Listening to the HysterSisters: Online Conversations about Hysterectomy

Recovery

Arpit M DAVÉ MD
Department of Medical and Surgical Gynecology, Mayo Clinic, Phoenix, AZ

Mr. Andy BOOTHE MSSTC
W2O Group, Austin, TX

Mr. Jeffrey BYRNE BA
W2O Group, Austin, TX

Helene BRASHEAR PhD
W2O Group, Austin, TX

Yash P GAD PhD
W2O Group, Austin, TX

Johnny YI MD
Department of Medical and Surgical Gynecology, Mayo Clinic, Phoenix, AZ

Corresponding Author
Arpit Davé, MD, Department of Medical and Surgical Gynecology, Mayo Clinic, Phoenix AZ.
5777 E Mayo Blvd, Phoenix, AZ 85054
Work Phone: +1-480-342-0612
Mobile Phone: +1-832-724-3470
Email: amdave@gmail.com
Abstract

Background

Despite increased focus on patient-centered care, physicians remain pressured by time constraints. Physicians must optimize perioperative counseling during this limited time. Although patients experience major complications infrequently, minor complications are more common and can negatively impact quality of life. These complications may be inadequately addressed during clinical counseling prior to surgery. As a result, less time may be spent discussing common but non-life threatening symptoms. However, these still significantly impact patient quality of life. This creates an information gap that patients attempt to bridge, often through phone calls during the recovery period. Increasingly, patients are turning to social media such as online health communities to seek answers and reassurance.

One such community is HysterSisters, which is “dedicated to medical and emotional issues surrounding the hysterectomy experience […], supporting women from diagnosis, to treatment, to recovery.” It offers a unique view into patients’ conversations surrounding hysterectomy and other gynecologic care.

Objective

To characterize conversation about hysterectomy recovery as experienced by members of the HysterSisters online community.
Study Design

A retrospective keyword frequency analysis of the HysterSisters Hysterectomy Recovery forum.

Results

Over 1.78 million posts in total were captured from the HysterSisters forum.

Among the users who created these posts were 69,950 patients who declared their hysterectomy type and date.

Among these posts were also 80,704 threads from the Hysterectomy Recovery board that were posted since 2005 and during the author’s first 12 weeks post-op by 33,311 unique patients who declared hysterectomy type and date. A symptom taxonomy of 8 primary symptom groups was created using a seed list of symptoms generated from a three-gram keyword frequency analysis of these threads.

Patient post volumes and distribution of symptom mentions over time reveal key times for potential beneficial symptom-specific patient engagement during recovery.

Pain and bleeding were the two most mentioned symptom groups and account for 49.75% of all symptom mentions (19,965 out of 40,127). Minimally invasive hysterectomies were compared against abdominal hysterectomy. There is no significant difference in the proportion of patients who mention pain- and hormone/emotion-related keywords during their recovery across all procedures. As
compared to the abdominal hysterectomy group, mentions of bleeding-related 
keyword mentions were more common in the laparoscopic group (p=0.01), while 
urinary and intimacy-related keywords were more common in the vaginal 
hysterectomy group (p<0.001, p<0.001). Nevertheless, the interquartile difference in 
days for the final mention of these keywords is significantly earlier across all 
keyword groups for the minimally invasive procedures.

**Conclusion**

Analysis of the HysterSisters Hysterectomy Recovery forum reveals a rich source of 
information about patient experience and provides novel actionable insights that 
can improve patient-centered care during the postoperative period.

**Keywords**

hysterectomy; social media; symptom assessment
Introduction

Hysterectomy continues to be a commonly performed procedure whose major surgical risks are well-described [1,2,3]. Although patients experience these major complications infrequently, minor complications are more common and can negatively impact quality of life [4]. These complications may be inadequately addressed during clinical counseling prior to surgery [5].

Patient face-to-face time with providers continues to be limited despite new patient-centered payment models seeking to increase engagement [6]. In 2013, the median length of OB-Gyn visits was 19 minutes [7]. Patients will attempt to fill in any gaps in their knowledge and expectations on their own [8], often by phone calls to providers or turning to alternate information resources, including online communities, for more information [9]. A 2013 Pew report indicated that 72% of internet users report seeking health information online [10]. Adults who reported delays in getting doctors’ appointments or reported limited doctor’s office access were twice as likely to report using the internet for health answers [11].

