ABSTRACT:

Purpose: Organ donation is a significant gift able to improve survival and quality of life for patients with severe, chronic conditions. Unfortunately, there remains a shortage of donors in many countries. Understanding information seeking behaviour (ISB) related to organ donation may provide additional insight for health professionals and administrators in developing a more appropriate, guided approach for this complex area. The primary aim of our study is the novel use of Google Trends to evaluate interest in organ donation and transplant related queries with an emphasis on eye donation.

Methods: Retrospective review of Google Trends application. Data was accessed for analysis between October 2010 and October 2020. Data was mined at worldwide and national levels as appropriate.

Results: Seventy-three countries registered a relative search value (RSV) for corneal transplantation. The mean percentage change in RSV across countries was 26.4% indicating an overall increase in Internet interest over the study period. The mean value for eye donation was 5.8 ± 1.8 and 50.3 ± 10.8 for organ donation within Australia. The search volume for organ tissue donation within Australia increased significantly during a national organ donation initiative (Donate Life Week p = 0.027). The increase extended through the following 2 months however did not maintain statistical significance.

Conclusion: Understanding public interest and awareness is critical to developing communication campaigns and general information provided to patients. Using Google Trends we have identified several novel patterns that may assist donation and or specialist organisations to refine existing programs.

Key Words: Organ donation; eye; Google, Internet search, transplant

Organ donation leading to transplantation can provide improved survival and quality of life for patients with significant disease. Donation levels fluctuate across countries reflecting differences in both administration and attitudes between governments, health professionals and the community itself. Unfortunately in most countries, the demand for organs and tissue is exceeded by availability representing an ongoing concern for all stakeholders.

Initiatives to increase organ donation have been met with varied levels of success suggesting a complex interplay between cognitive and emotional requirements. Continued education of health professionals and increasing donor staff levels have been shown to provide local advantages albeit with limited ability to significantly upscale benefits. The role of external information in developing organ donation has been identified previously and remains variable. Although targeted, well-executed media campaigns may provide small to moderate benefits on knowledge, beliefs and long-term behaviours, this is balanced by the potential negative impact of controversial or exaggerated

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media reports on organ donation.9,10 Concurrently, the role of the internet and social media in health education and awareness continues to develop.11 Eighty percent of American adults use the internet with almost two-thirds (59%) acknowledging they have looked online for health information.12 Although these values will vary between countries, this would suggest that the internet is a significant destination for health information providing a range of opportunities to develop health care and awareness.

Traditional techniques in understanding patterns of health awareness are costly, time-intensive and limited by geographic scope.13,14 This provides a significant disadvantage in developing representative, timely health data and policy choices for health professionals and policy makers.15 Subsequently, utilising internet search data has been shown to efficiently supplement standard data collection methods. Google represents the most frequently accessed search engine accounting for approximately 86% of internet searches.16 Google provides an opportunity to access volume search data via the Google Trends feature and researchers have utilised this to explore public interest in a wide variety of health related topics.16-18 Although not without limitations, the use of this application has provided positive insight to health and search patterns.13-15

Understanding information seeking behaviour related to organ donation may provide additional insight for health professionals and administrators in developing a more appropriate and guided approach for this complex area. The primary aim of our study is the novel use of Google Trends as a method for evaluating interest in organ donation and transplant related queries with an additional emphasis on corneal transplantation and eye donation.

METHOD

Google Search provides volume data based on search terms from 2004 onwards via the Google Trends feature (http://www.google.com/trends/explore#). Search data may be localised to country, state and in some cases, city locations. Google Trends produces relative search volume (RSV) scaled to the highest search proportion time point for the given region. The use of an RSV indirectly corrects for both population size and internet access or availability. Maximal RSV is 100 with subsequent scores representing a direct percentage of the highest observed search proportion during the requested study period. Google Trends allows web searches by search term or topic and can compare multiple terms within the same query.

We undertook a retrospective review of Google Trends to understand the online information seeking behaviour surrounding organ transplantation with an emphasis on eye donation and corneal transplantation. In our study, Google Trends data was accessed and downloaded on 10th November 2020. The time periods selected for analysis were for the previous decade (October 2010 to October 2020). Google Trends was mined at worldwide and national levels as appropriate. An additional search was undertaken to review the potential impact of Donate Life Week across Australia. Donate Life Week is led by the Organ and Tissue Authority (Australia) and represents a key part of the national platform to both initiate conversation and increase registration for organ and tissue donation. Donate Life Week began in February 2011 following the launch of a national revision of the organ donation program. From 2015, the program moved to late July-early August. For comparison, values for the 3 months (quarter) prior to Donate Life Week and the 2 months following were identified and compared. We matched searches against the number of corneal transplants over time. The number of transplants were taken from the national Donate Life network values across the same search period (Australian Government Organ & Tissue Authority).19

Australia has an opt-in process for organ donation. The Australian Organ Donation Registry (AODR, https://donatelife.gov.au/register) is the federal initiative enabling potential donors to register an intention to donate after death. Of note however is the additional requirement to consult a legal next-of-kin (if available) to establish consent for donation. Relatives have the ability to override a person’s registered donation wishes at the time of this consent conversation.

