

# Breast Cancer Characterization Patient Break-Out Discussion Notes

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**Question:** When collecting data to ensure it can answer key questions in research: What data is important to collect?

- What are your Symptoms/Concerns & How are (have) you managing your symptoms? (See the Table at end of document)

## **Additional thoughts and questions that were expressed during the discussions:**

- Long-term effect on bone loss
  - What is shown to reduce this?
    - Exercise
    - Weight-bearing
- Cognitive impact of Chemo/anti-hormone treatments?
- Impact of radiation on heart and lungs???
  - Most women do not realize many of the treatments for breast cancer can increase their risk for heart disease. What is the impact? Is it short or long term?
- Collect evidence to create justification to pay for alternate treatments
  - Need research to show other integrative/complementary therapies can be effective in managing sides effects so that they can be reimbursed
- When you are diagnosed, you don't always get told what to expect.
  - Lymphedema is still not well addressed.
  - Tell people common things that happen, so that they know what common things to expect (these can be side-effect symptoms validated through research)
- Would like to know root cause - so gather data such as:
  - Occupation
  - Area of city in which you live
  - Water sample
  - Air sample
  - Pesticides/dirt sample
  - Make-up / skin care products
- Food concerns...hormone/chemically-laden, etc. meats, and other food sources
  - Had children vs. not had children / lactation
    - How much / long of breast feeding is best for prevention?
      - Does age make a difference?
      - Would prophylactic breast feeding for women who do not have children be beneficial?

- People don't know breast feeding reduces chances of BC
- Information on how to safely and effectively get back in to exercise / past activities. Loss of muscle, strength, and/or endurance is a problem. Cancer rehabilitation therapy could be helpful
- Fertility concerns...including the impact of fertility drugs on BC risk for mother and baby
- Long-term impact of radiation (needs more research)
  - Also, what is the cumulative effect of all of the scans, etc.
- 3D vs. 2D
  - How much is found earlier with 3D? And are we finding cancers that will become problematic.
- Dealing with post-treatment can be harder
  - More anxiety than during treatment
  - To family, the cancer is gone, so what's the problem?
  - Will it come back?
  - Very different emotions in post-treatment

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What are Breast Cancer Survivors concerned about???	Column3
Symptoms, Concerns and Side Effects of Treatment	Non-medical Interventions Used
Pain	acupuncture, mediation
Joint/muscle pain	massage, mind/body, yoga, swimming, pilates
lymphedema	exercise, lymphatic massage
insomnia	supplements, exercise, relaxation techniques, Rx
bone loss--Fractures	supplements, exercise, pilates
nausea	supplements (ginger, aloe juice)
constipation	
physical fatigue/endurance & strength	exercise?/cancer rehab or restorative therapy to build strength
mental or general fatigue	yoga
Cognitive challenges - memory, difficulty multitasking, foggy, not as sharp or quick	supplements
neuropathy	
hair loss (short & long term)	
increased respiratory illnesses (post radiation/longer term)	
Bone pain vs arthritis ...which is it???	
stress/anxiety	meditation, yoga, exercise, relaxation techniques, journaling, therapy
Sexual dysfunction - vaginal dryness/pain; no/low libo; body image; loss of intimacy	What's safe? Is estrogen inserted in vaginally ok in ER+???
Fertility	What's the long term effect of drugs used to promote fertility in BC patients? Effect on mother and baby???
Long term impact of radiation on breast tissue, organs, skin???	
Cumulative effect of radiation via all the treatments, medical testing, etc???	
Fibrosytic breast disease?	
Psychological impact:	
*Trusting your body	
*Fear of recurrence	
**Feel more anxiety/stress post treatment vs during treatment	
**Family and friends think the cancer is gone so what's the problem?"	
Weight gain	