HysterSisters is one such online community “dedicated to medical and emotional issues surrounding the hysterectomy experience [...] from diagnosis, to treatment, to recovery.” [12] Although online communities are frequently documented as a hub of psychosocial support, a survey of the HysterSisters community showed that patients indicated much higher web site usage for informational support and advice (61%) than for emotional support (31%). Patients reported their top motivations for
posting were obtaining information (87%), experience sharing (76%), and offering advice or information (70%) [13].

To date, no studies we found have attempted to utilize the actual content of HysterSisters as a source of information about the patient medical experience.

The present analysis attempted to characterize more completely the recovery experience of patients in the HysterSisters community by studying the subject headings of patients’ own publicly-available posts to “listen” to patient conversations outside the physician’s office. Though myriad topics are discussed on the HysterSisters website, this analysis focuses on the largest forum on the website dedicated to hysterectomy recovery. Therefore, the objective was to lay the groundwork for utilizing forum data from Hystersisters to provide both patients and providers with unique insight into the real-world complications and symptoms experienced during hysterectomy recovery.

**Methods**

In accordance with the Code of Federal Regulations 45 CFR 46, the Mayo Clinic Institutional Review Board deemed this study does not require IRB review on the basis that publicly accessible contributions to the HysterSisters forums do not constitute private behavior.
Data Collection

The HysterSisters website provided users with the option to enter structured data including type of hysterectomy, ovarian status and exact date of procedure [12]. The forum's taxonomy of hysterectomy types were categorized for analysis into “treatment groups” by surgical approach (Table 1). SILS/LESS represented fewer than 100 individuals and was excluded from the analysis.

<table>
<thead>
<tr>
<th>Abdominal</th>
<th>Vaginal</th>
<th>Laparoscopic</th>
</tr>
</thead>
<tbody>
<tr>
<td>TAH (total abdominal)</td>
<td>TVH (total vaginal)</td>
<td>TLH (total laparoscopic)</td>
</tr>
<tr>
<td>SAH (supracervical abdominal)</td>
<td>LAVH (laparoscopic-assisted vaginal)</td>
<td>LSH (laparoscopic supracervical)</td>
</tr>
<tr>
<td>TAH/SAH (either, not specified)</td>
<td>DVH (Da Vinci)</td>
<td>SILS/LESS (single-incision laparoscopic)</td>
</tr>
</tbody>
</table>

Table 1. HysterSisters website taxonomy for hysterectomy. Available hysterectomy types categorized into “treatment group” columns, by surgical approach.

The “Hysterectomy Recovery (post hysterectomy)” board was selected to focus specifically on patients who were post-hysterectomy and in early recovery. This board was constrained to posts from hysterectomy patients who were initiating a conversation. This was accomplished by selecting only the subject heading from the first post in each thread. The initial post body and subsequent thread replies were excluded. Posts from users who did not declare a hysterectomy type and date were excluded. Posts preceding the patients’ hysterectomy date or more than twelve weeks afterwards were also excluded. No filtering was performed based on ovary status data. Even though posts in the board were public, data collection preserved anonymity by processing forum text and metadata without the username.
Symptom Keyword Frequency Analysis

Term frequency analysis is an analytical technique that characterizes the differences between two text corpora by comparing the relative frequencies at which n-grams appear in each corpus [14,15]. This analysis used a log likelihood approach to term frequency analysis because it offers a test for significance [16]. To gain understanding of how patients in different treatment groups discussed the same symptom differently, one corpus each was constructed from the subjects of the posts mentioning the given symptom for the two treatment groups to compare, and then term frequency analysis was applied to compare the two corpora. For this analysis, the abdominal treatment group subject headers were used as the base corpus, against which each other group was individually compared. These analyses yielded a list of n-grams used more by each treatment group when mentioning each symptom versus the abdominal treatment group; these lists prioritized and motivated any manual, qualitative review of matching posts. All comparisons used equality to the abdominal treatment group's mention frequency as the null hypothesis to allow comparison of the set of minimally invasive procedures to the traditional approach.

