors in shaping the trajectory of a technologies’ development over time with Marres and Moats (Marres & Moats, 2015). For this paper, the approach has been appropriated to focus on the development of public engagement on a social media platform rather than a specific (material) technology. However, it also examines the role of YouTube’s related videos feature in framing discourse.

In later works, Marres (2015) classified controversy analyses as those that: (1) typify knowledge claims as legitimate or illegitimate (mapping ontologies); (2) uncover discursive ‘relations between substantive arguments and socially and politically located actors...by analyzing which claims and issue terms have support from which actors’ (Marres, 2015, p. 663) to see which groups of actors support one another; or (3) start from a (radically) constructivist position of ‘...making no decisions on the site of study upfront’ (Ibid.). This paper takes a discursive approach, treating YouTube videos, users (channels and subscribers), playlists, hashtags, and comments as actors. Rather than speaking to rare disease debates as a topic that can be reconciled, the paper uses ‘issue-network’ to signify its focus on mapping connections between users and groups and issue(s) constructed through their dialogue. As such, this framework enables the paper to look at which videos are
foregrounded (most viewed/most commented), which actors’ knowledge claims are dominant in each, and how they connect to one another to construct discourse around rare diseases on YouTube.

Methods
Gathering data for social network and applied thematic analyses
The paper discusses data gathered through ‘Data Tools for YouTube’ (DTFY) on 19-May-2021. DTFY is a SQL-based tool developed by the University of Amsterdam’s Digital Methods Initiative which interacts with YouTube’s API (v3.0) through various modules (Reider, 2015a), starting from either a set channel/video or text query. As inclusion criteria, this paper uses DTFY’s ‘video network’ module to gather videos via a text query using ‘rare disease’ as a search term, with no pre-set date range or geolocative parameters. All returned videos have been included in this research. The module ‘creates a network of relations between videos, starting from a search... [and a] network of channels based on the same relations...[by] retrieving ‘related videos’ from the search/list#relatedToVideoId API endpoint’ (Reider, 2015a). It combines two YouTube API elements: (1) the ‘list’ operator (by keyword) retrieves ‘the first 25 search results associated with the keyword... including videos, playlists, and channels’ (Google, 2021). Setting DTFY to the maximum 10 query iterations increases results to the 250 most-viewed videos with ‘rare disease’ in their title; and (2) the ‘relatedToVideoId’ parameter. Setting a crawl depth of 1 returned the 250 most-viewed videos about rare disease (seeds) and any associated with them within one generation by crawling from those seeds. For example, videos recommended by the ‘related videos’ feature, within the same playlist, or frequently watched by users immediately before/after one of the 250 most popular ones. Here, YouTube’s algorithm offers a potential source of bias in as far as the process by which it accounts for videos being within the 25 most watch is not documented. Likewise, the use of an English language search term could potentially limit the scope of the research linguistically and/or geographically. As an overall sample, DTFY returned 7,469 nodes (individual videos with unique URLs posted between 28-Jun-2006 and 19-May-2021), 7,167 of which contain “rare disease” in their title. These represent the most watched videos when users search YouTube for rare disease related content. Within the sample, only 396 are ‘related videos’ recommendations, highlighting that a narrow selection of videos are repeatedly encountered as recommendations by multiple users. As eligibility criteria, all videos returned by DTFY have been included in this research. As an overall sample, DTFY returned 7,469 nodes (individual videos with unique URLs posted between 28-Jun-2006 and 19-May-2021), 7,167 of which contain “rare disease” in their title. These represent the most watched videos when users search YouTube for rare disease related content. Within the sample, only 396 are ‘related videos’ recommendations, highlighting that a narrow selection of videos are repeatedly encountered as recommendations by multiple users.

DTFY returns data in GDF, a file format suitable for SNA. It includes the video title, URL, channel, date of upload, and video category (assigned by channel owners). It also includes a count of comments, dislikes, favourites, likes, and views for each video. The gathered dataset has 72,927 edges, each representing a connection between two nodes, i.e., where a user watches a video immediately before or after another one. These are directed, meaning one video may be recommended to users (or viewed) more often than others. Nodes with more edges are potentially more influential in shaping discourse. Analysing the data in Gephi (0.9.2), an open-source data visualisation software, enables SNA and representation via social graphs (see below) alongside generation of various statistics on the network. In the SNA, each video is a node while clusters are sets of nodes with more connecting edges than the network average.

Examining content and interactions surrounding videos provides useful insights about how/why particular videos circulate within each cluster. Here, the research incorporates applied thematic analysis (ATA), a three-stage process of: (1) qualitatively open-coding data manually; (2) then iteratively amalgamating and whittling down codes to a narrowed set; before (3) arriving at a set of conceptual themes (Guest et al., 2014) aligned with the SNA. As a research design, conducting SNA before ATA enables connections between various subclusters to be established as an exploratory issue-mapping exercise before delving into their narratives and the constitution of rare disease discourse across it.

