

## Session Notes

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## “You have cancer - Please hold”

A review of review of issues in timeliness, communication and hand-offs in breast care.



Facilitated and Moderated by:

### Panelists:

Kathy Powers  
Diana Salgado  
Christine Weldon  
Tabitha Williams  
Peggy Kupres

[weldon@centerforbusinessmodels.com](mailto:weldon@centerforbusinessmodels.com)

### Moderator:

Julia Trosman

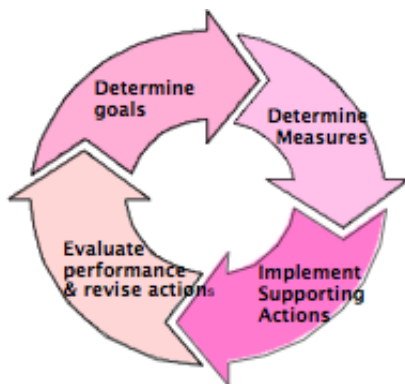
[trosman@centerforbusinessmodels.com](mailto:trosman@centerforbusinessmodels.com)

## Presentation Notes

### Learning Objectives of Session Today

1. Summarize key patient touch points / communication points
2. Analyze the impact of handoffs between providers on timeliness of patient care
3. Formulate communication and timing methods that could positively impact the breast care they provide

### Rapid Cycle Improvement Process



### Measures – Quality Treatment From Data Collection

Conduct < 10% excisional biopsies.  
~20% of facilities could NOT demonstrate

Provide timely treatment.  
~25% of facilities could NOT demonstrate

Provide radiation after breast conserving surgery  
~30% of facilities could NOT demonstrate

Test patients for hormone receptors  
~5% of facilities could NOT demonstrate

## Measures – Quality Treatment Summary of Participating Environmental Scan Sites

Same Day Diagnostic available	32%
Same day biopsy available	33%
Radiologist calls ordering physician for patients with BIRAD Scores of 4 or 5	63%
Tracking of patient with cancer diagnosis	52%
Provision of Navigation Services	33%
Breast Imaging Center Organizes Care, directs newly diagnosed breast cancer patients through care <i>71% of sites shared that physician who ordered breast imaging directs care.</i>	29%

	Median	Minimum	Maximum
Number of days for patients to receive screening results	10	3	30
Number of days waiting for a diagnostic appt	4	1	42
Number of days waiting for an imaged guided biopsy / tissue sample appointment	7	1	14
No show rate for diagnostic callbacks	7.5%	1%	50%

## Discussion of Actions - Key Communication Points - Biopsy

How do you tell a patient she needs a breast biopsy?

- Example #1:
  - patients are called back for a diagnostic are told that they will speak with radiologist about their exam and to let them know if they are to have further testing. We let them know that not all bumps etc are cancer, be upbeat, may not be anything, but if there is a change, it needs to be looked at again. Use myself as an example of a patient that has been called back.
  - If the radiologist says they need biopsy, I take over, prep them and tell them what they need to do and what to expect.
  - On the day of the procedure it's reinforced how it's going to be done, how long it will take to receive their results
  - give them my number if they need to call me
  - sit with them throughout their biopsy

- let them know that I'll call them the next day to see how they're doing. This is a courtesy call and that I won't have the results.
- women want to know what the likelihood of it being cancer is and I let them know that I cannot answer that question for them. Don't like to put the radiologist on the spot but if they have a low suspicion you can feel pretty much comfortable, if high suspicion they are honest with the patients saying "we feel that we will need to connect you with one of our breast surgeons". This helps to ease their minds.
- Example #2:
  - if abnormal screening, tech will call the radiologist, they would send patient up for an ultrasound.
  - if patient does need a biopsy, has it done same day
  - all done same day unless HMO or staff patient
  - if HMO, schedule the next appointment for their return that day and follow up with their physician to let them know what is needed
  - explain what goes on during the biopsy
  - will sit there and hold their hand, have a conversation with them to get their mind off what is going on
- Example #3
  - the majority of patients who come to us have either gotten a letter, a phone call or a referral, or they feel something in their breast.
  - we explain the different types of biopsies and why we are doing a particular type
  - not all biopsies are diagnostic, might mean further diagnostic biopsies are needed or other imaging.
- Example #4
  - we do same day, the radiologist call the primary physician to get the order for the biopsy and as long as the patient is done by noon, they have their results next day. If after noon, it's 48 hours. Our radiologists talk to the patients.
- General Comments
  - a navigator is extremely important on relating to the radiologist and getting everybody on board, that they have a patient "that needs to know now!"
  - Medicare and Blue Cross Blue Shield, don't need to be pre-certified, but some of the other insurances require it.
  - have not had an issue with Blue Cross Blue Shield HMO

How many of your sites have a navigator? A good show of hands of those people in the audience indicating they have them.

