

RESEARCH

Using a Diabetes Discussion Forum and Wikipedia to Detect the Alignment of Public Interests and the Research Literature

Fereshteh Didegah¹, Zahra Ghaseminik² and Juan Pablo Alperin^{1,3}

¹ Scholarly Communications Lab, CA

² Islamic World Science Citation Center, IR

³ Simon Fraser University, CA

Corresponding author: Juan Pablo Alperin (juan@alperin.ca)

Diabetes is a chronic disease that affects millions of people worldwide. It is therefore unsurprising that there is a high volume of public discussions, resources, and research tackling various aspects of the disease. This study describes a new method for identifying areas of public interest in issues like diabetes and compares them to the topics being discussed in research. We tested our method by using posts from a popular diabetes discussion forum (DiabeticConnect), pages (articles) about diabetes published on Wikipedia, and the titles and abstracts of research articles about diabetes from the Scopus database. Tags assigned to each post in the discussion forum were used along with the post itself to compute a Labeled Latent Dirichlet Allocation (LLDA) model, which was then used to classify the Wikipedia pages and research articles. The resulting classifications were then used to compare the prevalence of the topics found in the discussion forum with that in the other two sources. The results show that the public interest in diabetes is not necessarily addressed by researchers. More importantly, the alignment and misalignment in the changes in relative interest over the various topics are evidence that LLDA modeling can be useful for comparing a public corpus, like a diabetes forum, and an academic one, like research article titles and abstracts. The success of using LLDA to classify research articles based on the tags assigned to posts in a public discussion forum shows that this is a promising method for better understanding how the scientific community responds to public interests and needs.

Keywords: topic modeling; public interests; public understanding of science; diabetes; wikipedia

Introduction

Diabetes is a serious health problem that has nearly doubled in prevalence among adults in the last three decades. In 2012, 3.7 million people died from diabetes or high blood glucose (WHO 2012). As the prevalence of the disease grows, so has the wealth of information that is available about it online; although some clinicians and health care professionals warn about risks of misinformation on the Web and online platforms (Murray et al. 2003), patients are more inclined to search online than to ask their doctors when looking for support and guidance in making health care decisions (Greene et al. 2011).

Of course, not all online sources are the same. Some spaces, like online community forums, have been found to be largely free of misinformation (Balkhi et al. 2014). Such forums have become spaces where diabetes patients share their experiences, seek information, ask for help, and receive support from others who have the same health concerns (Hilliard et al. 2015; Greene et al. 2011; Ravert, Hancock, & Ingersoll 2004). Moreover, research shows that online social ties, such as those that develop when interacting in an online forum, can have a positive impact on improving health and decreasing health-related anxiety among patients with chronic diseases, including diabetes (Hilliard et al. 2015; Balkhi et al. 2014; Sarasohn-Kahn, 2008).

As patients and the general public access information and find value in online discussion forums, we posit that their posts and discussions can also be valuable sources of information to learn what the public is interested in and concerned about. This information may in turn inform a broad community, including patients, practitioners, researchers, civil society organizations, and private firms, in determining policies and taking appropriate actions to improve health outcomes for those affected by diabetes. As such, the present research examines whether it is possible to measure the alignment and misalignment between what people discuss online and what researchers write about by comparing the

text in online discussions and Wikipedia pages about diabetes, as a measure of public interest or concern, with the text of scholarly publications, as a measure of researcher interests. Doing so will shed light on the extent to which researchers are responding to the public's interests and concerns and on the level of uptake of research in the public sphere.

Literature Review

Research alignment with public needs

This work is not the first attempt to use online communities to understand public interest in health issues. Tools like 'Healthmap.org' and 'Google Flu Trends' collect health-related information from different online sources such as news outlets, government newsletters, and web searchers to monitor public health problems (Brownstein & Freifeld 2007). Google has recently started a project, 'Searching for Health', to develop a tool¹ showing how Google searches for health information correlate with actual incidences of diseases. The tool covers information about several highly searched diseases, such as obesity and diabetes. The correlations show a rather strong relationship between Google searches in an area in the US and occurrences of diabetes in the same area. However, issues raised on online platforms have not been compared to the issues researched and published in journals to find out whether or to what extent research addresses issues that are highly searched online. For example, research may ignore socio-economic-political issues raised by online communities and mainly focus on the scientific-technical problems. Poor interactions and communication between the science community and the rest of society may cause scientists to remain uninformed of public demands in specific areas, as pointed out in previous studies (Yegros et al. 2018; Cassi et al. 2017). Hence, public engagement in research projects is widely encouraged, especially for health-related topics (Marris & Rose 2010), including an increased emphasis on involving the public in the research process even before projects start (Boëte 2011).