Ethical considerations
The research presented in this paper received approval from the University of Sheffield research ethics committee (reference: 040659) on 14-Jun-2021. The open access dataset this paper draws on uses pseudonyms to preserve YouTube channels and users (subscribers) with the exception of public figures when acting in public capacity. These alterations have not distorted scientific meaning.

Results
As noted in the methods section above, this paper draws on sample of 7,469 videos (as nodes) posted on YouTube between 28-Jun-2006 and 19-May-2021, gathered using DTFY on 19-May-2021 (Hanchard, 2021). Within this, 7,167 videos contain the term “rare disease” in their title and 396 are ‘related videos’, i.e. algorithmically generated recommendations based videos with “rare disease” in their title having been viewed. There are 72,927 edges connecting the nodes. This section examines the data by using all the nodes and edges returned by DTFY (rather than focussing on any subset). Through modularity it finds that there are 54 clusters, within which it identifies eight distinct patterns in the pre-set categories assigned to YouTube videos at upload (see Figure 1). These are: activist, current affairs, educational, follower, entertainment, infotainment, socially concerned, and specific interest.

The section shows that each pattern comprises a particular level of: focus on rare disease content; engagement between content and viewers, i.e., likes/dislikes and comments surrounding videos; permeability of videos between categories; and repetition in viewers watching the same video. Across six of
Eight patterns of interaction amongst rare disease related video categories

The overall network is tightly knit (Figure 2) with all videos connected through eight neighbours (average path length 7.99) up to a maximum of 26 (network diameter). The average weighted degree of 9.64 also depicts ~9-10 edges per node. In short, rare disease content viewers watch almost twice as many videos than is typical on YouTube – consonant with (Godskesen et al., 2021). Within a 0.76 modularity there are 54 clusters (0 to 53 below) based on video URLs watched together. These range from a giant 843-video cluster to one with 12. Thus, not only do people receive (and watch) recommendations for multiple videos when searching for “rare disease” content, there are similarities (homophily) between the videos they watch. This opens questions about the importance of recommendations and video categories assigned at upload.

Within the 20 most viewed videos, 19 are in the Music category (Figure 2; Table 1); a unsurprising predominance given YouTube’s status as highly popular platform for music video sharing (Airoldi et al., 2016; Allgaier, 2013; Yu & Schroeder, 2018). Whilst this indicates categories are important, Music videos also hold a low average clustering coefficient of 0.32 (1 would indicate all are from the same category, 0 that none are). Likewise, the most and least likely category for videos to be watched together are Autos & Vehicles and Science & Technology, respectively, holding cluster coefficients of 0.25 and 0.50. In short, although Music videos are popular when searching for rare disease content, users often go on to watch videos from other categories. So, although YouTube’s pre-set categories are important, they have limited impact on the 54 clusters’ formation and/or users’ viewing choices. This opens questions about whether there are any patterns in the categories of videos people watch surrounding rare disease, an examination of which (which also attends to crossover between categories) reveals eight distinct patterns:

1. **Activist** clusters (16, 18 and 28) have ~1.5 times the network average videos per cluster, with Nonprofit & Activism categories featuring strongly - often crossed with Education and People & Blogs. They hold divergent
Table 1. The 10 most viewed ‘rare disease’ related YouTube videos.

<table>
<thead>
<tr>
<th>Video label</th>
<th>Channel</th>
<th>Views million</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christina Perri - A Thousand Years [Official Music Video]</td>
<td>Christina Perri</td>
<td>1847</td>
<td>Music</td>
</tr>
<tr>
<td>Lukas Graham - 7 Years [Official Music Video]</td>
<td>Lukas Graham</td>
<td>1133</td>
<td>Music</td>
</tr>
<tr>
<td>Bebe Rexha - Meant to Be (feat. Florida Georgia Line) [Official Music Video]</td>
<td>Bebe Rexha</td>
<td>993</td>
<td>Music</td>
</tr>
<tr>
<td>Rick Astley - Never Gonna Give You Up (Video)</td>
<td>RickAstleyVEVO</td>
<td>946</td>
<td>Music</td>
</tr>
<tr>
<td>Eagles - Hotel California</td>
<td>Chili World</td>
<td>609</td>
<td>Music</td>
</tr>
<tr>
<td>Galantis - No Money (Official Video)</td>
<td>Galantis</td>
<td>590</td>
<td>Music</td>
</tr>
<tr>
<td>James Blunt - You re Beautiful (Video)</td>
<td>James Blunt</td>
<td>546</td>
<td>Music</td>
</tr>
<tr>
<td>Dua Lipa - Be The One [Official Music Video]</td>
<td>Dua Lipa</td>
<td>507</td>
<td>Music</td>
</tr>
<tr>
<td>His Voice Is So Emotional That Even Simon Started To Cry!</td>
<td>Viral Feed</td>
<td>401</td>
<td>Entertainment</td>
</tr>
</tbody>
</table>