How to prepare for a breast biopsy, here is a link that may be useful:

<http://www.mayoclinic.com/health/breast-biopsy/MY00301/DSECTION=how-you-prepare>

What do patients need and want during time (hours or days) they are waiting for biopsy?

- the only same day biopsies we can do is if it's a palpable mass and we do it in the clinic.
- just today scheduled a stereotactic for a patient and our next appointment time available is December 22<sup>nd</sup>. Pretty common for image guided biopsies at our facility.
  - We rarely do excisional and are happy when the community doesn't do them as well.
  - Know that this time is psychologically hard for women, try to impress upon them the majority of image abnormalities on Category 4 mammogram are not cancer and that in the long run, a couple of weeks is not going to change their outlook and prognosis.
- at a community hospital, have some patients in the IBCCP, have clients coming in for screenings and needing diagnostic follow-ups
- certain physicians /OBGYN want to see their patients themselves to tell them and refer them to their surgeons
- other physicians/OBGYN we can call and they will approve getting them the biopsy
- need to know why the physicians /OBGYN are and who they refer to
- some primary care physicians require an appointment be made to have an encounter before they will actually give them the paperwork for a biopsy.
- try to inform the patient that it's what they want. If they want to have a same day biopsy, they can have it. If they want to see their doctor, that is ok too.
  - tell them that a doctor can fax an order or sometimes give a verbal
  - try to keep the patient educated and engaged
  - give them a phone number to call if they are having a hard time getting in to see their doctor so they can get help to facilitate that. If you reiterate how important this is, they too see the importance of following up.
  - would love to do same day, but sometimes you can't.
  - if patient is going off site, make sure they have their films and if on Plavix or Aspirin.
  - With IBCCP need paperwork and prior approval in order to get that service approved. If a woman is on the table, ready to go ahead, paperwork is in order, we can probably say go ahead thinking it's going to get approved. If we don't have all the paperwork, we can't go ahead.
  - also with IBCCP, if coming in for screening, tell them to check off "diagnostics" or "biopsy". Will be halted if the patient's results come back positive. Have to wait to get them scheduled to see the breast surgeon.

How do patients learn about their biopsy results?

- Example #1:
  - give our patients options. Majority are telephone, ask them first when they come in how they would like to be notified, by phone, in person with the radiologist, return back to their primary care doctor.

- if it's a senior citizen or someone else is involved with the patient, have them sign a form saying it's ok to talk with this other person regarding results
- tell them that if the results are good or bad, if we call you, that they'll be ok. Want to be sure about that.
- also tell them if you hear from me, it's a good sign. If you hear from the doctor, it could be either or.
- Example #2:
  - when get the biopsy results, we call the physician. Call the patient to follow up with their physician
  - let the physician know we have a breast cancer clinic on Wednesdays
  - schedule her appt as soon as possible
  - do not give out results over the phone
- Example #3:
  - do not give out results over the phone. The majority of the reason is that we want to make sure the results clearly.
  - have women come back in for results
  - if it's positive, it starts a whole process they need to go through
  - if it's negative, we always get a 6 month follow up baseline to be sure nothing has change
  - if it's an intermediary, atypical ductal hyperplasia, or something that needs further surgery, when they come back we can set that surgery up for them.
- Example #4
  - give patients the option to come back in or over the phone.
  - once get a positive diagnosis, set them up with our multidisciplinary clinic and we make the appt for them. There they will see the surgeon, oncologist, radiation oncology.

Good resource for understanding pathology report:

<http://ww5.komen.org/BreastCancer/ContentsofaPathologyReport.html>

- General Comments
  - for sites that have to send patients back to their primary care physicians, it's really important to follow up on them as this is a place where they can get lost
- Example #5
  - if it's an obvious cancer, have an appt set up with the breast specialist 3 day later to get their results in person. We say it's to just get the results and get a breast exam
  - if it's an IBCCP patient and looks like it's a malignant lesion or a lesion that has to come out no matter what because it looks highly suspicious, they'll get an appt with the surgeon within 3 days of the biopsy. This is to capture them so we don't have to go out and find them.
  - we give no results over the phone unless they start screaming.