For public health concerns like obesity, the alignment/misalignment between the research community and societal interests has been explored. Cassi et al. (2017) explored societal demands through the questions received by the European Parliament between 2009–2014 and found that a few topics identified by the public, such as sugar and food economy, are ignored by the scientific community and also that obesity research mainly focuses on biomedical science while largely neglecting socio-economic factors (Cassi et al. 2017). Similarly, misalignments were found between public health issues measured through disease burden rate and the amount of research published on the same issues. For example, depression and stroke were found to be prevalent issues around the world, but there is minimal research published in these areas (Rafols & Yegros 2018). Additionally, no correlation was found between the rate of global diseases and disability burden and the number of medical articles published in MEDLINE that are relevant to those diseases. Moreover, health research publications were not relevant to the health issues in poor countries (Evans, Shim, & Ioannidis 2014).

Another study explored whether pharmaceutical research published by the top 23 pharma companies was associated with a reduction in disease burden rates and found a mismatch between burden of diseases and the amount of relevant research published by the pharma companies (Yegros et al. 2018). Yegros et al. (2018) also found no alignment between pharmaceutical research (with a disproportionate focus on cancerous tumors) and global health trends (where infectious and parasitic diseases are the main causes of deaths worldwide), which may be unsurprising, given that pharma companies are not tasked with addressing global health concerns directly.

Forums and Wikipedia

While comparing research to disease prevalence provides a window into topics of public interest, other sources are needed to capture the public's concerns over time. This study suggests that online discussion forums and Wikipedia are valuable sources that can provide up-to-date information on what topics and issues are more discussed among the public. In the case of diabetes, the increasing number of discussion forums focused on the disease clearly shows the public's interest in discussing their concerns in such online platforms (Hilliard et al. 2015). Similarly, the popularity of Wikipedia, currently the fifth most accessed page on the Web (Alexa 2018), makes it an important place to observe which topics the public consults and contributes when seeking information about a wide range of topics, including health in general and diabetes in particular. Kousha and Thelwall (2017) argue that Wikipedia represents both the public and academic domains considering its coverage, readers, and the scientific references used in creating Wikipedia pages. However, we are not aware of any previous empirical research that examined these platforms as sources of information about public health concerns.

Unlike many social media platforms, forums' functionality allows high levels of engagement and interaction. Forums are usually focused on narrow topics, such as specific health problems and diseases, and participants are mainly those affected, either directly or indirectly, by the concern. On health-related forums, members can ask questions and receive answers from other members, who range from patients or family members of those affected to health practitioners and experts who contribute to the discussion. Patients also often use forums to discuss complementary or alternative medicines that their physicians may be less aware of (Eysenbach 2003).

Online communications through different platforms, including forums, have been debated by physicians due to the increasing rate of misinformation found online (Ahmad et al. 2006) and the potentially hurtful communication that takes place there (Crocco, Villasis-Keever, & Jadad 2002). However, Balkhi et al. (2014) found no signs of misinformation

¹ <http://www.searching-for-health.com>.

on diabetes forums. More than half of parents who had a child suffering from diabetes signed up on the forums to receive/share information, and they believed their participation in the forums helped them to better take care of their children (Balkhi et al. 2014). Some parents used forums for to gain specialized knowledge from experts and researchers (Greene et al. 2011), and patients found forums the most suitable place to express their feelings (Ebrahim 2009).

In a study of forums for youth with diabetes, around 49% of the posts contained requests for information, and another 50% of the posts sought social support, indicating the role of forums as more than sources of information. Other topics, such as medical care, disease management, psychological effects, and, naturally, factual information about diabetes, were also discussed in the forums (Ravert, Hancock, & Ingersoll 2004).

Rolia et al. (2013) suggest that medical forums are also important sources of information for medical experts and healthcare providers, as they provide the opportunity to stay informed of health issues and concerns from a patient's perspective, which in turn allows them to consider patients' perspectives in their practice. This type of use has been especially effective in forums with the ability to allow patients registered in a personal health record portal to access related forums, find the most relevant groups and topics, and browse relevant information (Rolia et al. 2013). While health practitioners in Rolia et al.'s study would personally read forums to understand patient perspectives, our study explores automated ways of gathering the collective concerns of forum members.

In a very different way than forums, Wikipedia is another popular source for health information and is widely used by the general public, health professionals, and researchers alike (Herbert et al. 2015). It is the common starting point for patients to look for their required health information (Thomas, Eng, de Wolff, & Grover 2013), and for good reason: in searches for medical research articles, Wikipedia was ranked highest by Google in searches for both general health and rare diseases (Laurent & Vickers 2009). Although the reliability of Wikipedia has been debated and people are asked to critically read Wikipedia pages about health-related topics (Hasty et al. 2014), Viseur (2014) found the platform comparable with its commercial competitors and also comparable to peer-reviewed platforms for the effectiveness of the peer-production model that allows readers and a community of editors to detect and correct errors quickly. As a result of its wide adoption and its model, Wikipedia plays a synthesizing role, where the public collaborates to summarize what is known about different aspects of diseases like diabetes. Its use as a source of health information is likely to continue, as clinicians continue to recommend that patients contribute to Wikipedia instead of spreading their time and energy across a wider set of tools (Heilman et al. 2011).