Figure 2. Social graph of the full network.
foci too. Cluster 18, for instance, attracted >6.5 million views of just 796 videos surrounding ‘Rare Disease Day’ (of various years), accruing a mean of 72,456 likes, 3,273 dislikes, and 3,216 comments per video. Cluster 16, by contrast, garnered only 201,884 views of 51 videos, centering around the charitable work of public figures. Its high cluster coefficient of 0.66 suggests greater homophily amongst videos watched/recommended. However, it attracted only 55 comments per video (mean average) and >20 times more likes than dislikes, pointing at a relatively shallow level of engagement. Overall, ‘activist’ clusters hold a narrow remit, focussing on videos about famous people and/or educational content, with some category crossover. The latter includes a focus on rare disease slanted towards particular politics. For example, 65 of cluster 28’s videos are from the official ‘National Organization for Rare Disorders (NORD)’ channel (a US-based patient organisation with a strong advocacy focus), holding a mean outdegree of 32.76. Thus, it shows that activism on social media tends to revolve around a ‘committed minority amplifying the group position’ (Recuero et al., 2019, p. 9), marking the pattern as a potential site for advocacy, with clusters 18 and 28 particularly relevant for rare disease.

(2) Current affairs clusters (0, 4, 5, and 9) contain 551 videos focussed on News & Politics and Entertainment categories, with minor crossover into others ranging from Nonprofits & Activism to Science and Technology. Together they received >7 million views with a mean 125,943 likes to 3,100 dislikes per video, with similarly weighted in/out degrees of 6.08 and 6.41 show content to be relatively evenly dispersed between being watched and shared. This suggests a reasonably well-focussed level of engagement, equally notable in the fairly high cluster coefficient of 0.44 and mean 4,257 comments per video, marking the pattern clusters as potential sites for dialogue and exchange. In terms of content, however, the focus sits on news stories and political events worldwide, not rare diseases specifically. Videos on the latter are, instead, interspersed with general health videos alongside personal testimony and/or news on a broad spectrum of topics.

(3) Educational clusters (6, 17, 19, 21, 23, 30, 35, 39, 44, 46, 51, and 53) hone-in on informative and educational content, generating a mean average cluster coefficient of 0.47. The 12 pattern clusters collectively hold only 1,757 videos - yet garner over 3.3 billion views, with the same set of videos watched and recommended repeatedly. This is notable in the high mean of views per video (1,883,985.17 for seeds and 1,985,631.76 or non seeds). Here, no particular videos dominate, with educational clusters collectively holding fairly equal weighted in/out degrees (9.94 and 9.93). In terms of engagement with content, the pattern holds 22,973 mean likes to 1,017 dislikes per video, but fewer than 1,624 comments. This varies between clusters, with a general focus on health providing cluster 17 with almost 2.4 times the comments of cluster 23. Whilst the latter focuses narrowly on rare diseases, it includes 32 videos (>10% of the cluster total) from Belgium-based biopharmaceutical company ‘UCB’. These range from individual researchers’ presentations at Rare Disease Day 2020 to informative clinical studies about how medicines are made. Likewise, cluster 44 is composed entirely of 77 videos on the US ‘Food and Drug Administration’ (FDA) channel, covering general health and rare disease information alike. In addition, particular channels are central to communication flow between educational clusters as influencers (cf. Vicari, 2017). This is pronounced in cluster 30, where a vlog by ‘Chronically Jenni’ with 26 videos (>12% of the cluster total) covers individual chronic health conditions in an educational manner. Overall, the cluster pattern shows that rare disease discourse is not always advocacy-orientated or found only within the most popular clusters.

(4) Entertainment clusters (12, 15, 25, and 27) revolve around YouTube’s Entertainment and Music categories, with Relaxing Sleep Music = Deep Sleeping Music Relaxing Music Stress Relief Meditation Music (Flying) on the ‘Soothing Relaxation’ channel its most watched video (272 million views since 03-Jul-2016). There is crossover between categories, despite the high average cluster coefficient of 0.53. In part, this is due to repeat viewing - where 252 videos have been collectively watched ~7.7 million times. In engagement terms, entertainment pattern clusters garner 53,304 mean likes to 3,516 dislikes per video and 3,823 comments. This suggests people tend not to generate participate in discussion around its videos, watching and occasionally ‘liking’ them instead – as reflected in the high weighted average in-degree than out-degree (9.55 to 9.06). By extension, in cluster 15 ‘EURORDIS’s channel (a major figure in European rare disease advocacy) has a video labelled Rare Diseases: we are 30 million in Europe. Each of us is a real person. Despite receiving 17,259 views since 12-Nov-2012, it has only 4 comments, 82 likes, and 1 dislike - highlighting a very shallow level of engagement. This is typical across entertainment pattern clusters where an average eigenvector centrality of 0.04 depicts only moderate potential for its videos to shape the construction of discourse. Channels within entertainment clusters often blur boundaries with others too when dealing with rare disease related content. ‘Sanofi Genzyme Europe’ (the European wing of a large US-based biotechnology company), for example, posted a video of their awareness-raising flashmob in Amsterdam at the end of Rare Disease Day 2011. Although the video sits within an entertainment cluster, it overlaps with information and infotainment pattern ones through recommendations and viewing choices. Thus, it highlights a fluidity in videos and channels moving between clusters - and with it, permeability between pattern boundaries.

