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Increase in Contralateral Prophylactic Mastectomy Conversation Online Unrelated to Decision-Making

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Abstract

Background—The increased uptake of contralateral prophylactic mastectomy (CPM) among breast cancer patients remains poorly understood. We hypothesized that the increased rate of CPM is represented in conversations on an online breast cancer community and may contribute to patients choosing this operation.

Methods—We downloaded 328,763 posts and their dates of creation from an online breast cancer community from August 1, 2000 to May 22, 2016. We then performed a keyword search to identify posts which mentioned breast cancer surgeries: contralateral prophylactic mastectomy (n=7,095), mastectomy (n=10,889) and lumpectomy (n=9,694). We graphed the percentage of CPM-related, lumpectomy-related and mastectomy-related conversations over time. We also graphed the frequency of posts which mentioned multiple operations over time. Finally, we performed a qualitative study to identify factors influencing the observed trends.

Results—Surgically-related posts (e.g., mentioning at least one operation) made up a small percentage (n=27,678; 8.4%) of all posts on this community. The percentage of surgically-related posts mentioning CPM was found to increase over time, whereas the percentage of surgically-related posts mentioning mastectomy decreased over time. Among posts that mentioned more than one operation, mastectomy and lumpectomy were the procedures most commonly mentioned

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together, followed by mastectomy and CPM. There was no change over time in the frequency of posts that mentioned more than one operation. Our qualitative review found that the majority of posts mentioning a single operation were unrelated to surgical decision-making; rather the operation was mentioned only in the context of the patient's cancer history. Conversely, the majority of posts mentioning multiple operations centered around the patients' surgical decision-making process.

Conclusions—CPM-related conversation is increasing on this online breast cancer community, while mastectomy-related conversation is decreasing. These results appear to be primarily informed by patients reporting the types of operations they have undergone, and thus appear to correspond to the known increased uptake of CPM.

Keywords

breast cancer; contralateral prophylactic mastectomy; online health community; qualitative research; patient decision-making

Background

The rising rate of contralateral prophylactic mastectomy (CPM) is a well-established phenomenon in the U.S. Cemal et. al. [1] examined the National Inpatient Sample and found that the rate of CPM in the setting of unilateral breast cancer rose from 39 to 207 per 1,000 mastectomies between 1998 and 2008. During this same interval, the rates of unilateral mastectomy have decreased [2]. Similarly well-studied is the relatively low risk of breast cancer recurrence in BRCA-negative women with early stage early stage cancer treated with breast conserving surgery (BCS) and adjuvant systemic therapy [3–6]. In spite of this information, women who would otherwise be good candidates for breast conserving therapy are requesting CPM at increasing rates over the last decade, despite a lack of evidence for improved survival and a greater risk of perioperative complications from the procedure [7].

The increased uptake of the procedure continues to perplex breast surgeons, many of whom report discomfort with performing CPM at some point during their career [8]. Additionally, while the majority of patients who have undergone the procedure report that they would choose it again, many do report unanticipated negative consequences of the procedure [9].

Prior studies have identified factors associated with increased uptake of CPM including: age younger than 50 years, white ethnicity, family history of breast cancer, BRCA1/2 mutation testing, invasive lobular histology, clinical stage, use of reconstruction, tumor size, multicentric disease, surgeon gender (female), undergoing MRI and experiences of family/friends with cancer [10–14]. Additionally, some researchers have hypothesized that exposure of patients to online information may be leading to an increased rate of the procedure [6].

Research has demonstrated that approximately 40% of breast cancer patients report some or frequent online communications [15,16]. Schmidt et. al. [17] found that patients who used the internet more frequently were more likely to undergo a bilateral mastectomy.

Online health communities (OHCs) are interactive forums on the internet where patients, caregivers and others can turn to receive information as well as emotional support [18].

Similar to in-person support groups, they have been shown to benefit breast cancer patients by decreasing depression, cancer-related trauma and perceived stress [19]. For researchers, OHCs serve as a rich data source, providing insight into patient decision-making, temporal trends and concerns expressed by caregivers.

We sought to identify if the rate of conversation about CPM on an OHC was increasing and what factors may be contributing to the trends we observed.

