

Using Technology to Expand Genetic Testing: Recognizing and Empowering Those at High Risk in Community Settings

Tenille Oderwald, RN, BSN, CN-BN
OSF HealthCare

Feyi Olopade Ayodele, MBA
CancerIQ CEO and Founder



We have no financial
disclosures



Agenda

- Background
- Overcoming Challenges
 1. Identifying and referring high risk patients
 2. Scaling genetic counseling services
 3. Building a high risk clinic and managing patients over time
- Patient Impact Story

Background

- **629 Bed Hospital**
 - Level 1 Trauma Center
 - NAPBC and CoC Certified
 - 26 County Region in Central IL
- **Breast Center**
 - 4 Sites
 - Over 30,000 Patients/Year
 - 23,000 Screening
 - 9,000 Diagnostic
 - 416 New Cancers Diagnosed in 2017

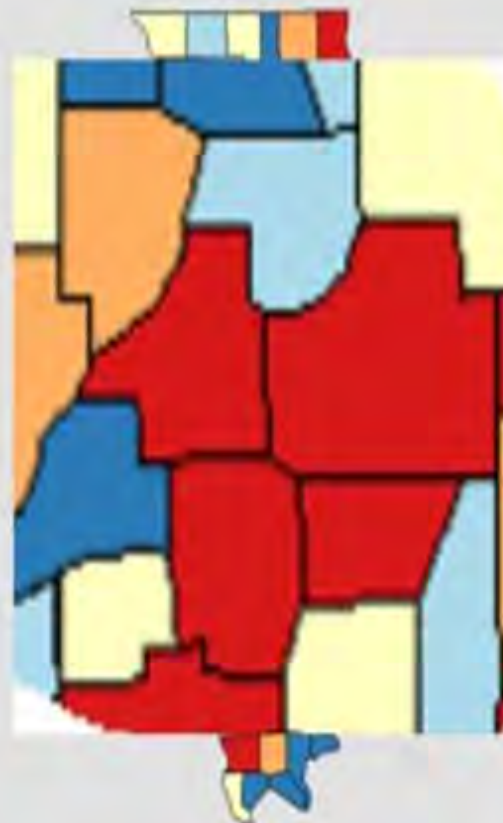


A QUALITY PROGRAM
of the AMERICAN COLLEGE
OF SURGEONS



Incidence Rates for Illinois

Incidence Rates[†] for Illinois
Breast, 2011 - 2015
All Races (includes Hispanic), Female, All Ages



Age-Adjusted
Annual Incidence Rate
(Cases per 100,000)

[Quantile Intervals](#)



US (SEER + NPCR)
Rate (95% CI)
124.7 (124.4 - 124.9)

Illinois
Rate (95% CI)
131.7 (130.5 - 132.9)

Notes:

[State Cancer Registries](#) may provide more current or more local data.

Data presented on the State Cancer Profiles Web Site may differ from statistics reported by the State Cancer Registries ([for more information](#)).

[†] Incidence rates (cases per 100,000 population per year) are age-adjusted to the [2000 US standard population](#) (19 age groups: <1, 1-4, 5-9, ..., 80-84, 85+). Rates are for invasive cancer only (except for bladder which is invasive and in situ) or unless otherwise specified. Rates calculated using SEER*Stat. Population counts for denominators are based on Census populations as modified by NCI. The [1968-2013 US Population Data](#) File is used for SEER and NPCR incidence rates.

Data for the United States does not include data from Puerto Rico.

Breast Cancer Statistics 2015-2018

OSF Healthcare Saint Francis Medical Centers for Breast Health

	# of women diagnosed by age group 2015	% of women diagnosed by age group 2015	# of women diagnosed by age group 2016	% of women diagnosed by age group 2016	# of women diagnosed by age group 2017	% of women diagnosed by age group 2017	# of women diagnosed by age group 2018 Jan-June	% of women diagnosed by age group 2018
< 40	18	4.6%	14	3.0%	21	4.7%	10	5.4%
40 - 49	54	13.7%	67	14.4%	53	11.8%	24	13.0%
50 - 59	91	23.0%	96	20.6%	89	19.8%	34	18.4.0%
60 - 69	108	27.3%	171	36.8%	143	31.8%	56	30.3%
70 - 79	85	21.5%	88	18.9%	105	23.3%	46	24.8%
80 - 89	35	8.9%	25	5.4%	39	8.7%	15	8.1%
> 90	4	1.0%	4	0.9%	0	0.0%	0	0%
	395	100.0%	465	100.0%	450	100.0%	185	100.0%

The Problems

- The Patient
 - Multiple referrals
 - Delayed treatment
 - No clear process
- The Family Members
 - No clear follow-up
 - No management
 - Confusion and poor satisfaction

What can we do?