(5) Follower clusters (13 and 22) revolve around influencers and/or public figures, with little crossover to other types; notable in high average cluster coefficients of 0.67 for both clusters. This follows across all 101 videos,
gathering a mean average of 5,346 likes to 91 dislikes per video, and 434 comments. However, when combined with fairly equal weighted in and out degrees (19.25 and 19.94) these figures depict a very shallow level of engagement. The pattern also contains only one video directly related to rare disease - A Trip to DC for RARE Disease Day | RAGE REGARDLESS RY !!! on ‘The Wharton family’ channel (a US-based social media influencer), gathering 94,760 views but only 274 comments. As such, the pattern revolves around people following particularly influential channels, encompassing videos on a myriad of topics, albeit with little or no direct focus on rare disease content.

(6) Infotainment clusters (2, 7, 8, and 10) sit between educational and entertainment patterns in terms of content, with a middling-to-average cluster coefficient of 0.48 and 2.9 million views of 223 videos. Despite the high viewing figures, infotainment videos only gather a mean average of 65,323 likes to 3,544 dislikes and 4,157 comments, meaning repeat viewing features strongly and discussion with others is limited. Likewise, the relatively even average weighted in and out degrees (means 6.06 and 6.33) show no single type of video dominating. Popular videos like Relaxing Jazz Music - Background Chill Out Music - Music For Relax Study Work on the ‘Cafe Music BGM’ channel and NBA RARE Moves Part 1 on ‘Kawhi Not’ respectively gained ~58 million and >16 million views (since 18-Feb-2017 and 30-Oct-2017), highlighting the popularity of Sports and Music videos - and their crossover. As an outlier, cluster 8 holds some rare disease related videos. These, however, tend to be interspersed with general health-related ones, garnering little direct interaction - with almost half on the ‘Autoimmune Hepatitis’ channel, covering a broad range of related concerns. One video (posted 08-Mar-2021), for instance, questioningly titled Is the Johnson & Johnson Vaccine Safe for AIH Patients? gathers only 81 likes, 3 dislikes, and no comments. Similarly, another explanatory expert presentation (posted 19-Aug-2019), asks rhetorically Who Did It? How Did I Catch Autoimmune Hepatitis?, gaining only 2 comments over 1,482 views. Both highlight limited dialogue around infotainment videos.

(7) Socially concerned clusters (1, 3, 26, 31, 32, 38, 41, 45, and 49) had >3.6 million views of 2,281 videos, showing high repeat viewing. Meanwhile, means of 24,564 to 916 dislikes, and 2,787 comments per video, pointed to low engagement further supported by fairly equal yet relatively high average in and out degrees (10.03 and 9.09). Paired with a mildly low average cluster coefficient of 0.39, these figures depict socially concerned clusters as less focussed on video categories than other patterns. Although social concerned clusters had little impact on rare disease discourse, cluster 1 and 26 were outliers. With an average cluster coefficient of 0.28 and thus greater crossover with other categories, cluster 1 covered variable content including 19 videos on the ‘VASCERN ERN Rare Vascular Diseases’ channel and 10 on ‘EveryLife Foundation for Rare Diseases’, making it a hub for rare disease content albeit interspersed with children’s cartoons and music videos. Meanwhile, cluster 26 held content on specific rare diseases, including 32 videos on ‘Sanofi Genzyme’ (a biotech company) with translated counterparts on ‘Sanofi Genzyme Europe’ e.g., Celebrating Pompe disease translated into Ukrainian and Russian. As such, they highlight potential for a subset of clusters within the socially concerned pattern to influence rare disease discourse, even if only to a limited extent. As such, cluster patterns are shown to have variable levels of internal consistency.