Research Questions

Taken together, online discussion forums and Wikipedia capture a significant amount of user-generated content about health topics like diabetes. This study therefore seeks to examine the nature of this content for the purpose of understanding the topics that are of greatest interest to the public and their relationship to the topics most explored by the scientific community. By analyzing the relationships between a diabetes forum, Wikipedia, and research articles, this paper aims to not only uncover the alignment or misalignment on topics but also to understand who is driving discussions about topics: the public or academics. In particular, this study investigates to what extent discussions on the public online forum DiabeticConnect and on Wikipedia align with academic research on diabetes found in the Scopus database. In doing so, it answers the following related questions:

1. To what extent do the topics discussed on the online forum DiabeticConnect align with the diabetes topics most edited on Wikipedia and with research papers about diabetes found in the Scopus database?
2. Are the topics and language of the online forums later found in the research in ways that suggest researchers are tuned in to public interests? Or is it the other way around?

By answering these questions through the use of topic-modeling techniques, this work points to a new class of indicators that have the potential to create a greater understanding of how research circulates and influences the public sphere, so that research agenda and knowledge mobilization strategies can be changed in ways that lead to better health outcomes.

Methods

Three types of data—forum discussions, Wikipedia edits, and research articles—were derived from three sources: the diabetes forum DiabeticConnect,² Wikipedia, and the Scopus database. Data collection from all sources was carried out between July and August 2017.

Forum

DiabeticConnect is a diabetes discussion forum with free membership for everyone with any questions or concerns about diabetes. The forum helps patients connect to other patients and experts and researchers in diabetes and, at the time of data extraction, had collectively 26,845 posts between 2008 and 2016. Each discussion thread is assigned at least one 'tag' by forum moderators to reflect the topics of the discussion. Because these tags are assigned by modera-

² <http://www.diabeticconnect.com/>.

tors and not by the members themselves, they are applied across threads in a relatively consistent manner and provide the basis for understanding the topics discussed in the forum.

After obtaining permission from two moderators via private messages on the forum (on September 2 and November 15, 2016), we extracted all the discussion posts from the forum that included the text of the post, the date it was made, and the tags assigned (no user or other personally identifying information was gathered). We restricted these posts to the 26,845 that were published between 2008 and 2016. We manually scanned the list of tags that were assigned to each post to normalize obvious variants such as ‘type 2 diabetes’, which could also be found as ‘type 2’ and ‘type ii’. We followed this procedure for the 100 most frequent tags to ensure that every instance of each topic was counted when we subsequently selected the 10 most frequently used (**Table 1**).

Wikipedia

Wikipedia is an online encyclopedia that allows readers to collaboratively create and edit pages on any notable topic. By searching for the word stem ‘diabe*’ in the Wikipedia API,³ we identified 693 articles on the English edition of Wikipedia (as allowed by Wikipedia’s Terms of Use⁴). We then filtered out 484 articles that were about celebrities who had died from diabetes using the list found on the Wikipedia page ‘Deaths from Diabetes’ (Wikipedia July 2017). We subsequently queried the remaining 207 articles in the Wikipedia API for the content of the page along with the edit history, including the numbers of deletions and additions and the total number of edits made to the page. In total, the 207 pages were edited 23,627 times, with an average of 17.42 edits per page per year (median: 8; sd: 25.07) and 16.95 edits per page over the 9 years studied (median: 8; sd: 24.64).

Scopus

Scopus is the largest abstract-indexing database in the world, with over 69 million records from more than 36,377 journals. Using a copy of the Scopus data available at the Centre for Science and Technology Studies (CWTS), we identified 108,180 articles from Scopus by searching the online portal for articles with the word stem ‘diabe*’ in their title, abstract, and author-supplied keywords with a published date between 2008 and 2016. The title, abstract, and published date were retrieved for each article. Titles were on average 13.27 words (median: 13; sd: 5.39), and abstracts on average 203.43 words (median: 205; sd: 74.96).

Topic-Modeling Procedure

Because our primary interest was to understand the public’s concerns about diabetes, we used the forum discussions as the basis for understanding the topics that the public is interested in. Using the tags as labels and the text of the discussion posts as the content, we computed a Labeled Latent Dirichlet Allocation (LLDA) model (Ramage, Hall, Nallapati, & Manning 2009). Topic models are a type of text-mining tool that uses word frequencies and co-occurrences (when two words are found in the same document) to produce clusters of words that have a high probability of being found together within given corpora (i.e., a set of documents). Unlike their unlabeled counterparts (Latent Dirichlet Allocation, LDA) that begin with a set of words and produce an unspecified number of word clusters (without labels), LLDA models begin by grouping documents into a fixed set of clusters (one for each label) and then produce a set of words most likely to be associated with each. In both types of models, each word is also assigned a weight relative to that word’s contribution to the cluster. While an LDA model would be appropriate for uncovering latent topics found in the

Table 1: Most common tags on DiabeticConnect forum.