Methods

Following the IRB approval, we developed a JSON based script to automatically download posts (n=328,763) from a well-known, publicly-available online breast cancer community from January 2000 to May 2016. JSON is a programming language that enables the execution of customized, automatic downloads of web page content. Each post was linked with: time and date of creation, screen name of author and thread that the post belonged to. We then performed a keyword search of all posts to identify those mentioning operations (Table 1). Keywords were selected based on common terminology used to refer to the operations as well as a key posted on the community to help users identify relevant posts. The first author validated the results by manually reviewing 50 randomly selected posts for each procedure to ensure that the keywords used in the resulting posts matched our intended use of the keyword (e.g., “double” referred to bilateral mastectomy and not two of something else). All 150 randomly selected posts used the keywords in concordance with our intended meaning.

Next we study the trends of surgery-related posts that mention one or multiple operations. Given certain pattern of operations, their trends over time are evaluated by two metrics: the incidence rate ratio (IRR) and the association between the counts of surgery-related posts (CSRP) and time based on the Cochran-Armitage test [20,21]. Here, we consider two different categories of patterns of operations: (1) one target operation was mentioned (e.g. including the keyword of CPM) in a post; (2) multiple target operations were mentioned (e.g. mentioning both CPM and mastectomy) in a post. A list of possible patterns has been listed in Table 2. We perform the evaluation on a yearly basis using the CSRP based on the above two patterns. Table 2 shows a contingency table for CSRP under a certain pattern of operations P_j within K consecutive years from t_1 to t_K. For year t_i, let us denote by n^j_{i1} and n^j_{i0} CSRP with the pattern P_j or not, respectively. In addition, we define $N^j_i = n^j_{i0} + n^j_{i1}$ as the total CSRP in i year for pattern P_j and n^j_{i1}/N^j_i as the incidence rate for year i. Afterwards, IRRs can be calculated based on the incidence rates, which measure the trend of percentages of a given pattern P_j among total posts. Given a period of time from t_i to t_l, $1 \le i < l \le K$, IRR is calculated by

$$IRR = \exp\left[\log \frac{(n^j{}_{l1}/N^j{}_l)}{(n^j{}_{i1}/N_i)} / (l-i)\right] \quad (1)$$

Generally, it shows an increasing trend when IRR is greater than one, otherwise, it indicates a decreasing trend.

Moreover, we also perform Cochran-Armitage test to evaluate the association between CSRP of each pattern and time. Let us denote by R^j_1 and R^j_0 the total CSRP with or without pattern P_j within K consecutive years, respectively. The trend test statistic τ is estimated by $\tau=\sum_{i=1}^{K}(n^j{}_{i1}R^j{}_0-n^j{}_{i0}R^j{}_1)$. Then, the variance can be computed by:

$$Var\{\tau\}=\frac{R^j{}_1R^j{}_0}{N}\sum_{i=1}^{K}N^j{}_i(N-N^j{}_i)-2\sum_{i=1}^{K}\sum_{l=1}^{K}(N^j{}_iN^j{}_l) \quad (2)$$

The p-values are derived by assuming $\tau/\sqrt{Var\{\tau\}}\sim N(0,1)$.

Finally, we divided the study period into six-month segments and performed a content analysis of randomly selected posts from each segment (a total of 50 posts from each group e.g. 50 lumpectomy posts were reviewed and 50 CPM and mastectomy posts were reviewed). Content analysis focused on whether or not the post discussed surgical decision-making. Posts in which the authors explained why they had selected their operation, or in which the authors were attempting to make a decision about which operation to have were coded as decision-making posts. We used a Pearson chi-square test to assess for an association between posts which mentioned multiple operations and decision-making.

Results

Keyword search revealed that posts mentioning operations made up a very small percentage of all community posts (Table 3). Of posts mentioning operations, mastectomy was the most commonly mentioned, followed by lumpectomy. Posts that mentioned more than one operation (e.g. lumpectomy and mastectomy) were uncommon on the community making up just 1.2% of all posts.

Pearson chi-square test showed that posts which mentioned more than one operation were more likely to discuss the patient's surgical decision-making process and factors which influenced their surgical ultimate decision ($\chi 2 = 212.28$, $p < .001$) (Figure 1). Posts which only mentioned one operation were most often unrelated to surgery; rather, the operation was mentioned in passing to give context about the patient's cancer history (e.g. "I had a Lumpectomy and node removal. Just to let you know, the port you had put in is probably one of the best decisions you made. Although it bothers you now, it will get less noticeable. Saves a lot on your veins.") In contrast, posts which mentioned more than one operation often described the patient's decision-making process and explained why she had chosen one operation in lieu of another (Table 4).