What We Did

- Investigated software programs
- Engaged administration support
- Engaged local oncology practice



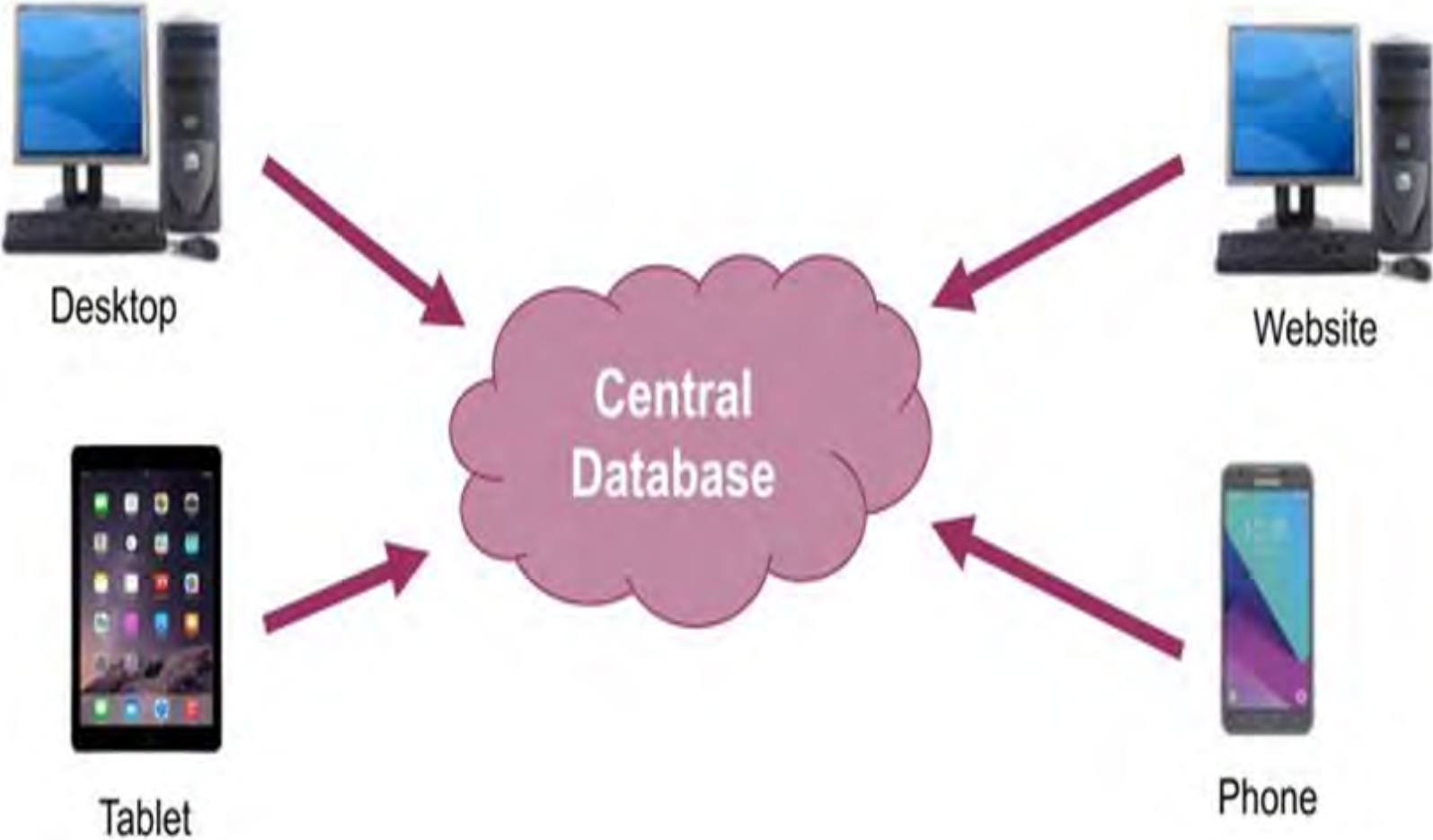
Cancer IQ – 2014


- New innovative start up company
 - Short web-based tool
 - Worked with our needs
- Working from ground zero
 - Multiple planning sessions
 - Trial runs
- IRB approved Clinical Trial
 - “Innovative Technology to Improve Navigation for Genetic Cancer risk Assessment Services”