Tag	No. of discussions	%discussions
Type 2	7178	26.74
Emotional support	3165	11.79
Diet	2808	10.46
Type 1	2585	9.63
Diagnosis	1627	6.06
Treatment	1447	5.39
Weight loss/Obesity	1348	5.02
Medication	1291	4.81
Control	1071	3.99
Blood sugar	808	3.01

³ <https://en.wikipedia.org/w/api.php>.

⁴ https://foundation.wikimedia.org/wiki/Terms_of_Use/en.

discussion posts, an LLDA model is more appropriate for uncovering which are the words most likely to be associated with each of the tags assigned by the moderators, as well as the relative weight of each word.

We thus used the 10 most frequent tags found in the discussion forum (**Table 1**) and computed the LLDA model (i.e., the list of words and associated probabilities) using Mallet software.⁵ This model was then used to classify each of the documents in the other two corpora (i.e., Wikipedia and Scopus). As a result, every Wikipedia page and research article were assigned the tag from the forum whose words (as per the computed LLDA model) most closely resembled the content.

Lead/lag visualization

To observe the interest in each of the topics, we plotted the numbers of posts, edits, and articles with each of the tags as a percentage of the total number of forum posts or research articles or as a percentage of the total number of Wikipedia edits. It was necessary to use the number of Wikipedia edits as a measure of interest in a topic given the dynamic nature of Wikipedia and the relative rarity of creation of new Wikipedia entries related to diabetes. These values were calculated for every year, using publication date for the forum posts and the research articles and the date of the edit on Wikipedia.

These time series are used to depict the relative rise and fall in activity on each topic across the three platforms. We were interested in seeing if changes in relative interest in one topic led to a change in the others (e.g., if the public's growing interest in a topic led to more research about it, or vice versa). To better compare such lead/lag patterns between the three platforms, we normalized each time series by subtracting frequencies of the topic over years by the mean frequency and then dividing by the standard deviation. These normalized graphs were then manually shifted back and forth in time to find the best alignment, similar to the strategy used by Shi et al. (2010).

Results

The alignment between the forum, Wikipedia, and research topics

Health is the most frequent topic extracted from both research articles (around 25% of articles are classified under health) and Wikipedia articles (around 30% of articles are classified under health), but since it is a very general topic and does not specifically relate to diabetes, we excluded the topic from further analysis. With that omission, the top five forum tags assigned to research articles by our LLDA model were, in descending order of frequency, A1C test, diabetes treatment, diabetes control, type 1 diabetes, and diabetes complications. The top five tags assigned to Wikipedia pages were, in descending order of frequency, diabetes control, type 1 diabetes, diabetes treatment, A1C test, and insulin. On the DiabeticConnect forum, the five most frequent tags were type 2 diabetes, emotional support, diabetes diet, type 1 diabetes, and diabetes diagnosis (**Table 2**).

The topics on each platform already show that not all the highly discussed topics on the forum are of interest to researchers, nor to the people who edit Wikipedia. While a high percentage of the research articles and Wikipedia articles are about diabetes testing (especially the A1C test), control, and treatments, a large number of forum posts discussed emotional support and motivation for patients and diabetes diet, topics that are not found among the most popular topics in the research literature. On the other hand, the most edited topics on Wikipedia have greater overlap with the topics of research articles.

Table 2: Top 10 topics across the three platforms.

Forum		Wikipedia		Research	
Topic	%discussions	Topic	%edits	Topic	%articles
Type 2	26.74	Control	11.97	A1C test	16.81
Emotional support	11.79	Type 1	11.12	Treatments	13.47
Diet	10.46	Treatments	10.13	Control	13.16
Type 1	9.63	A1C test	8.86	Type 1	9.60
Diagnosis	6.06	Insulin	4.61	Complications	6.05
Treatments	5.39	Blood sugar	4.13	Awareness	3.09
Weight loss/Obesity	5.02	Symptoms	4.04	Symptoms	2.93
Medication	4.81	Complications	3.95	Neuropathy	1.84
Control	3.99	Diet	3.73	Insulin	1.71
Blood sugar	3.01	Awareness	2.99	Diet	1.21

⁵ <http://mallet.cs.umass.edu/>.

The lead/lag between public discussions, research, and Wikipedia

We traced the prevalence of some of the most discussed topics in the forum over time and compared it with the prevalence of those topics in the research found in Scopus and on the Wikipedia pages about diabetes. We plotted the relative interest in the topics over time across the three platforms for the top ten most discussed forum topics. These time series allowed us to visualize whether the rise and fall in the interest in topics in the discussion forum lead or lag similar changes in the research literature and in Wikipedia articles about diabetes.

