

Comparing topics of interest in forum discussions and research articles in search of new indicators of the public's interest in Diabetes

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The social web has become an important place for exchanging information about health instantly and widely. Many with health concerns are active on social platforms where they seek advice, information and experience from other patients or experts related to their issues (Ravert, Hancock, & Ingersoll, 2004). Such a community can be found around diabetes, a serious and growing health problem that has grown in prevalence among adults aged 18 or older from 4.7% in 1980 to 8.5% in 2014. In 2012, 3.7 million people died for diabetes and high blood glucose (WHO, 2017). Although some clinicians and health care professionals warn about risks of misinformation on the web and online platforms, previous research shows that participants in a diabetes forum find that discussions are a good source of knowledge and social support (Balkhi et al., 2014), and state that they use such forums and online groups for gaining specialized knowledge from experts and researchers and emotional and social support (Greene et al., 2011). As such, the topics and discussions communicated in online venues may be useful to learn what the general public is interested in and concerned about in ways that leads to a greater understanding of how the public simultaneously informs and is informed by research activity.

In search of this objective, this study aims to uncover the areas of interest and needs of the general public related to diabetes, as seen in online platforms, and their relationship to the research on those topics. In particular, this study investigates to what extent discussions on public online platforms align with academic research in diabetes and explores whether topics first discussed in online platforms eventually become the subject of research, or vice versa.

Methods

To understand the potential and limitations of metrics related to diabetes derived from online platforms, this study looks beyond currently used social media metrics by examining the topics discussed on DiabeticConnect, 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. This study then relates the topics discussed in the forum with the research on diabetes indexed in the Scopus platform.

We extracted the text from 22,845 posts dating back to 2008 from the DiabeticConnect forum, along with the tags assigned by forum moderators. We also identified 108,180 articles from Scopus by searching for articles with the word stem 'diabe*' in their title, abstract and author-supplied keywords. We used a Labeled Latent Dirichlet Allocation (LLDA) to classify the Scopus articles under the topics (tags) extracted from the forum and make the two platforms comparable.

Results

The results show that not all the highly discussed topics on the forum are of interest to researchers, and vice versa. While a high percentage of articles in Scopus are about diabetes testing (especially a1c test), control or treatments, a large number of forum posts discussed emotional support and

motivation for patients and diabetes diet. We also 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 articles. The results show that only about few topics such as ‘diabetes control’ or ‘diabetes neuropathy’, when there is an increased discussion on the forum, a similar increase can be also seen in the number of research articles that are classified under the same topics using LLDA. Other topics, such as ‘type 1 diabetes’ shows a peak of attention between 2010 and 2013 on the forum, while there is a steady increase in the percentage of research published around this topic. Moreover,

Discussion

Current altmetric indicators such as Tweets and Wikipedia citations only have limited coverage of diabetes publications (mentioning only 22.4% and 0.5% of publications respectively). This low coverage may be due to limitation in altmetric.com data coverage but it implies that altmetric indicators especially wiki citations may not be suitable for measuring social mentions of research publications in diabetes. Our preliminary analysis begins to uncover the potential of using new sources, like public discussion forums, as sources for altmetric indicators that can lead to a greater understanding of the connection between researcher’s topic of interest and the public’s interest. While much of the research may not be directly linked from forums, the relationship between topics of interest to the public and topics of interest to researchers suggests a link between the two that warrants further exploration, and that can be used to situate and contextualize individual articles.

Future Directions

In the future work, we will apply LLDA to Wikipedia where we identified 209 Wikipedia articles containing the word stem “diabe*” (excluding 200 articles about celebrities who have or have had diabetes). Wikipedia plays a synthesizing role, where the public has worked collaboratively to summarize what is known about different aspects of diabetes. By analyzing the relationship between the diabetes forums, Wikipedia, and the research articles, we hope to uncover who is driving discussions about topics: the public, or academics? If successful, this work will point to a new class of indicators that, although less convenient to calculate, has the potential to lead to a greater understanding of how research circulates and influences the public sphere.

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