- We give benign results over the phone.
- Example #6
  - pathologists call the physicians if positive and the nurses in the practice fax results to the physicians. If positive we also call the physician. If they are they are physicians we don't see routinely, we follow up every few weeks calling to get the update and status on the patient and where she is in her treatment.
- Example #7
  - when a patient has a biopsy, we also schedule them to see a breast surgeon and that is how they get their result. This appt is 5 days out.
  - Tell them to bring someone with them even if negative

Do you communicate with the family at any point in this process?

- HIPAA dictate this. Only if the patient signs the appropriate paperwork can family be informed.

Any other comments on biopsies?

- try to describe, go step by step, even the table and how it's designed, the hole, the anesthesia.
- if able, take them in and show them the room, how they will be positioned
- show them the ultrasound if they will get one of those
- confirm the appt 3-5 days prior and ask if they have any questions
- tell them about the noise, they'll hear a vacuum, suction, and clicks. The noise is the most startling thing to the patient always.
- If you tell them these things, they will be way more accepting of what is going to happen.
- plan to get the woman smoothly on the table. Some need a lot of help. It's important to have a team approach with this. One does nursing assessments ahead of time with the patient getting on the table to be sure they can do it or not.
- tell them all the restrictions such as not being able to drive for 10 days
- should have a list of restrictions that can be shared with the patients
- having the patient have a good experience will ensure they come back for future ones if needed.

Who communicates/directs the first steps for a newly diagnosed breast cancer patient?

- Example #1:
  - radiologist notify the patient that it is positive have a surgical consult available, the care is from this point on handled by the surgeon
- Example #2:
  - any positive result, the pathologist will page the doctor who is on the order
  - everyone is given their follow up appt at the time that they have their biopsy. If they don't show up, we call a couple of times then send certified letter.

- if they don't come back, they're afraid so it's a matter of tracking them down
- once they are back, we get everything lined up for them.
- Example #3:
  - set up an appt at the breast cancer clinic
  - if they don't make it to their oncologist or surgeon appointments, they call the navigators and we follow up
  - let any programs know if they are affiliated with one
- Example #4:
  - if patient comes in to get the result, the patient sits with the radiologist and a nurse or navigator to receive the result.
  - we explain what the next steps are
  - make their appointments
- General Comment
  - women tend to ask "what is my stage?"
  - try to explain the grade verses the stage
  - try to calm the patient as when they hear the word "cancer" they get panicked.
  - tell them there is nothing they did or didn't do to cause this
  - encourage all to create a pathway for patients so the burden doesn't have to fall into the primary care doctors hands. Only 29% of the task
  - force hospitals have the ability to navigate the patient. Encourage them to send their patients to those with breast cancer experience.
  - patients have changed doctors when having to wait for a long time for results
  - have had physicians that will not let the patients know they have cancer and let the surgeon tell them. This could be that the PCP doesn't feel comfortable discussing the options with the patient.
  - encourage patients to write down question they have for the surgeon

What situations may change the approach to care?

- send to breast care clinic, see the oncologist and the surgeon at the same time
- go over the diagnosis with them, (ER/PR, etc), tell them if they are going on the internet to look up only their type of cancer, go through the pathology stage and grade.

What external organizations do you direct patients to?

- Educare (Breast Cancer Handbook, an excellent resource, but take out the page with survivor names, as some listed are deceased)
- ACS (has a personal care manager organizer journal for patients)
- Sister's Network
- Gilda's Club
- Susan G Komen <http://ww5.komen.org/BreastCancer/UnderstandingBreastCancer.html>
- Cancer 101 (has an organizer for free you can order from them)

- tell patients to be careful where they get their info from, not just from anyone, get from legitimate sources
- Why Me
- NCCN guidelines has a patient flow sheet
- Breast cancer organizer journals -help patients ask the right questions.
- There is a challenge getting resources in other languages.

What else do patients need to support their treatment planning? Who's responsible for tracking patients in your organization?