We normalized the values for each year by dividing the percentage of posts or articles by the average across all years and plotted both the standard percentages (**Figure 1a–j**, left) and the normalized values (**Figure 1a–j**, right). These figures show that in six of the 10 topics ('emotional support', 'diet', 'type 1 diabetes', 'diagnosis', 'medication', and 'blood sugar'), the time series align across the three platforms, with corresponding peaks and valleys for each, indicating that changes in public interest in these topics are accompanied by similar changes in what research is published and what topics are edited on Wikipedia. While these topics are at the core of all discussions about diabetes, it is notable that the fluctuations in interest align over time across the very different contexts.

We found a lead/lag pattern for two of the topics ('type 2 diabetes' and 'diabetes treatments') (**Figure 1a & 1j**). In the case of 'type 2 diabetes', the normalized and shifted time series show that Wikipedia edits lag forum discussions by one year, while research articles lead forum discussions by a year. This shows that there was increased activity by forum users on posts about type 2 diabetes one year ahead of editors of Wikipedia pages, but that researchers had published more on the topic one year ahead of forum users. In the case of 'diabetes treatments', forum discussions lead the research by one year and the Wikipedia edits by two years. Forum users discussed treatments for diabetes more frequently in 2009, and one year later, in 2010, there was a rise in the number of articles that may have taken up the language from the forum. Then, the following year, the Wikipedia pages that used similar language were edited more heavily (peaking in 2011). Public knowledge of the health care system and general medical treatments has developed over time. That could presumably be the reason why the treatments are picked by the forum users in the first place.

The remaining two topics had a different pattern. Posts and articles about 'weight loss/obesity' show alignments across the three platforms between 2008 and 2011 but diverge in the following years (**Figure 1f**). From 2012 onwards, changes in forum discussions seem to trail published research and pages edited on Wikipedia. Wikipedia edits about articles related to "weight loss/obesity" dramatically increased in 2012, when academic research and forum discussions had their lowest number. The pattern is the reverse for 'diabetes control', where the three platforms do not align prior to 2012, but all show increased interest in the topic starting in 2012 (**Figure 1h**). For this topic, forum posts and research articles are relatively aligned, with low levels of activity, while Wikipedia edits on pages associated with the topic show a different pattern, rising dramatically in 2010.

Limitations

The main limitation of this study is the use of single sources for data. We cannot make any claims that DiabeticConnect is representative of the many discussion forums online where issues related to diabetes are discussed, nor can we claim that Scopus captures all of the research on the topic. Investigating additional forums, including platforms like Reddit, as well as additional research corpora, including PubMed, could offer a more representative sample than the one we chose, but we were limited in the data and resources we had available for this study. Using additional sources would have also introduced challenges in standardizing the various sources (e.g., finding equivalent tags in the forums). We are also aware that the search query used to identify Wikipedia and research articles is limited and excludes many topics and articles on both platforms that are related to diabetes (either directly or indirectly). While there is value in the simplicity of choosing articles that include the word stem 'diabe*', additional work might examine a more comprehensive search strategy. Finally, we are aware of the limitation of counting edits as an indicator of interest in Wikipedia articles, especially as the number of edits ignores both the size and the quality of the edits. However, choosing alternatives, like the number of characters changed, would have also suffered from limitations.

Discussion and Conclusion

This case study explores the potential of using new sources, like public discussion forums, to better understand the connection between the topics of interest to the public and those published in the research literature and edited on Wikipedia. The alignment in the rise and fall of relative interest over time in six of the top 10 topics (i.e., 'emotional support', 'diet', 'type 1 diabetes', 'diagnosis', 'medication', and 'blood sugar') is evidence that the topic-modeling approach used can be useful for comparing across platforms, even when these vary significantly in their function, users, and language. In particular, it demonstrates the success of using the LLDA model as a strategy for classifying research and Wikipedia articles based on the language used by posts in a public community discussion forum. Moreover, the time-shifted alignment found in a couple of the series (i.e., type 2 diabetes and treatment) suggests that the method may be useful for detecting when topics gain popularity in one arena ahead of another. In these cases, rises and drops in interest by researchers happened both ahead of and after corresponding changes in relative interest in the discussion forum. The last two cases (weight loss/obesity and diabetes control) analyzed show that the method does not always find alignment between changes in relative interest in topics. These two cases reveal that the LLDA models are not mirroring each other but are reflecting varying degrees of interest in the topics across the three corpora.