Symptom Taxonomy

A symptom keyword taxonomy was developed using an iterative, collaborative process between the medical and computational researchers. The initial keywords were identified using a n-gram (n=1,2,3) frequency analysis of all posts in the “Hysterectomy Recovery” board, which revealed a “seed” list of commonly-reported symptoms. The list was then expanded by alternately searching by keywords and
inspecting text that was both included and excluded by search queries. Keyword searches were used to pull relevant subject headers and then new keywords were added to the list after manually examining relevant conversations. This process continued until the keyword searches maintained a consistent conversation indexing. Individual keywords were chosen to prioritize specificity over sensitivity; sensitivity was maximized by including many keywords.

The final keyword symptom groups emerged as “Pain,” “Sleep & Fatigue,” “Hormones & Emotions,” “Digestion,” “Swelling,” “Bleeding,” “Urination,” “Intimacy,” “Odd Sensations,” “Drugs,” “Fever & Infection,” and “Family.” The set of all words for the keyword symptom groups included technically accurate terms (“gastritis”), proper English words (ex. “itches,” “burns”), slangs (ex. “weepies,” “swellybelly”), and common typographical and spelling errors (ex. “achey,” “vomitting”). Appendix A shows the keyword symptom groups and all included words.

**Symptom Keyword-Mention Frequency Analysis**

The symptom mention frequency analysis compared the number of patients who mentioned each symptom broken out by hysterectomy approach. The subject headers were tagged for symptom mentions by searching tokenized post subjects for the corresponding symptom keywords from the taxonomy. Responses were aggregated by patient in order to compile the list of symptoms each patient mentioned during the twelve-week post-operative recovery period. A chi-squared test for homogeneity was used to compare the mention frequencies of each symptom among patients in each hysterectomy group to the abdominal group.
Symptom Keyword-Mention Survival Analysis

The same set of tagged subject headers was grouped by patient and sorted chronologically to determine each patient’s latest mention of each symptom. Patients who did not mention a symptom were excluded from the survival analysis of that symptom only; no cases were considered “censored.” These latest mentions form a Kaplan-Meier curve among patient conversations for each symptom group [17]. A log rank test was used to compare the survival curves of each symptom among each treatment group. All comparisons used equality to the abdominal treatment group’s corresponding symptom survival curve as the null hypothesis. Mean interquartile difference between survival curve pairs were calculated to quantify which group ceased to mention symptom keywords earlier.

Software

All data processing and analysis was done using free, open source libraries written in Python (Python Software Foundation, Beaverton, OR). Data processing and aggregation was performed using the "pandas" library, text processing with the "nltk" library, statistical analysis using the "scipy" library, and Kaplan-Meier analysis using the "lifelines" library.

Results

There were 33,311 unique patients in the Hysterectomy Recovery forum making at least one mention of a symptom in the taxonomy. Among these patients, the procedure distribution is as follows: abdominal=13,306 (39.94%), vaginal=10,589 (31.79%), and laparoscopic=9,416 (28.27%). Among patients who provided ovary
status data, there were more who kept at least one ovary (55.97% of all patients) than patients who had both removed (36.96%); some patients did not specify their ovary status (7.06%). Ovary status by surgical approach is seen in Figure 1.

![Bar chart showing ovary status by surgical approach](chart.png)

**Figure 1. Ovary status by surgical approach.** Total number of procedures reported by HysterSisters patients mentioning at least one symptom included in the taxonomy, stratified by surgical approach. Each procedure is broken down by ovary status. Unknown indicates patients did not provide ovary status data.

**Conversation Volume**

Patients with completed profiles created a total of 80,704 top-level posts during the first twelve weeks of their respective recoveries. The subjects of 34,242 (42.43%) of
these posts mentioned at least one symptom as defined by the symptom taxonomy; the remaining 46,462 (57.57%) mentioned none.

Posting behavior was heavily skewed, with most posts (53.17%) happening within the first three weeks of the twelve-week recovery period being studied. Figure 2 shows a histogram of posts, segmented by days post-op day and stratified by symptom mention count. The median post was made during day 19 ($\mu$=day 23.80, $\sigma$=18.56 days). The median posts per patient was 1 post ($\mu$=2.42 posts, $\sigma$=3.10 posts).