STATISTICAL ANALYSIS

Values were charted over time. A polynomial trendline (4th order) was used to indicate broad gain and loss over time. Paired T-Test was used to compare mean values prior to Donate Life Week and following the event. Independent T-test was used to compare mean scores across queries. Pearson correlation coefficient was used to examine the association between search terms and the number of corneal transplants and donors over the time period.

We modified significance points using the Bonferroni correction to adjust for multiple testing. An equivalent p value of 0.05 was considered statistically significant. All p-values and tests are reported.
RESULTS

Corneal transplant (worldwide) [search term] and Corneal Transplantation (worldwide) [topic]

The mean value for the search term over the 10 year time period was 70.4 ± 12.4 (range 35 to 100, median 73). [Figure 1] Only 12 countries registered a value for the search term over time between 2010 and 2020 however 70 countries registered values for the broader topic of corneal transplantation [Figure 2]. The mean percentage change in score (baseline value/final value x 100) across countries was 26.4% indicating an overall increase in internet interest over the study period (range 5.0% to 100%, median 18.8%).

Figure 1: Monthly Relative Search Volume scores for “corneal transplant” search term between October 2010 to October 2020 Worldwide.

Figure 2: Geographic location of search terms (Left) search term “corneal transplant” and (right) topic of “corneal transplantation.”
Search term: Corneal transplantation vs. corneal donation (worldwide)

The mean value of comparative search terms were 36.4 ± 18.5 and 15.5 ± 12.2 for “corneal transplantation” and “corneal donation” respectively.

Search term: Eye Bank and Eye Banking (worldwide)

Seventeen countries provided enough search interest in “eye banks” as a search term to register a value, namely Australia, Bangladesh, Canada, Germany, Hong Kong, India, Indonesia, Ireland, Malaysia, Nigeria, Pakistan, Philippines, Singapore, South Africa, UAE, UK and USA.

Search term: Corneal and/or eye donation vs. organ donation (Worldwide)

The mean value for eye donation was 5.8 ± 1.8 and 50.3 ± 10.8 for organ donation within Australia. Figure 3 indicates the values over time with both terms exhibiting general stability in interest.

Search term: Organ donation vs. Australian Organ Donation Register (Australia)

The mean comparative value for organ donation was 46.9 ± 18.4 vs. 12.1 ± 5.7 for AODR. Figure 4 charts the values over time.

Figure 3: Monthly Relative Search Volume scores comparison between “eye donation” and “organ donation” topic between October 2010 to October 2020 Worldwide.

Figure 4: National Monthly Relative Search Volume scores comparison between “Organ Donation” and “Australian Organ Donation Register” topic between October 2010 to October 2020.
Do search terms reflect performance? Correlation between search terms and outcomes:

There was a significant inverse correlation between organ donation search values and the number of corneal transplants across the search period for Australia (p = 0.007, r = -0.789). There was a significant correlation between corneal transplantation as a search and the number of corneal transplants performed (p = 0.025, r = -0.697).

Impact of government initiative (Donate Life Week) on internet search interest:

There was a mean increase in search interest for the topic of AODR during the month of Donate Life week compared to the prior quarter (p = 0.027) [Table 1]. This was statistically significant with interest appearing to remain high through the first month post Donate Life Week before returning to pre-quarter values by the second month.

Similarly, the search request for topic of organ tissue donation within Australia increased significantly during the month of Donate Life Week (p = 0.000). The mean increase in interest was maintained through the following month prior to again returning to previous levels

Table 1: Breakdown of mean search terms following government initiative

<table>
<thead>
<tr>
<th></th>
<th>Australian Organ Donation Registry</th>
<th>Organ Tissue Donation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Search Score (SD)</td>
<td>Significance (p value)</td>
<td>Mean Search Score (SD)</td>
</tr>
<tr>
<td>Quarter immediately prior to Donate Life Week</td>
<td>7.7 (1.8)</td>
<td>-</td>
</tr>
<tr>
<td>Donate Life Week (Month)</td>
<td>13.0 (6.9)</td>
<td>0.027*</td>
</tr>
<tr>
<td>1st Month post Donate Life Week</td>
<td>9.3 (3.7)</td>
<td>0.107</td>
</tr>
<tr>
<td>2nd Month post Donate Life Week</td>
<td>7.5 (1.9)</td>
<td>0.030*</td>
</tr>
</tbody>
</table>

DISCUSSION

Understanding public interest and awareness is critical to developing communication campaigns and general information provided to patients, or in the case of organ and tissue donation to potential donors. Google Trends provides an alternative tool for researchers to understand information-seeking behaviour and has been shown to supplement existing epidemiological measures such as surveys and interviews to help inform healthcare delivery.