(8) Specific interest clusters (11, 14, 20, 24, 29, 33, 34, 36, 37, 40, 42, 43, 47, 48, 50 and 52) focus tightly on particular topics - reflected by a high average cluster coefficient of 0.57. This rises to 0.67 and 0.70 for clusters 29 and 34, which both revolve primarily around a single video category (News & Politics and Science & Technology). Overall, specific interest cluster videos average >6.9 million mean views per video, accruing 106,192 likes to 4,341 dislikes, and 5,517 comments (<20 per video), suggesting shallow engagement. This follows into category crossover and video content too; a limited range of specific interest videos cover rare diseases and tend to be interspersed with general health matters. As outliers, clusters 47, 50, and 52 focus specifically on rare diseases. Cluster 47 has 72 videos centred the Nonprofits & Activism category, with 42 on the ‘EURORDIS’ channel, depicting the cluster as potential locus for rare disease advocacy. Cluster 50 has 134 videos split evenly between Entertainment, People & Blogs, and Science & Technology categories. While 42 of its videos are on the ‘Rare Disease Report’ channel, others are on equally informative channels targeting patients and clinicians, i.e. ‘The Mayo Clinic’ and ‘VJHemOnc - Video Journal of Hematological Oncology’. However, paired with 92 comments per video (mean), the cluster holds only limited potential to influence rare disease discourse. As such, specific interest clusters focus on narrow topic areas, with some holding a higher-than-average number of videos on the channels of medical authorities, industry bodies, or advocacy groups. While the latter often hold a focus on rare diseases, they remain limited as sites of discourse generation.

In summary, rare disease related YouTube videos cluster around pre-set categories in eight patterns. Each pattern revolves around different levels of: (1) focus - on one or more categories (from tight to loose) - measured by averaged cluster coefficients; (2) engagement - with content and discussion, measured as counts of likes/dislikes and comments (from shallow to in-depth); (3) permeability - between video category boundaries and between clusters; and (4) repetition – (high to low) measured as a count of users repeatedly viewing the same videos. Here, YouTube’s ‘related videos’ feature is shown
to have only a limited impact video choice. Instead, specific clusters contribute towards the construction of rare disease discourse in a particular way, raising questions about how different actor engage which other around rare disease content and the role of medical authorities.

Three rare disease audiences constructed through communication strategies

This section examines video content and surrounding comments in rare disease relevant clusters (identified above) to identify a YouTube rare disease issue-network (Figure 3). It finds three communication strategies at play, each aimed at a particular set of audiences and associated with a specific form of engagement (general, insider, and professional).

Videos from rare disease relevant clusters attract comparatively little interaction compared to those elsewhere and are often interspersed with videos from other topics with variable levels of focus. In cluster 18, for instance, the ten most viewed and commented videos (averaging 326 million and 115,457 per video respectively) both primarily comprise Music category ones (Figure 4a and Figure 4b). Meanwhile, the ten least viewed and commented largely comprise rare disease related content, gathering <20 mean views per video - often paired with few comments (six received none).

Despite their overall unpopularity, rare disease videos garner high levels of focus and engagement within some clusters - bound together through particular videos. For example, in cluster 1, the video 'Europe and Rare Disease by Prof Germano acts as a bridging node. It is part of subcluster catering to a ‘professional’ audience of clinicians (Figure 5a). Other videos in the subcluster offer information about dealing medically with specific conditions (i.e., What is aortic root replacement and when is it indicated?) and technical guidance (i.e., Downloading Dicom studies into Desktop). While these three videos are all on the ‘VASCERN ERN – Rare Vascular Diseases’ channel, the same bridging node connects these videos to a

![Figure 3. Social graph filtered to rare disease relevant clusters.](image)
Figure 4a. The ten most viewed videos around rare disease.

Figure 4b. The ten most commented on videos around rare disease.
French-language subcluster (also within cluster 1) with various videos and channels surrounding a Canadian conference about the evolutionary psychology of Bernard de Montréal. It also ties both subclusters to another containing informative videos about various rare diseases, i.e., Marfan Syndrome and Klippel-Trenaunay syndrome. As such, it illustrates a permeability of bridging nodes (videos) in moving between categories to connect different subclusters into a network.

This permeability is not only found within clusters, but across them too. Here, one cluster 18 video on the ‘National Organization for Rare Disorders (NORD)’ channel labelled Living with Cornelia de Lange Syndrome (CdLS) has 12,347 views but only 5 comments. With a betweenness centrality of 232,403 (versus mean averages of 13,648 and 18,815 across all rare disease related clusters) it bridges to various clusters/subclusters. For example, it connects with a specific rare disease related subcluster of informative CdLS-based videos such as Cornelia de Lange Syndrome (CdLS) Awareness Video (on the ‘Cornelia de Lange Syndrome’ channel) and CDLS The Rollercoaster Ride on ‘Andrew Borge’ (channel of former CdLS Foundation UK and Ireland board member and trustee) - both in cluster 18 (Figure 5b). It also ties these to a cluster 28 subcluster aimed at patients and patient groups, such as one covering the 2013 NORD webinar labelled Patient Registries: What They Are and How to Start One and another labelled Advocating For A Rare Disease Advisory Council In Your State (in cluster 28). These connections between subclusters pass via Living with Cornelia de Lange Syndrome where a single video bridges between subclusters across two activist clusters (18 and 28). Thus, bridging node videos connect the issue-network by bringing together various rare-disease related subclusters and clusters.