We also analyzed the trend of surgery-related posts mentioning single or multiple target operations over a period of 11 years (2005–2015). Figure 2 shows the trends of percentage of posts related to single or multiple target operations. In Figure 2, the data for 2001–2004 were dropped because overall community participation rapidly increased during this period, but stabilized after 2005. As shown in Table 5, we considered the trends of 10 patterns of operations. For each pattern, yearly counts were segmented into two time periods, (i.e.,

2005–2010 and 2011–2015) for comparing trend differences in terms of the IRR and Cochran Armitage test. For evaluation, incidence rate ratios (IRRs) were computed to indicate their increasing and decreasing trends and Cochran Armitage tests were performed to assess the trends for statistical significance. Here, IRRs are shown in terms of counts per 1000 posts.

We performed three analyses. First, we considered posts which mentioned any of the target operations, regardless of whether they mentioned a single or multiple operations. Figure 2(a) illustrates the results of this analysis and demonstrates that there is a decreasing rate of posts mentioning mastectomy and an increasing rate of posts mentioning CPM throughout the study period. The IRRs for the trend analyses were found to be significant for both periods of the study, with the rate of posts mentioning CPM increasing throughout. Our second analysis considered posts which mentioned only one operation. On this analysis, the previously described trends became increasingly clear [Figure 2(b)], with a significant increase in the rate of posts mentioning CPM and a significant decrease in the rate of posts mentioning mastectomy. Our final analysis considered posts which mentioned more than one operation, as shown in Figure 2(c). When we examine posts that mention more than one operation no clear trend is obvious; there is no significant increase or decrease in the rate of posts mentioning more than one operation.

Discussion

The increased uptake of CPM has coincided with the increasing popularity of OHCs among patients. Although prior research has suggested that OHCs and social media may be contributing to this trend [6,17], our study suggests otherwise. The steady rise in posts mentioning CPM closely parallels the increased uptake of the procedure which has been described in previous work [1,2]. On closer evaluation, we observe that although there are clear trends for posts that mention only one operation, with increased frequency of posts mentioning CPM throughout the study period, there is no significant change for posts that mention more than one operation. Careful qualitative review of posts indicates that posts mentioning more than one operation frequently illustrate either a patient's decision-making process, or come from a poster trying to decide between two or more operations. In contrast, posts mentioning only one operation are often unrelated to surgery or surgical decision-making. Rather, the surgery is mentioned only in the context of the patient's brief cancer history, before she discusses something else. Our findings parallel prior work on a separate community [22] which revealed that surgery (including reconstruction) was an infrequent topic of conversation in members' initial posts and that very few posts discussed surgical decision-making. Similarly, our findings support Wallner et. al.'s research that few newly-diagnosed patients use social media and OHCs during the surgical decision-making process [15].

These findings stand in contrast to prior work which has suggested that internet-based communications may be contributing, in part, to the trend of increased uptake of CPM among breast cancer patients [6,17]. On this community, few posts which mentioned operations actually discussed surgical decision-making. Additionally, posters seeking help making a decision about surgery were very uncommon. The steady increase observed for

posts mentioning CPM was noted only for posts mentioning the one operation. These findings combined suggest that the observed increase is likely secondary to the increased uptake of the procedure and not vice versa.

Our finding that there is little conversation on this well-known community regarding surgical decision-making suggests that many patients may be unaware of OHCs at the earliest stages of their diagnosis or did not yet have the need to find OHCs. However, as patients assimilate their diagnosis, they may learn about additional resources, find utility in OHCs, and join active conversations as OHC members. Chemotherapy and radiation are frequent topics of conversation among posts that mention only one operation. Patients utilize the community to obtain informational and emotional support during these non-surgical treatments. Prior research has described the benefits of participation in OHCs for breast cancer patients [23]. Wallner et. al. [15] found that higher levels of online participation were associated with increased satisfaction about surgical decision-making. OHCs may be a helpful resource for the newly-diagnosed, who are attempting to synthesize a large amount of information and make a decision regarding surgical treatment of their breast cancer. However, our study suggests that they are likely being under-utilized as a resource by many patients during the surgical decision-making process.