- Example #1:
  - track all the 4's, 5's and 0. At the end of the month, get a list of all patients with these BIRADS and be sure they attended their appointments
  - if a patient has missed that appt, send a certified letter, but first call them. Get the PCP involved too with a call.
- Example #2:
  - with our 3 navigators, follow up on all BIRADS 0's, 3's, 4's and 5's
  - if patient needs a biopsy, that whole chart comes to me. If they need a 3 month follow up, it goes to one of the other navigators. Charts are easily accessible to all who may need to see if that navigator is away.
- Example #3:
  - Use a paper system, essentially a "bible" with a line for each patient to keep track they came back for their biopsy. Even techs then have a quick access to what happened with the patient. The team can access this info quick.
  - techs can learn from this book that what they saw biopsied to what. Can see what was ordered.
  - it's important that staff can find the data fast. If the patient feels you are stumbling for info, leaves them uncomfortable. This book allows us to stumble less.
- Example #4:
  - use a form with 2 copies. One given to the patient to take to the front desk to make the appt and the second one is given to me and I track them with it.
- Example #5:
  - all diagnosed patients are presented at Breast Conference. If the surgeons don't have them on their list the navigator knows to follow through. Very few of our patients are referred out, but we'll double check on them.

Who make sure the patients gets to all the specialists down the line?

- Example #1:
  - Oncologists or the surgeons ask the navigators to assist them with this. We navigate the patient from abnormal mammogram all the way to once treatment has started.

- navigators chart everything, the appointments. If they missed an appt, we will call the patient and ask if they can be of help.
- call after each phase of treatment to be sure the next appt is set up. Uses a roster type method to keep track, using a paper system
- Example #2:
  - have a breast planning clinic for who received what the previous week
- Example #3:
  - all of our newly diagnosed are sent to Multidisciplinary Clinic so they see all the specialists in one day
- General Comment
  - if patient is not reachable by phone, send certified letter
  - if letter is returned, contact the physicians. Track who ever saw the patient last to try to get a hold of them.
  - it is important to let patients know how to get a hold of you. Especially with patients whose phone numbers/addresses change often.
  - it's important to let patients know there are a lot of steps in this process and give them the sense that it is their responsibility as well to keep track.
  - have patients on an Excel spread sheet where we can view each other's data to help us stay on top of who we are case managing.

What do sites with no Navigators do?

- don't have enough resources
- only 52% of the Task Force sites track patients
- they may not have enough volume
- trying to come up with a Shared Navigator role for institutions who have none
- love to see the Excel spread sheet example for site that don't have other means.

Where are the biggest frustrations for patients?

- delay with no previous screens
- delay with getting biopsy, out of patient's control
- transportation issues
- not getting the referrals needed. Can take up to 2-3 weeks.
- co-morbidities, cumbersome to be cleared for surgery. Can take 5-6 weeks.
- poverty patients get care here and there where they can get it, hard to follow
- undocumented people, huge delay, all have to go to Stroger only
- going across organization walls

Survivorship

- 6 week boot camp funded by Live Strong. Patients have been so taken care of and when they are done with their treatment, might be uncomfortable being told they don't have to see anyone for a year.

- ASCO has a good template for a survivorship care plan
- NCCN has some disease specific survivorship care plans
- have started a monthly education meeting. We explain that they are survivors since the day they were diagnosed.
- include the care givers for support
- IBCCP can't get follow up care as a survivor, will put on the list for the task force to follow up on. For those who are below 133% of the Federal Poverty act, you will remain eligible for Medicaid until eligible for Medicare or when able to hopefully afford insurance through the exchange (Health Care Reform)
- co-morbidities that patients are at risk for due to their treatments. They need to be supported with this. Need more education on these side effects to PCPs.

### **Evaluate Performance and Revise Actions**

#### ***- What are some actions you may take?***

- Evaluate how you interact with patients and identify improvements
- Update your knowledge of all aspects of breast cancer treatment
- Ask to attend a tumor board/breast conference, talk to colleagues and/or read up (resources: [www.chicagobreastcancer.org](http://www.chicagobreastcancer.org) , <http://www5.komen.org/BreastCancer/Treatment.html> , Breast Cancer Treatment Handbook).
- Provide your patients with a list of resources (websites, phone numbers, and support groups).
- List issues/challenges you encounter, share with co-workers (and task force), work together on solutions

### **Evaluate Performance and Revise Actions**

#### ***- What are some actions you may influence in your organization?***

- Encourage a small pilot/test of directing newly diagnosed patients to a breast focused surgeon and/or comprehensive breast cancer clinic
- Encourage scheduling all new breast cancer patients on a specific day of the week so they can meet back to back with surgical oncologist, medical oncologist, radiation oncologist, etc.
- Evaluate how your site tracks and interacts with breast cancer survivors, look for opportunities to improve.