In terms of discourse, comments surrounding rare disease videos involve three discernible communication strategies. For instance, in cluster 50, one subcluster revolves around amyloidosis (AL), a condition where amyloid proteins build up in the body, causing organs and tissues not to work properly (NHS, 2020). Its videos are informative and aimed towards a general audience with an interest in the disease. However, as is typical of health videos on YouTube (cf. Gardner et al., 2019) it includes persuasive marketing. For example, one video on ‘The Mayo Clinic’ channel labelled Amyloidosis: What
you need to know - Mayo Clinic offers a 4.5-minute video of Dr. Morie Gertz giving a simplified expert explanation of AL; what it is, the main symptoms, effects, and current types of treatment. The video says getting AL diagnosed can be difficult as a patient, before extolling the professional expertise about AL at the Mayo Clinic. Thus, the video markets a commercial service under the guise of providing public information. Comments surrounding the video express variable levels of engagement with its content. At times, one-way feedback and appraisal of the videos’ informational value sit at the fore. For example one users remarks that the video provides a ‘clear introduction to amyloidosis [in] less than 4.5 minutes’ given by an expert with more than 30 years of experience.’ The same video also connects patients by acting as forum for sharing advice and experiences. For example, Bushra K asks: ‘Has anyone found [a] cure for amyloidosis on the skin?’ To which, the following replies ranged from expressions of support and empathy (practices of community-building) to suggestions for a specific medicine to use (information sharing), through to offering a specific clinician’s details (as form of resource sharing):

Franfran7904: Do you have it on your skin? I do. I don’t know anyone else with it. It’s so frustrating and depressing. If you have it maybe we can email and talk about our experiences and compare treatments etc

Wooof: I have on skin from eczema i hope one day its cured so depressing and upsetting

Tracey Uberdown: +Franfran7902 I do. It really is terrible. sigh

juan garcia: Bushra K.. a Proteolytic Enzyme: Which will Consume Amyloid Plaques!!best Brand: Serretia ..

Films Seek: I have same problem on my skin

Aaradhya Paatni: Me too have the same problem on my skin.

Figure 5b. Example of nodes bridging across subclusters.
It’s so irritating😊

*Grace Driver - keow:* That’s so sad to hear you are still suffering from this same situation. Am feeling for you right now, I know of a doctor who can help you get rid of this. He also help me from this same situation, He can also help cure yours permanently.

As their conversation illustrates, the comment-space surrounding YouTube videos provides opportunity for people to share experiences, information, and resources as part of an ‘insider’ communication strategy of patients co-constructing a community around shared knowledges of living with a rare disease.

Rather than the accounts of living a rare disease being isolated to an ‘insider’ strategy, it occurs frequently across other clusters with less interactive audiences too. In the ‘educational’ pattern, for instance, cluster 44 is composed entirely of ‘FDA’ channel videos (*Figure 5c*). One subcluster presents patient testimony of day-to-day life with specific rare diseases, e.g., *Chris Carroll’s Rare Disease Story* of living with type 2D Limb-girdle Muscular Dystrophy (causing limb and muscle deterioration throughout the body) and/or *Nancy Rose Spector’s*...
**Rare Disease Story** of living with Von Hippel Lindau (VHL) syndrome (causing cysts and tumour development in multiple organs). Inline with the FDA's broader strategy of bringing together different actors for better dialogue and engagement (Bauer, 2017), the videos are curated to suit a partisan audience of clinicians, patients, policymakers, and patients. Nancy Rose, for example, describes her personal medical history and lived experience before espousing the importance of advocacy for better access to care and treatment. However, despite an overarching policy rhetoric of public engagement and the FDAs formalised stance of being patient-inclusive (Bauer, 2017), they have adopted a communication strategy aimed towards a ‘general’ audience, composed of various publics rather than seeking to engage with ‘insider audiences’. This is notable where the FDA have disabled comments on their videos, curtailing a potentially fruitful space for dialogue and exchange. Instead, YouTube is treated as a one-way means of outputting information, serving to legitimate the FDA’s authority as arbiter of public knowledge about rare diseases. The same approach is taken up by other medical authorities too, as noted above in the discussion of cluster 1 videos around *What is aortic root replacement and when is it indicated?* and *Downloading Dicom studies into Desktop*. Here, a professional audience of clinicians can watch videos on YouTube but are provided no space for shared discussion; comments are again disabled.