Our findings have practical implications for researchers, clinicians, and patients. Given our findings that mentioning multiple posts is an indicator of decision making, we can use text processing tools to automatically detect who mentioned multiple surgeries. We can then provide information aids to help with surgical decision making attempted in OHCs. As found from our study, OHCs is a true reflection of patients' trends in uptake of various procedures. OHCs can serve as a reflective platform in helping researchers and clinicians understand uptake of new procedures and patients' opinions and experiences around those procedures.

Limitations

Our study has several limitations. As it has included only one OHC, its results are not generalizable beyond this community. Additionally, we have randomly sampled posts for content analysis throughout the study period to assess what factors may be influencing the trends we have visually observed; however, without close review of all posts we cannot definitively say that there are other factors involved. As with all OHC research, we are only able to describe trends among participants who have actively posted on the community. We are unable to describe how many patients may have read postings about the various operations on the community and how that activity may influence decision-making. However, prior research has demonstrated that, among breast cancer patients participating in an OHC, lurkers (who had never posted) had a longer period of time since diagnosis as compared with members who actively posted to the group [24]. This suggests that lurkers on the community we have analyzed might also be further along in their disease course as compared with posters, and thus may have already made most of their surgical decisions. Lastly, the decision to separate the study period into two five-year periods is somewhat arbitrary and although previous studies have incorporated this methodology this is a potential limitation of our work.

Future Directions

Future work will identify when during the treatment process patients most commonly start posting in OHCs. We will need to assess patients' awareness of OHCs as a resource for informational and emotional support throughout their diagnosis and treatment course. Lastly, it will be important to assess the utility of OHCs as a tool to support patients during their surgical decision-making process.

Conclusions

Our study suggests that overall conversation mentioning CPM on this community has increased. This is not a result of increasing conversation regarding surgical decision-making. Rather, the observed trend is most likely a result of increased uptake of the procedure. The paucity of conversation surrounding surgical decision-making suggests that patients may be unaware of OHCs during the earliest stages of their diagnosis and treatment, or they do not yet perceive OHCs to be a helpful place to make decisions. Future work must carefully elucidate potential benefits of OHC participation for breast cancer patients around the time of their diagnosis and surgical decision-making. However, our findings suggest that currently OHCs are unlikely to be contributing to the increased uptake of the procedure.