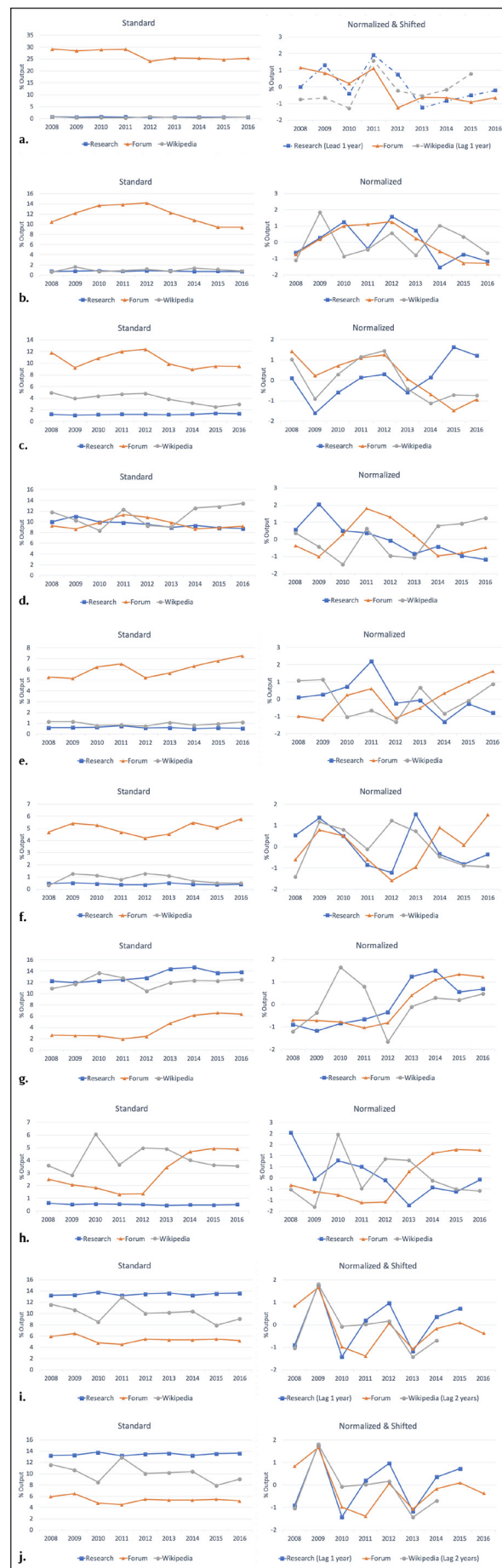


Figure 1a-j: Percentage of research articles, Wikipedia articles, and forum discussions over years for the top ten forum topics.

Beyond comparisons to each other, several topics show a turning point in 2011 and 2012. The year 2012 specifically is an important date in the history of diabetes, when the death of 3.7 million diabetic patients was reported (WHO 2012). The diabetes control trend increases across all platforms in 2012, and it continues increasing onwards (**Figure 1h**). A dramatic increase is also seen in diet trends in 2012, but the trends start dropping afterwards (**Figure 1c**). A similar trend is seen for emotional support, where all the three trends peak in 2012 but start decreasing afterwards (**Figure 1b**). This report received widespread attention and shifted the public conversation about diabetes (WHO 2012; The Cleaner 2014). Although we cannot make direct connections between the publishing of the report and the observed changes in topics of interest, this alignment is an encouraging sign that the LLDA approach applied to a discussion forum captures changes in public interests.

Using the LLDA method and assigning a more consistent set of topics to records in each platform eased and ensured the comparison task between a technical research corpus and a lay discussion corpus that has not been taken on in previous studies. In fact, no earlier study touched upon a lay discussion platform like a forum to detect community needs regarding a certain topic, while such social platforms bear a great potential for detecting the most recent issues and concerns arising in a certain community. Previous research has instead focused on disease burden rates and global health trends as a way of measuring public interest (Yegros, et al. 2018; Rafols & Yegros 2018). In addition to research, project tools such as ‘Searching for Health’, which was developed to show how Google searches for health information associate with actual incidences of diseases, does not shed light on the alignment of online searches with published research. Our proposed approach, piloted here, provides a more direct measure of a community’s interest, which could, in the future, be used in conjunction with the kind of public health data used in previous studies.

With regards to diabetes itself and the analysis of diabetes-related content, the results show that diabetes testing (especially the A1C test), diabetes control, and treatments are the most frequent topics in research articles indexed in Scopus and pages edited in Wikipedia, while users of the discussion forum have a larger preoccupation with emotional support and motivation for patients and diabetes diet. Using the topics and the language found in the discussion forum, our topic model and time series show that the topics of published research and of the Wikipedia articles that are edited seem to largely correspond with one another. This shows that the Wikipedia community follows scientific outputs more closely, something that is likely expected, given that Wikipedia editors are instructed to cite their sources using sources like peer-reviewed research in their work (Wikipedia 2017) and that Wikipedia solicits scholars’ contributions (Corbyn, 2011). In this way and to the extent that we studied it through the ten most popular topics, the results suggest that the content on Wikipedia is influenced and updated based on the conversations happening within the research community, more than the conversations happening between individuals affected by diabetes. The relationship between topics of interest on Wikipedia and in research stands in contrast to the misalignment between them and the discussions taking place on the forum. This gap between public discussions and published research concurs with the results of previous studies that showed no/little correlation between health issues based on disease burden rate and research published in academia (Rafols & Yegros 2018; Yegros et al. 2018; Evans, Shim, & Ioannidis 2014).