Elsewhere medical authorities are more open. For example, one cluster 23 subcluster hosts informative videos about covering Friedreich’s Ataxia (a progressive rare disease-causing nervous system damage)attracting a generally interested lay audience and/or patients with limited levels of engagement. Meanwhile another connected subcluster caters to a professional audience of clinicians with videos on rehabilitation around rare and non-rare diseases ([Figure 5c](#)), i.e. a Webinar: *Paroxysmal dyskinesias: update on clinical and genetic features* by Giovanna Zorz and Webinar: *Hereditary Spastic Paraplegia (HSP) clinical disease course* by Rebecca Schüle - both on the European Reference Network ‘ERN-RND’ channel. Whilst ‘ERN-RND’ allows comments, its videos have received only one each and no replies. As such, they follow other educational cluster pattern videos in being treated by viewers as one-way information sources rather than sites of exchange despite the platform offering a space for potential dialogue between actors.

**Discussion and conclusion**

There are patterns combining the YouTube categories pre-assigned to videos at upload, that emerge within use (through viewing). Some categories are highly significant, i.e., Music, accounts for over half of all YouTube videos about ‘rare disease’. Rather than standalone categories bearing strongly on rare disease discourse, across 54 modularity clusters they are combined within eight distinct patterns (activist, current affairs, educational, entertainment, follower, infotainment, social, and specific interest) – with six relevant for rare disease discourse. Each pattern is defined by its constituent clusters’ specific levels of: *focus* on rare-disease content in the videos each of their constituent clusters contain; *engagement* they garner from users in terms of likes and comments; *repetition* with which their videos are watched; and *permeability* in videos moving between patterns (as bridging nodes). Within these patterns, YouTube’s ‘related videos’ feature is of limited importance in shaping video choice.

Examining connections between rare disease relevant clusters revealed an issue-network between across the six patterns, with three communications strategies - each steeped in a particular type of engagement: (1) a general one in which rare disease videos are typically watched for entertainment, infotainment, or education alongside other topics, with little engagement between actors or with content; (2) a professional one, with medical authorities targeting clinicians with a narrow set of repeatedly watched videos focussed on technical guidance and advice, offering few spaces for dialogue or exchange – and thus limiting depth of engagement; and (3) an insider one where videos offer personal testimony, information, and education about living with a rare disease - often with underlying marketing or promotion of products/services - aimed at patients, their friends, family members, and carers. Here, viewers generate self-organised communities by sharing discussion, information, and resources in comment spaces around particular videos. Together, the three communication strategies portray an issue-network around YouTube rare disease videos in which actors are afforded few spaces to engage with one another or directly with medical authorities. It is worth noting, however, that a key limitation of the paper is that it relies on an English-language only search term and therefore different patterns may be found when applying the same method to a similar search in other languages.

Together, the three communication strategies portray an issue-network around YouTube rare disease videos in which actors are afforded few spaces to engage with one another or directly with medical authorities. Relating this to policy rhetoric reveals a disparity between medical authorities stated aims around public engagement and their actions on YouTube. Here, potential for collaboration and exchange of knowledges between clinicians, patients, and key organisations - where patient experiences might be collated and discussed - is closed down. Instead, a top-down model is invoked as a means for medical authorities to re-legitimate their own position. Elsewhere, open spaces for dialogue and exchange are not fully exploited, and instead sit latent amidst shallow levels of engagement with video content. As a recommendation, this paper suggests that key institutions could foster more meaningful forms of public engagement around rare disease by identifying and targeting videos/channels that bridge between insider and professional audiences, and by actively engaging with comments and discussion (and opening space for it) around those videos. Here, issue-mapping provides a useful way to identify relevant videos and channels. The paper has shown what patterns to look for and what criteria make videos relevant for rare disease discourse. As such, it contributes an understanding of how
This project contains the following underlying data:

- Orphan Drugs - Dataset 2 - YouTube rare disease issue-network - Nodes - updated.csv

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).

Acknowledgements
Thanks go to my colleagues Dr. Jin Ding and Dr. Eva Hilberg for constructive feedback on the narrative of an early draft, and project Principal Investigator Prof. Paul Martin for constructive feedback/comments and for allowing me time and space to write the paper. Also, to the Gephi community on Facebook for their technical advice, tips, and support.


McKee K, Richardson K: Improving access and awareness of rare disease trials through patient and registries. World Orphan Drug Congress USA, 2021. Reference Source


Reider B: Introducing YouTube Data Tools. 2015a. Reference Source


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Narelle Warren
School of Social Sciences, Faculty of Arts, Monash University, Melbourne, Vic, Australia

Thank you for a very interesting paper, that shifts from a focus on users to focus on the videos themselves as agentic and as the focus of analysis. This shift in lens potentially offers particular insights in terms of discourse construction that are useful for people working directly with patients and also for other social media researchers. In reading the paper, the discourse construction is only a small part of the analysis, with greater attention given to the algorithms and what they reveal. It may perhaps benefit the paper to make these two different goals - and the different types of data generated in achieving them - explicit at the start.