Problem #1

**Identifying Patients and Generating
Referrals to Genetics**

Central Database with Cancer IQ



A person's hands are holding a black tablet computer. The tablet screen is dark grey and displays white text. The background is a vibrant, colorful sky with pink, purple, and blue hues and white clouds. The text on the screen is centered and reads: "Allow the patient to enter own data into a database", "Decrease the labor intensive effort required of clinicians", "Automatic analysis", and "Pedigree creation".

Allow the patient to enter own data into a database

Decrease the labor intensive effort required of clinicians

Automatic analysis

Pedigree creation

Cancer IQ Survey

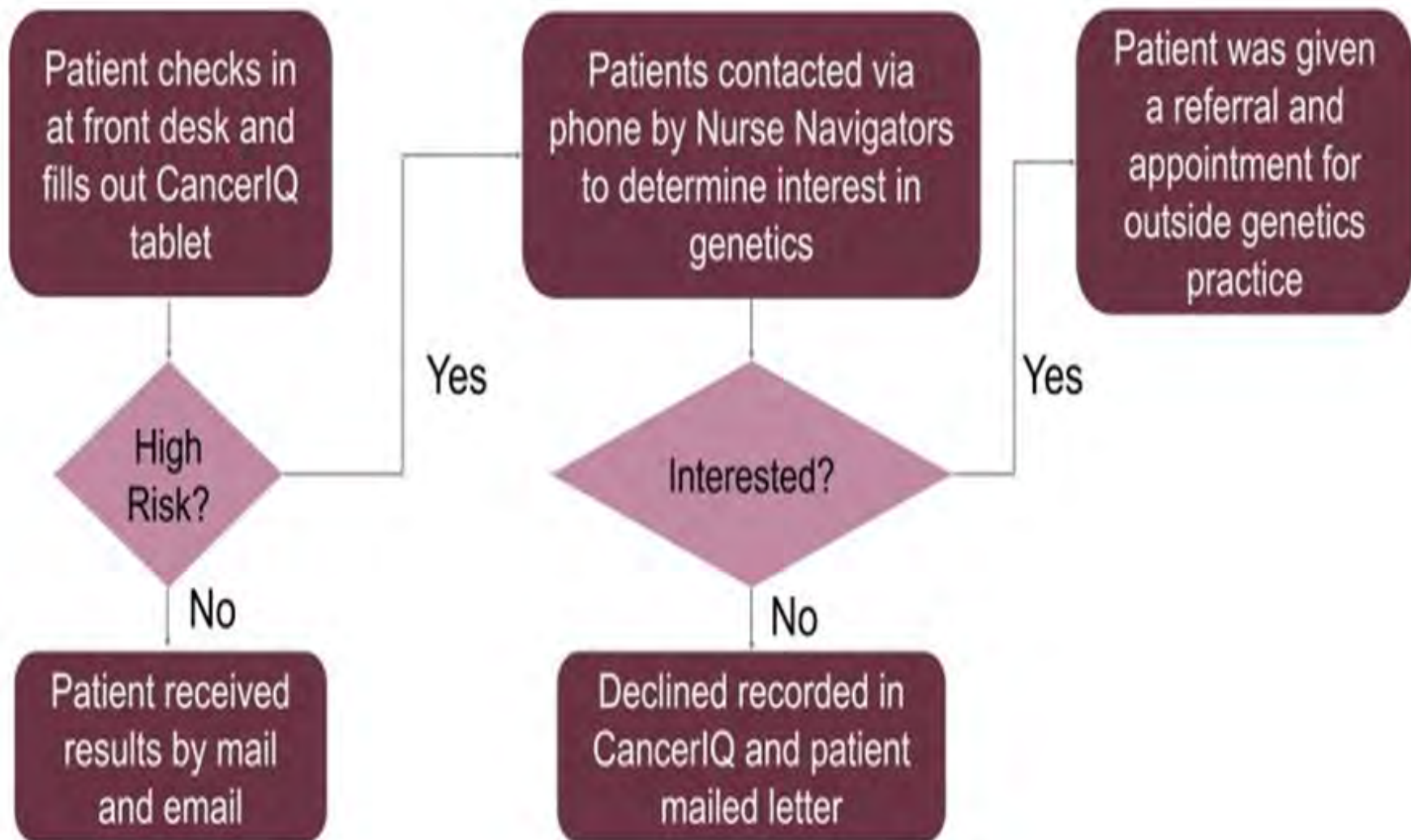
Complete your

 Cancer IQ

screening survey today to
learn your cancer risk and
take action!