**Figure 2. Post volume by days post-op.** Bars indicate total number of posts created by HysterSisters patients, grouped by the number of whole days post-operation the post was created. Bars are broken down by number of symptoms each post subject mentions according to the symptom taxonomy.
Symptom Mention Volume

Figure 3 shows a histogram of patients who mention each symptom. The top three symptoms by volume of mentions are pain, bleeding, and "hormones & emotions" for both the aggregate conversation and each of the conversations by procedure.

Figure 3. Patients who mention a symptom during the recovery period. Each patient is counted at most once per symptom, even if the symptom was mentioned multiple times.

Sorting by relevance

The 34,242 subject headers which mention at least one symptom contain 40,127 total symptom mentions. The symptoms mentioned the most were pain (12,474
posts, 31.08% of subject headers that mention at least 1 symptom) and bleeding (7,491, 18.67%); together, these symptoms account for half of all symptom mentions. Relevant posting behavior follows overall posting volume very closely. Proportional symptom mentions per unit time remain generally flat throughout the first twelve weeks of recovery with few important exceptions (Figure 4).

Figure 4. Symptom mention distribution over time, by week. Distribution of all symptom mentions, grouped by number of whole weeks post-operation.

Patient Symptom Keyword Mention Frequency Analysis

There is a significant difference between the number of patients who mention a symptom at any point during recovery for a given surgical approach versus the abdominal approach for some symptoms. For example, vaginal hysterectomy patients mentioned urinary and intimacy keywords proportionally more. Laparoscopic hysterectomy patients mentioned bleeding proportionally more. Both mentioned swelling and sleep/fatigue-related keywords less. There were no
differences in frequency of mentions of pain and hormone/emotion keywords. Table 2 shows the absolute percentage difference in mentions for each surgical approach/symptom permutation versus the abdominal surgical approach.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Laparoscopic</th>
<th>Vaginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>-0.05%</td>
<td>0.38%</td>
</tr>
<tr>
<td>Drugs</td>
<td>-0.81%</td>
<td>-0.60%</td>
</tr>
<tr>
<td>Urinary</td>
<td>-0.50%</td>
<td>2.29%***</td>
</tr>
<tr>
<td>Hormones &amp; Emotions</td>
<td>-0.49%</td>
<td>0.28%</td>
</tr>
<tr>
<td>Intimacy</td>
<td>-0.25%</td>
<td>2.38%***</td>
</tr>
<tr>
<td>Sleep &amp; Fatigue</td>
<td>-2.22%**</td>
<td>-1.69%*</td>
</tr>
<tr>
<td>Swelling</td>
<td>-2.94%**</td>
<td>-3.04%***</td>
</tr>
<tr>
<td>Pain</td>
<td>0.21%</td>
<td>0.98%</td>
</tr>
<tr>
<td>Fever &amp; Infection</td>
<td>-0.42%</td>
<td>0.39%</td>
</tr>
<tr>
<td>Digestion</td>
<td>1.55%</td>
<td>0.41%</td>
</tr>
<tr>
<td>Odd Sensations</td>
<td>-0.43%</td>
<td>-0.96%</td>
</tr>
<tr>
<td>Bleeding</td>
<td>3.03%**</td>
<td>-1.46%</td>
</tr>
</tbody>
</table>

Table 2. Absolute percentage difference for mentions of a given symptom by procedure as compared to the abdominal approach. Positive numbers indicate the abdominal cohort mentions
the symptom more; negative numbers indicate the abdominal cohort mentions the symptoms less. Asterisks indicate significance at p-values: 0.05*, 0.01**, and 0.001***.

**Patient Symptom Keyword Mention Survival Analysis**

Patients in the minimally invasive treatment groups ceased to mention nearly all of the symptoms being studied significantly earlier versus the abdominal group, even in cases where proportionally more patients mentioned the symptom. For example, laparoscopic hysterectomy patients ceased to mention bleeding at a mean interquartile difference of 1.66 days sooner (p=0.0029) than abdominal hysterectomy patients. Vaginal hysterectomy patients ceased to mention pain keywords at a mean interquartile difference of 4.00 days sooner (p<0.0001) than abdominal hysterectomy patients. Table 3 lists the mean interquartile differences in days between the timing of cessation of each symptom mention by approach compared to the abdominal hysterectomy cohort. Survival curves for symptoms mentions of pain (Figure 5) and bleeding (Figure 6) are shown.