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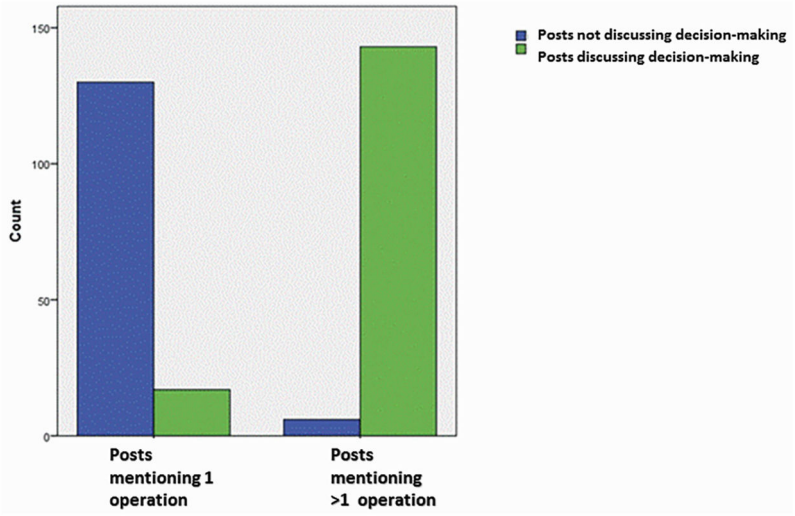
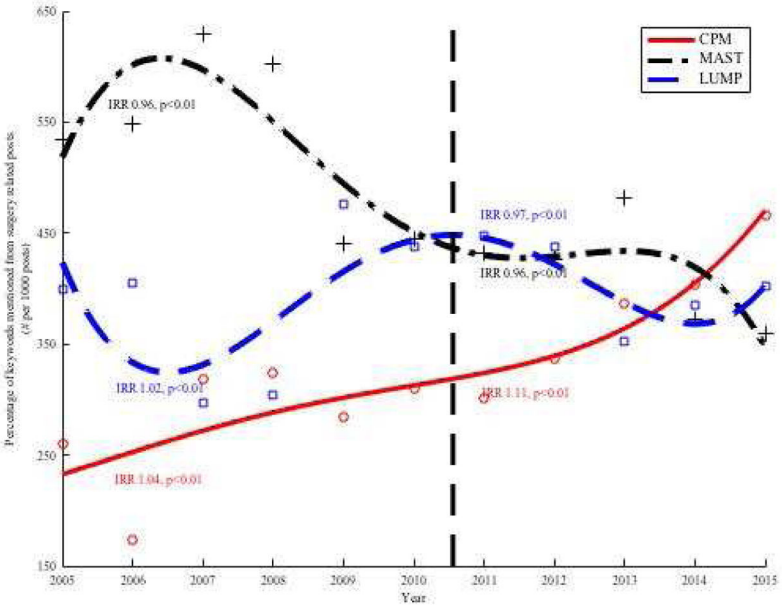
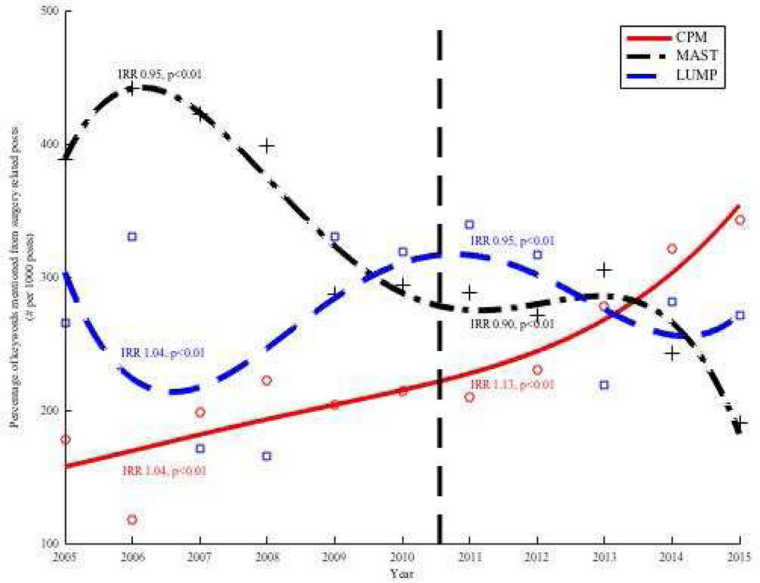


Figure 1.





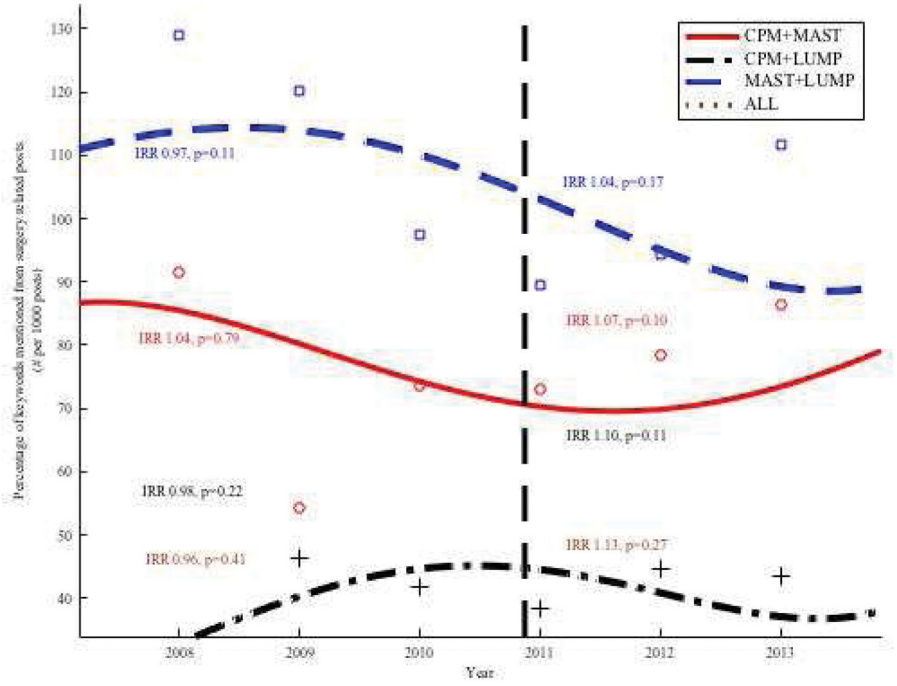


Figure 2.