Although the topics do not thoroughly align between the forum and the research platforms, a time series analysis shows similar trends, with similar peaks and valleys from 2008–2016 for most topics, including ‘emotional support’, ‘diet’, ‘type 1 diabetes’, ‘diagnosis’, ‘medication’, and ‘blood sugar’. We found a lead/lag pattern for two of the topics (‘type 2 diabetes’ and ‘diabetes treatments’). In the case of ‘diabetes treatments’, the slow publication process (time between submission and publication) may have caused the research lag one year behind the public discussions.

In a nutshell, the three platforms examined—the DiabeticConnect forum, Wikipedia, and Scopus—have different natures, so it is not expected to find a perfect alignment between their topics and their prevalence. It is logical that researchers are more interested in testing, control techniques, and treatments than the general public, as they are the experts responsible for the technical experiments and researching new methods, with wide access to laboratories and equipment. It is also logical for the public to be mainly interested in their daily-life issues, such as emotions, mood, stress, support, and food. However, the misalignment found between research interest and public interest may be informative for the scientific community and health policy makers in diabetes to value some understudied areas that are of higher interest to the public.

Future Directions

Our work is a first attempt at using discussion forums as a source of data for research indicators and can be extended in various ways. First, future work may consider using additional data sources, including multiple discussion forums and different research databases. In particular, multiple discussion forums on the same health topic—including, but not limited to, diabetes—should be considered. Similarly, a research article database with wider coverage of medical research, such as PubMed, should also be used for comparison.

While this study takes a global perspective, future studies might consider comparing the results across different geographical locations. Both the location of the public posting on the forums and the location of the researchers are likely to offer an interesting perspective that is worth exploring.

Another recommendation for future consideration is to look at additional social media platforms where discussions take place, such as Twitter and Reddit, to investigate the public interest in diabetes and compare the results across different online communities.

Competing Interests

The authors have no competing interests to declare.

References

- Ahmad, F., Hudak, P. L., Bercovitz, K., Hollenberg, E., & Levinson, W. (2006). Are physicians ready for patients with internet-based health information? *J Med Internet Res*, 8, e22. DOI: <https://doi.org/10.2196/jmir.8.3.e22>
- Alexa. (2018). *The top 500 sites on the web*. Available at: <https://www.alexa.com/topsites>. Retrieved: August 2018.
- Balkhi, A. M., Reid, A. M., McNamara, J. P., & Geffken, G. R. (2014). The diabetes online community: The importance of forum use in parents of children with type 1 diabetes. *Pediatric diabetes*, 15(6), 408–415. DOI: <https://doi.org/10.1111/pedi.12110>
- Boëte, C. (2011). Scientists and public involvement: A consultation on the relation between malaria, vector control and transgenic mosquitoes. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 105(12), 704–710. DOI: <https://doi.org/10.1016/j.trstmh.2011.08.006>
- Brownstein, J. S., & Freifeld, C. C. (2007). HealthMap: The development of automated real-time internet surveillance for epidemic intelligence. *Euro surveill*, 12(11), E071129. DOI: <https://doi.org/10.2807/esw.12.48.03322-en>
- Cassi, L., Lahatte, A., Rafols, I., Sautier, P., & De Turckheim, E. (2017). Improving fitness: Mapping research priorities against societal needs on obesity. *Journal of Informetrics*, 11(4), 1095–1113. DOI: <https://doi.org/10.1016/j.joi.2017.09.010>
- Corbyn, Z. (2011, March 29). Wikipedia wants more contributions from academics. *The Guardian: Higher education*. Available at: <http://www.guardian.co.uk/education/2011/mar/29/wikipedia-survey-academiccontributions>. Retrieved: April 2018.
- Crocco, A. G., Villasis-Keever, M., & Jadad, A. R. (2002). Analysis of cases of harm associated with use of health information on the internet. *JAMA*, 287, 2869–2871. DOI: <https://doi.org/10.1001/jama.287.21.2869>
- Ebrahim, R. (2009). Exploring technology impacts of Healthcare 2.0 initiatives. *Telemed J E Health*, 15(3), 255–60. DOI: <https://doi.org/10.1089/tmj.2008.0093>
- Evans, J. A., Shim, J. M., & Ioannidis, J. P. (2014). Attention to local health burden and the global disparity of health research. *PLoS One*, 9(4), e90147. DOI: <https://doi.org/10.1371/journal.pone.0090147>
- Eysenbach, G. (2003). The Impact of the Internet on Cancer Outcomes. *CA: A Cancer Journal for Clinicians*, 53, 356–371. DOI: <https://doi.org/10.3322/canjclin.53.6.356>
- Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of general internal medicine*, 26(3), 287–292. DOI: <https://doi.org/10.1007/s11606-010-1526-3>
- Hasty, R. T., Garbalosa, R. C., Barbato, V. A., Valdes, P. J., Jr, Powers, D. W., Hernandez, E., ... Jose, S. S. (2014). Wikipedia vs peer-reviewed medical literature for information about the 10 most costly medical conditions. *J Am Osteopath Assoc*, 114(5), 368–373. DOI: <https://doi.org/10.7556/jaoa.2014.035>
- Heilman, J. M., Kemmann, E., Bonert, M., Chatterjee, A., Ragar, B., Beards, G. M., ... Martone, M. F. (2011). Wikipedia: A key tool for global public health promotion. *Journal of medical Internet research*, 13(1). DOI: <https://doi.org/10.2196/jmir.1589>
- Herbert, V. G., Frings, A., Rehatschek, H., Richard, G., & Leithner, A. (2015). Wikipedia—challenges and new horizons in enhancing medical education. *BMC medical education*, 15(1), 32. DOI: <https://doi.org/10.1186/s12909-015-0309-2>
- Hilliard, M. E., Sparling, K. M., Hitchcock, J., Oser, T. K., & Hood, K. K. (2015). The emerging diabetes online community. *Current diabetes reviews*, 11(4), 261–272. DOI: <https://doi.org/10.2174/1573399811666150421123448>
- Laurent, M. R., & Vickers, T. J. (2009). Seeking Health Information Online: Does Wikipedia Matter? *Journal of the American Medical Informatics Association*, 16(4), 1. 471–479. DOI: <https://doi.org/10.1197/jamia.M3059>
- Marris, C., & Rose, N. (2010). Open engagement: Exploring public participation in the biosciences. *PLoS biology*, 8(11), e1000549. DOI: <https://doi.org/10.1371/journal.pbio.1000549>
- Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., ... Turner, R. (2003). The impact of health information on the Internet on health care and the physician-patient relationship: National US survey among 1,050 US physicians. *Journal of Medical Internet Research*, 5(3). DOI: <https://doi.org/10.2196/jmir.5.3.e17>
- Rafols, I., & Yegros, A. (2018). Is Research Responding to Health Needs? *Social Observatory of la Caixa*. March. DOI: <https://doi.org/10.2139/ssrn.3106713>
- Ramage, D., Hall, D., Nallapati, R., & Manning, C. D. (2009). Labeled LDA: A supervised topic model for credit attribution in multi-labeled corpora. In *Proceedings of the 2009 Conference on Empirical Methods in Natural Language Processing*, 1(248–256). Association for Computational Linguistics. DOI: <https://doi.org/10.3115/1699510.1699543>
- Ravert, R. D., Hancock, M. D., & Ingersoll, G. M. (2004). Online forum messages posted by adolescents with type 1 diabetes. *The Diabetes Educator*, 30(5), 827–834. DOI: <https://doi.org/10.1177/014572170403000518>
- Rolia, J., Yao, W., Basu, S., Lee, W. N., Singhal, S., Kumar, A., & Sabbella, S. R. (2013). Tell Me What I Don't Know—Making the Most of Social Health Forums. In *Healthcare Informatics (ICHI), 2013 IEEE International Conference* (pp. 447–454). IEEE. DOI: <https://doi.org/10.1109/ICHI.2013.45>