<table>
<thead>
<tr>
<th></th>
<th>laparoscopic</th>
<th>vaginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>-9.3***</td>
<td>-5.0**</td>
</tr>
<tr>
<td>Drugs</td>
<td>-3.6**</td>
<td>-1.3</td>
</tr>
<tr>
<td>Urinary</td>
<td>-7.6***</td>
<td>-4.6***</td>
</tr>
<tr>
<td>Hormones &amp; Emotions</td>
<td>-5.6***</td>
<td>-5.6***</td>
</tr>
<tr>
<td>Symptom</td>
<td>Mean Difference</td>
<td>Interquartile Difference</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>Intimacy</td>
<td>-0.3</td>
<td>1</td>
</tr>
<tr>
<td>Sleep &amp; Fatigue</td>
<td>-6.3***</td>
<td>-3.6**</td>
</tr>
<tr>
<td>Swelling</td>
<td>-7.0***</td>
<td>-4.0**</td>
</tr>
<tr>
<td>Pain</td>
<td>-7.0***</td>
<td>-4.0***</td>
</tr>
<tr>
<td>Fever &amp; Infection</td>
<td>-7.3***</td>
<td>-6.0***</td>
</tr>
<tr>
<td>Digestion</td>
<td>-4.0***</td>
<td>-2.3***</td>
</tr>
<tr>
<td>Odd Sensations</td>
<td>-4.3***</td>
<td>-2.6**</td>
</tr>
<tr>
<td>Bleeding</td>
<td>-1.6**</td>
<td>-2.0***</td>
</tr>
</tbody>
</table>

Table 3. Patient symptom keyword survival mean interquartile differences versus abdominal approach, in days. Negative numbers indicate an earlier cessation of mentions, positive numbers indicate later. Asterisks indicate significance at p-values: *0.05, **0.01, and ***0.001.
Figure 5. Symptom mention survival curve for "pain" symptom. Number of days post-op that patients cease to mention pain, among patients who mentioned pain during recovery, broken down by procedure type, with 95% confidence intervals.

Figure 6. Symptom mention survival curve for "bleeding" symptom. Number of days post-op that patients cease to mention bleeding, among patients who mentioned pain during recovery, broken down by procedure type, with 95% confidence intervals.
Discussion

The HysterSisters forum data set provides a unique opportunity to broadly sample patient online conversations regarding hysterectomy recovery outcomes and complications, benchmarked by date and type of procedure. Our data set represents the largest collection of self-reported hysterectomies to date.

Conversational Perspectives

Although internet search and online forum usage is rising among patients, patients still overwhelmingly turn to their doctor for medical expertise. In one study, 91% of patients sought their doctor for medical diagnosis. However, when asked about "practical advice for coping with day-to-day health situations," patients were more divided with 43% choosing their doctor and 46% choosing the group including fellow patients, friends, and family. Almost 60% were more likely to turn to this social group for emotional support as well [18].

This analysis has important a priori limitations. First, symptoms keywords were sorted into taxonomies by an iterative process that is necessarily subjective. As previously noted, the taxonomy maximizes specificity through word choice, but the authors must ultimately assign any word to a group. The complete taxonomy is therefore included as an appendix.

Second, this analysis does not address motivations for posting. Practically, the analysis does not equate mentions of symptoms with patient complaint. Indeed, previous research indicates motivations include not only clinical information
seeking, but also seeking psychosocial support or questions about personal experience. Deeper analysis could begin to explore subject headers, post content, and conversational patterns related to motivation.

Finally, almost 60% of posts in the Hysterectomy Recovery board did not fall into our taxonomy. Though the most popular format of subject headers in the forum was "[# of days/weeks] post-hysterectomy [symptom]," many of the headers did not fill in the symptom “field” of the format. The remaining excluded subject headers include a variety of content, including non-symptom issues (e.g. return to activity, comorbid condition issues, or nonmedical topics such as “makeup,” etc.), progress updates, or “chatter.” Additionally, some symptoms were not captured due to sparseness of typographical error, unanticipated slang, or proper medical terminology reported unassociated with a symptom (e.g. “catheter”). These excluded subject headers represent an untapped source of future study.