The 'framework' section (p.4) is quite brief, especially given the importance of the approach to the analysis itself, and could be strengthened through outlining more specifically how each of controversy analysis and social network analysis is conceptualised for this paper, and how they fit together for the operationalization of the analysis. I suspect that quite a lot of information relevant to this comment is already provided but is obscured by the logic of the paragraph/section.

Explain what is a crawl depth (p5).

A lot of information is provided on DTFY but little on the qualitative analysis. Please provide more detail on the content and interaction analysis. Were videos analysed for their content? How many videos were subject to this analysis? Can any further information be provided about these? Having this level of detail is important given the focus on discourse construction and the concern with disparities in the information for different users.

Under 'ethical considerations', were any attempts made to seek consent from any video producers? Samuel and Buchannan's 2020 Guest editorial on Ethical Issues in Social Media Research (doi: 10.1177/1556264619901215) may be useful to expand this section, and more fully explore the ethical implications of YouTube-based research.

The network analysis was interesting and includes a lot of detailed data. It may be useful for a
reader - and aid in keeping track of all of the different clusters - to include a table of the different clusters identified and how each of those contributes to the different patterns. The relevance and insights generated by analysing surrounding videos, for example, seem unclear - this may be emphasised in the revisions.

The three engagement categories offer great insights to policy makers and also people working in the broad field of engaging publics. These are elucidated in the discussion, which indicates the value of this research.

References

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Yes

*Competing Interests*: No competing interests were disclosed.

*Reviewer Expertise*: qualitative research, patient communities, patient communication, health sociology, medical anthropology

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 30 Mar 2022

**Matthew Hanchard**, University of Sheffield, Sheffield, UK

Thank you for your comments. I have addressed each below, point-by-point, and have detailed any changes made to the text, which is now far stronger for your input. I have submitted revised version including the changes below.
Reviewer 1 - Point 1
Thank you for a very interesting paper, that shifts from a focus on users to focus on the videos themselves as agentic and as the focus of analysis. This shift in lens potentially offers particular insights in terms of discourse construction that are useful for people working directly with patients and also for other social media researchers. In reading the paper, the discourse construction is only a small part of the analysis, with greater attention given to the algorithms and what they reveal. It may perhaps benefit the paper to make these two different goals - and the different types of data generated in achieving them - explicit at the start.

Response to: Reviewer 1 - Point 1
Likewise, thank you for the kind comments. I have now added a sentence to the end of Introduction section to clarify these as two separate goals. The text reads: “As such, the paper examines both the construction of discourse and the role of an algorithm in shaping it, with more weight given to examining the latter

Reviewer 1 - Point 2
The ‘framework’ section (p.4) is quite brief, especially given the importance of the approach to the analysis itself, and could be strengthened through outlining more specifically how each of controversy analysis and social network analysis is conceptualised for this paper, and how they fit together for the operationalization of the analysis. I suspect that quite a lot of information relevant to this comment is already provided but is obscured by the logic of the paragraph/section.

Response to: Reviewer 1 - Point 2
I have redrafted the Framework section, adding more detail in the second and third paragraphs.

Reviewer 1 - Point 3
Explain what is a crawl depth (p5).

Response to: Reviewer 1 - Point 3
I have now added a sentence to clarify what crawl depth means to t methods section. T reads: “Crawl depth depicts the depth to which search is conducted, and thus provides an incremental set of results. For this query, a crawl depth of 0 returned 50 videos, while a crawl depth of 1 returned 250”

Reviewer 1 - Point 4
A lot of information is provided on DTFY but little on the qualitative analysis. Please provide more detail on the content and interaction analysis. Were videos analysed for their content? How many videos were subject to this analysis? Can any further information be provided about these? Having this level of detail is important given the focus on discourse construction and the concern with disparities in the information for different users.

Response to: Reviewer 1 - Point 4
I have now added further detail on the qualitative research into the Methods section (in the last paragraph).

Reviewer 1 - Point 5
Under 'ethical considerations', were any attempts made to seek consent from any video producers? Samuel and Buchanan's 2020 Guest editorial on Ethical Issues in Social Media Research (doi: 10.1177/1556264619901215) may be useful to expand this section, and more fully explore the ethical implications of YouTube-based research.

Response to: Reviewer 1 - Point 5
I have now included producers within the ethical considerations section. They should have been included in the first version. The suggested paper will also be useful for an upcoming one I am writing based on Twitter data around rare diseases. My thanks to the reviewer.

Reviewer 1 - Point 6
The network analysis was interesting and includes a lot of detailed data. It may be useful for a reader - and aid in keeping track of all of the different clusters - to include a table of the different clusters identified and how each of those contributes to the different patterns. The relevance and insights generated by analysing surrounding videos, for example, seem unclear - this may be emphasised in the revisions.

Response to: Reviewer 1 - Point 6
I have created a table (Table 2) and submitted it as part of the revised paper.

Competing Interests: No competing interests were disclosed.