- Sarasohn-Kahn, J.** (2008). The wisdom of patients: Health care meets online social media.
- Shi, X., Nallapati, R., Leskovec, J., McFarland, D., & Jurafsky, D.** (2010). Who leads whom: Topical lead-lag analysis across corpora. *NIPS workshop*.
- The Cleaner.** (2014). Diabetes & Chikungunya: What You Need To Know. <http://jamaica-gleaner.com/article/health/20141112/diabetes-chikungunyawhat-you-need-know>
- Thomas, G. R., Eng, L., de Wolff, J. F., & Grover, S. C.** (2013). An evaluation of Wikipedia as a resource for patient education in nephrology. In *Seminars in Dialysis*, 26(2), 159–163. Blackwell Publishing Ltd. DOI: <https://doi.org/10.1111/sdi.12059>
- Viseur, R.** (2014). Reliability of user-generated data: The case of biographical data in Wikipedia. In *Proceedings of The International Symposium on Open Collaboration* (p. 31). ACM. DOI: <https://doi.org/10.1145/2641580.2641618>
- Wikipedia.** (2017). Writing an article. https://en.wikipedia.org/wiki/Wikipedia:Your_first_article
- World Health Organization.** (2012). Global Report on Diabetes. <https://apps.who.int>
- Yegros, A., Tijssen, R., Abad-García, M.-F., & Rafols, I.** (2018). Drug research priorities at odds with global disease toll. *Nature Index*, 16 March.

How to cite this article: Didegah, F., Ghaseminik, Z., & Alperin, J. P. (2020). Using a Diabetes Discussion Forum and Wikipedia to Detect the Alignment of Public Interests and the Research Literature. *Journal of Altmetrics*, 3(1): 4. DOI: <https://doi.org/10.29024/joa.26>

Submitted: 15 April 2020

Accepted: 28 May 2020

Published: 10 July 2020

Copyright: © 2020 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.