Results Analysis

Nevertheless, this analysis provides rich insight into the hysterectomy recovery experience. Users seek engagement most heavily in the first three weeks after hysterectomy. Peaks in conversation volume at one, three and six weeks after hysterectomy are key opportunities to engage patients. At one week, a relative increase in percentage of “bleeding” mentions suggests this as a potential focus of assessment, reassurance, or counseling for patients. At six weeks, the increase of “intimacy” mentions coincides with “approval” to return to sexual activity, however may also suggest the presence of a persistent information gap patients seek to fill.
That the distribution of keyword mentions remains otherwise constant throughout the twelve-week recovery indicates users do continue to desire engagement on all these topics throughout and beyond the standard recovery period.

Within procedure types, conversations about bleeding may warrant specific attention with women undergoing the various laparoscopic hysterectomies. Indeed, a three-gram analysis of the laparoscopic cohort notes “at weeks post” is mentioned significantly more (p<0.001) and examples include “Vaginal discharge at 10 weeks post hysterectomy,” “New slight spotting at 10 weeks post hysterectomy,” “Spotting and slight pain at 10 weeks post hysterectomy.” This suggests patients may experience resumption of bleeding after a perceived recovery. Though dissolution of delayed-absorbable suture is a ready explanation, this topic should be specifically addressed by anticipatory guidance from providers.

Women undergoing vaginal hysterectomy also make proportionally more mentions of urinary symptoms. This may be due to more women in this cohort undergoing concomitant prolapse or incontinence surgeries, which this analysis does not explore. Clearly, however, patients seek engagement here and addressing this conversation topic can optimize limited face-to-face time with physicians.

Notably, even though there are no significant differences in the frequency of mentions of pain-related symptoms, the survival analysis shows the last mention of pain occurring about 7 days earlier for the laparoscopic cohort with about half of these users ceasing to mentioning pain by postoperative day 20. It is tempting to interpret this as half of patients stop experiencing pain at three weeks, but this may
not be the case. More appropriately, as users’ experience begins to match their expectations for pain or any particular symptom, the need to engage socially may diminish. As noted above, re-engagement can occur when expectation-experience mismatching occurs.

The high levels of statistical significance seen throughout are due to the sample size, however the clinical significance is more readily ascertained through the interquartile differences. Although the curves are statistically different, the interquartile difference in days for cessation of bleeding mentions is only 2.0 days for the vaginal as compared to abdominal hysterectomy patients. Nevertheless, with the exception of intimacy-related keywords, cessation of symptom mentions occurs earlier in the vaginal and laparoscopic cohorts across all symptom groups.

**Future Directions**

The current study presents a first look into text analytics to explore the patient experience in gynecologic care. Focus is limited, however, to the subject headers of posts by patients. Utilizing text analytics approaches more broadly provides several avenues for future studies. By further analyzing the post body itself and other conversational elements and patterns, we can begin to ascertain the underlying motivation for posting, such as seeking medical information, psychosocial support, or other factors.

Our results demonstrate a timeline of posts with shifting conversational volume in specific areas and by approach, which suggests patients’ information and engagement needs change throughout recovery. Patient-centered care requires
equally dynamic engagement from providers. As the majority of posts occur in the first two weeks, planned calls from providers can elicit an individual patient’s need. Targeted detailed patient literature in addition to standardized discharge instructions about recovery expectations could also serve as an information resource.

Technology can be leveraged to automate or facilitate some of these interactions such as email listservs or e-portals for patients to “check in” after surgery. Designed carefully, these technologies can also meet "Meaningful Use" obligations. The literature surrounding asthma and diabetes supports the clinical use of more active engagement options such as “push” notifications delivered directly to patients’ mobile devices [18, 19, 20]. These also can be bidirectional, allowing patients to upload clinically relevant information. We hope that our results provide insight to the gynecologic surgeon as to what their patients are discussing after hysterectomy and using this information can better understand the needs of the patient.
Acknowledgements

No financial support was solicited or utilized for the conduct of this research.

Coauthors from W2O Group provided computational resources and statistical analysis services at no cost to the authors and participated in the preparation of the material and methods and results sections.
Conflicts of Interest

Authors AB, JB, HB and YG are employees of W2O Group. W2O Group lists Intuitive Surgical (Sunnyvale, CA) as a client. No funding from Intuitive Surgical was obtained for this study. W2O Group subsidiaries offer commercial data analytics and marketing services in numerous economic sectors, including healthcare.
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http://www.webcitation.org/6yVsJLzwc