In 2008, the Australian federal government allocated significant resources to improve the organ donation rate to match best practice. These initiatives included increases in specialty training and hospital-based positions, quality assurance support, coordination of national services and the creation of national community awareness programs such as Donate Life Week. Positively, this resulted in doubling the total organ donors from 2010 however the donor per million population rate is still yet to match leading donor countries. Organ and tissue donation however represents a complex decision for multiple parties including the donor and their families or carers. Given the opt-in culture of many countries including Australia, providing supplementary information to assist either the decision to register, or the eventual donation approval may represent an integral component in developing effective donation programs.

Our search found variable interest albeit trending downwards with respect to the term “corneal transplantation” for worldwide online searches over the previous decade. As the breakdown of the population is unavailable, the reason for the decrease remains unclear with a possibility that changes are driven by academic interest. Lamellar procedures, and thereby associated terminology, have been increasing in popularity which may have led to a dilution for the broader definition of corneal transplantation. Of consideration, only 17 countries registered enough searches to provide a search volume for the term Eye Bank. The majority of these countries would appear to have an established Eye Bank or importing protocol suggesting a possible correlation.

Comparing searches for surgery terminology (“corneal transplantation”) against an interest in donation (“corneal donation”) we noted that the surgical term had twice the interest of donation worldwide. Again, this may partially reflect the interest of academia however we believe that this may also represent personal investment in the disease and treatment processes, that is, patients with corneal disease are more likely to be interested in understanding the surgical options than the number of people considering donation directly. As the search terms remain relatively colloquial, we believe this is more likely to reflect the interest from patients or potential donors rather than of researchers. Identifying possible collaborations and opportunities to include donor information on disease-oriented websites may be a potential option to increase salient awareness in donor processes.
We found interest for organ donation dominated in comparison to the more direct search terms (corneal or eye donation). This is likely to reflect the broader applicability of organ donation and the breadth of options within this area although it may also indicate the nature of available information. The majority of information for cornea and eye donation is likely to be contained on specific websites devoted to the process itself, for example from Eye Bank associations. Given the relative concentration of information, a potential patient or donor is unlikely to require a range of searches for additional information thereby minimizing the respective relative search volume. This possible bias has been described previously and does not necessarily reflect a failing on behalf of interested research or health institutions in providing information.

Donate Life Week represents a significant local initiative aimed at increasing the awareness of organ donation in general terms as well as facilitating participation in the federal donation registry. We found that mean local interest for organ and tissue donation (search term) increased significantly during the month of Donate Life week suggesting a positive outcome for the campaign in terms of generating interest and follow up enquiries. This finding was regardless of the time the event was held. Perhaps of greater importance was the finding that the increase in interest was largely maintained through the month following Donate Life Week activities indicating continued message penetration. As health promotion messages are likely to have greater impact during periods of increased interest, developing follow up initiatives may present additional opportunities for organ and tissue organisations. An evaluation of AODR as a search term identified a similar positive pattern. The lower comparative values for AODR may demonstrate the nature of information sourced upon the internet search request, that is, the AODR likely represents the main source of related information thereby reducing the requirement for additional searches.

We found a significant inverse relationship between search term (organ donation) and the number of corneal transplants across Australia during the assessment period. We are unsure of the potential importance of this finding. This may simply reflect the end of the process, that is, once a patient understands the treatment protocol, or has proceeded to surgery directly, then no further information is sought outside that provided by the surgeon. Additional research is required to increase our understanding and the relevance of these findings.

Anecdotally, there appeared to be a reduction in search activity through 2020 for all topics and search terms. Given the significant global impact of COVID-19 and, more specifically the limitations placed on clinic visits and eye surgery, this would appear to make sense. Further follow-up over time would be of interest and may further reflect the course of recovery between nations.

The limitations of Google Trends have previously been described. The lack of specific demographic data available to identify population features within the search query results is a key issue although one with privacy limitations that would appear insurmountable at this stage. Working within these limitations however may still provide important information to complement additional, and more traditional research methodology.

We have provided a basic review of internet search based behaviour around the topics of organ and transplant donation. Using Google Trends we have identified several novel patterns that may assist donation and or specialist organisations to refine existing programs and available information.

**REFERENCES**


