

Appendix 2.

Category	Definition and Sample Submissions
Access to Services	<p>Definition: This included timeliness of IBR and DBR and access and availability of various services including physical therapy, exercise, psychosocial support services, financial support services, ect</p> <p>Sample Original Submissions: Will I require physiotherapy or any type of bodywork following breast reconstructive surgery and for how long will I have to have therapy?</p> <p>This is where much more could be done. Instructing women about exercises, physiotherapy options, massage therapy options, clothing options, support in the community. These are things that patients are left to find out for themselves... or not. Things to do to improve long term results etc.</p> <p>What are the surgical options available to women facing breast cancer treatment, how dependent are those options on type of cancer, and are they all available in all provinces? Essentially - how customizable is treatment?</p> <p>I am not familiar with wait times in our province nor how many physicians actually do the procedure.</p>
Decision Making	<p>Definition: This involved the entire decision making process, how involved the patients are and what helps them make a decision.</p> <p>Sample Original Submissions: Seeing the actual outcomes of different types of breast reconstruction was critical for me to make an informed decision about breast reconstruction.</p> <p>For women who have the choice between implants and autologous, a decision making tool may be useful in helping them choose. Also, speaking to and viewing results from women who have had various surgeries (like the Show & Tell lounge at BRA day) is very valuable. (resources)</p> <p>I think women should have information to review before going to see surgeon. Very overwhelming and had difficulty making any decision.</p> <p>Nobody discusses options with you. You have to google and come prepared. I would want someone to take the time to discuss what my options are instead of making a choice about my body without me</p>

<p>Experience and Advice</p> <p><i>*We categorized these submissions as out-of-scope</i></p>	<p>Definition: Submissions explaining an experience or sharing advice based on their experience.</p> <p>Sample Original Submissions: Do your homework on posture, healing time and all the pros and cons of each procedure</p> <p>Do some research on your own before you go and see the surgeon, therefore you can get the most from the information that the Doctor gives you. It will also help you understand the medical terminology that the surgeon uses.</p> <p>Do not get preoccupied with the reconstruction. The most important thing is curing you of the breast cancer first.</p> <p>Mine happened quickly as it coincided with the mastectomy surgery. I was happy with the discussion I had prior to my consultation as I had full confidence in my mastectomy surgeon.</p>
<p>Implants</p>	<p>Definition: This involved types of implants, and pros and cons of implants.</p> <p>Sample Original Submissions: Options about silicon vs saline, textured vs smooth</p> <p>My implants are under my pectoralis muscle and they scrunch up in certain situations. Are there other types of surgery that would look better?</p> <p>Do implants feel heavy in my body? Do they feel cold? What are the complications and what are the complication rates?</p> <p>Do implants need to be changed or only with problems</p>
<p>Breast Reconstruction Information</p>	<p>Definition: This included statistics/rates/likelihood of success, failure, satisfaction and factors that influenced the outcome</p> <p>Sample Original Submissions: What's the upper limit for BMI? Are smokers candidates and if so, when?</p> <p>Percentages - of complications, in case of prophylactic surgery odds of ever developing cancer with / without the surgery, etc.</p> <p>% of women who choose reconstruction who a) regret it subsequently</p>

Radiation and Chemotherapy	<p>Definition: This included the challenges and limitations of radiation and chemotherapy.</p> <p>Sample Original Submissions:</p> <p>Information about differences between women who have had radiation vs those who have not.</p> <p>What factors effect having reconstruction like masking recurrence or while ongoing chemo/ radiation?</p> <p>If I have reconstruction after chemo and/or radiation, how long must I be past those procedures to have surgery?</p>
Referrals	<p>Definition: This included any questions around patient referrals.</p> <p>Sample Original Submissions:</p> <p>Having the mastectomy surgeon actually make the referral and confirm It with the patient.</p> <p>I found it hard to know how to find or contact a plastic surgeon</p> <p>I was not allowed to make an appointment with the plastic surgeon until after completing chemotherapy. Then, I had to wait more than six months before my first appointment. The referral process should be done more quickly.</p>
Treatment techniques/options	<p>Definition: This included cancer detection post reconstruction and breast reconstruction treatment including the different aesthically enhancing techniques, the timing of the BR and the effects of treatment on BR</p> <p>Sample Original Submissions:</p> <p>The different types of reconstruction and the pros and cons of each and guidelines for how to pick each</p> <p>What are the different types of reconstruction available?</p> <p>Nipple reconstruction vs nipple sparing surgery</p> <p>How can fat injections help with breast reconstruction? Can it replace other more invasive procedures?</p>

Resources	<p>Definition: This includes the types of resources available, the reliability of the resources and the ability to access the resources.</p> <p>Sample Original Submissions: To have more information available for those that are at this point of their journey</p> <p>I wish I had more access to photos and information about average results of the various options, it seemed that I could only find excellent photos and stories or terrible ones, not the average</p> <p>Are there any support groups with contact information?</p>
What to Expect	<p>Definition: This includes what to expect before and after breast reconstruction surgery.</p> <p>Sample Original Submissions:</p> <p>What surgeries will I have to do in the future and when (I have an implant-based reconstruction)?</p> <p>Long term maintenance (i.e. ten years down the road)</p> <p>How much time would I have to take off work or could I go to work during the process?</p>
<p>Note: these were broad categories used to organize the data. The “Treatment” category was divided into three groups: ‘Treatment techniques/options’, ‘Radiation and Chemotherapy’ and ‘Implants’. Abbreviations: IBR: Immediate breast reconstruction; DBR: Delayed breast reconstruction</p>	