Table 1

Keywords used to identify posts

Operation	Example keywords
CPM	Bilateral, contralateral, prophylactic, double, CPM, mastectomy, BPM
Mastectomy	Mastectomy, mast, MX
Lumpectomy	Lump, lumpectomy

Table 2

Contingency table for a given pattern of operations within consecutive years.

Observed pattern P_j	Year					Total counts
	t_1	…	t_i	…	t_K	
True counts	n^j_{11}	…	n^j_{i1}	…	n^j_{K1}	R^j_1
False counts	n^j_{10}	…	n^j_{i0}	…	n^j_{K0}	R^j_0
Total counts	N^j_1	…	N^j_t	…	N^j_K	N

Table 3

Post counts and examples

Procedure	# of posts (%of all posts in the community)	% of the keyword search results	Example Posts
CPM	7, 095 (2.16)	25.6	"I had breast cancer in 1989 And a double mastectomy, then breast cancer again in 2000…My prognosis was not good, but I am still here and healthy after eight years!"
Lumpectomy	9, 694 (2.95)	35.0	"At my 6 month post lumpectomy surgery mammo, I was pronounced 'no significant findings'!"
Mastectomy	10, 889 (3.31)	39.3	"I had a TRAM flap reconstruction at the same time as my mastectomy and that can be radiated. Hope this helps!"
CPM/Mastectomy	1,189 (0.36)	4.30	"I didn't have a double mastectomy and regret that decision. I didn't want reconstruction and am now considering a mastectomy on the other side."
Mastectomy/Lumpectomy	1,945 (0.59)	7.03	"I just had a left mastectomy… I opted for immediate reconstruction after watching my mom deal with a prosthesis…She hated it, and I dealt with one for a few months after a lumpectomy left me really lopsided.I decided I didn't want to do this for the rest of my life"
CPM/Lumpectomy	480 (0.00)	1.73	"Newbie here. I've had a lumpectomy with a positive sentinel node followed by an axillary node dissection. I'd like to skip radiation and am thinking about a double mastectomy."
CPM/Lumpectomy/Mastectomy	438 (0.00)	1.58	"I had a lumpectomy…however after speaking with my surgeon they felt a mastectomy would be best… I had another meeting with my surgeon who said to me that if I were his wife he would recommend that I remove both breasts."
Posts unrelated to surgery	301, 095	0	"So sorry you're having such a rough day. Sounds like you have a very full plate and I hope tomorrow goes well for you. I understand and will keep you in thought."
Total	328,763	n/a	

Table 4

Posts Discussing Surgical Decision-Making

	N Posts Related to Decision-making	Example	N Posts Unrelated to Decision-making	Example
Posts Mentioning Multiple Operations	143	"I had a bilateral mastectomy from the get go. Before surgery, I had the option of a lumpectomy, but when the surgeon described the procedure and risk of recurrence, I just opted for the whole shebang."	6	"Good luck with your surgery. I didn't have a mastectomy, I had a lumpectomy, so, I didn't stay in the hospital or anything."
Posts Mentioning One Operation	17	"We found the tumor first and had to do the mastectomy. I opted to have both sides taken just because I didn't want to face it possibly spreading to my right side or any other issues…It may have been a radical choice but I feel better knowing that I have tried to do everything I can."	130	"I had a lumpectomy, chemo, and radiation…This weekend I noticed the coloration on my breast…I don't know if this might be a reaction to aramidex."

Table 5

Description of 10 observed patterns adopted for trend analysis.

	Observed pattern P_j	**Keywords mentioned**		
		CPM	**Lumpectomy**	**Mastectomy**
1	CPM	Yes	Yes/No	Yes/No
2	Lumpectomy	Yes/No	Yes	Yes/No
3	Mastectomy	Yes/No	Yes/No	Yes
4	CPM only	Yes	No	No
5	Lumpectomy only	No	Yes	No
6	Mastectomy only	No	No	Yes
7	CPM/Mastectomy	Yes	No	Yes
8	Mastectomy/Lumpectomy	No	Yes	Yes
9	CPM/Lumpectomy	Yes	Yes	No
10	CPM/Lumpectomy/Mastectomy	Yes	Yes	Yes