Initial Implementation – Referral Model



Screened Patients Archived

Screened Patient Registry

Export New Assessments

Name	Age	Hboc	Hrcc	Priority	Survey Date Taken	Consent	Method Preference	Status	Appointment	Contact
Test Patient17	48	High	Low	High	05/05/2015	Yes	None	Email Opened		
Test Patient18	37	High	Low	High	05/13/2015	Yes	None	Email Opened		
Test Patient19	30	High	Low	High	05/13/2015	Yes	None	Email Opened		
Test 1 Test	37	High	Low	High	05/13/2015	Yes	None	Email Opened		
Rain Rummy	41	High	Low	High	08/05/2015	Yes	Email	Email Opened		
Jasmine Test	38	High	Low	Med	02/27/2015	Yes	Email	Email Opened	Feb 28, 2015 11:30 AM	
Janet Dow	54	High	Low	Med	02/27/2015	Yes	Email	Email Opened	Feb 28, 2015 4:45 AM	
Test Patient34	68	High	High	Med	06/02/2015	Yes	None	Email Opened		
Test Test	68	High	Low	Low	09/14/2015	Yes	Email	Email Opened	Sep 14, 2015 11:22 PM	
Test Patient37	79	High	Low	High	05/14/2015	Yes	None	Email Sent		



Tracey Atkinson

Date of Birth: 09/13/1957

Age: 57

Gender: Female

Language: Polish/Dutch No

Admitted: Yes

Contact

✉ habo@canceriq.com

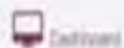
● 354 N Michigan Ave
Unit 3900 Chicago, IL
60601

☎ (877) 261-4423

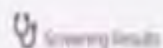
Preferred Time of Contact:

? around noon

Phone



Dashboard



Screening Results



Contact History

Intake Results for Tracey Atkinson

How did you contact Tracey Atkinson?

Phone



4719-08-02

 Action Required Pending Response

Called patient but she was unavailable

Cancel

Add

Today



Habo entered notes for Tracey Atkinson

Sample Comment that I entered
8/12/19 12:00 PM

Today



Tracey Atkinson status was changed to Email Sent

8/12/19

Today



Tracey Atkinson status was changed to New

8/12/19

Education

- Average Risk
 - Annual Mammography
 - Continue annual breast exam with provider
 - Encourage Breast Self Exam
 - Healthy Lifestyle
- Even at average risk, still at risk
 - Biggest risk factor is being a female



Education (Continued)

- Increased Risk
 - Stress Importance of Annual Screening
 - May need additional screening with MRI or Ultrasound
 - CBE, BSE
 - Healthy Lifestyle
 - Genetic Testing Education

How Lifestyle Affects Your Cancer Risk

Now we'll talk about ways to manage risk when it comes to alcohol, diet, exercise, and smoking.

Alcohol



Studies have found an increased risk of breast cancer due to alcohol drinking. A study brought together research on a total of 58,000 women with breast cancer. This study showed that women who drank more than 45 grams of alcohol per day (about three drinks) had 1.5 times the risk of developing breast cancer as nondrinkers (a modestly increased risk).

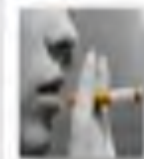
Diet & Exercise



Research has shown that being overweight or obese greatly raises a person's risk of getting endometrial (uterine), breast, prostate, and colorectal cancers. Overweight is defined as a body mass index (BMI) of 25 to 29. Obesity is defined as a BMI of 30 or higher.

Regular physical activity is important for good health. It is especially important if you're trying to lose weight or to maintain a healthy weight.

Smoking



Tobacco smoke is a mixture of more than 7000 chemicals. Many of them are poisons. When these chemicals get deep into your body's tissues, they cause damage. Your body must fight to heal the damage each time you smoke. Every cigarette you smoke increases your risk for developing cancer.

Above and Beyond Software



customer
success lead



implementation
strategist



product
specialist

Continuing
Process
Improvement



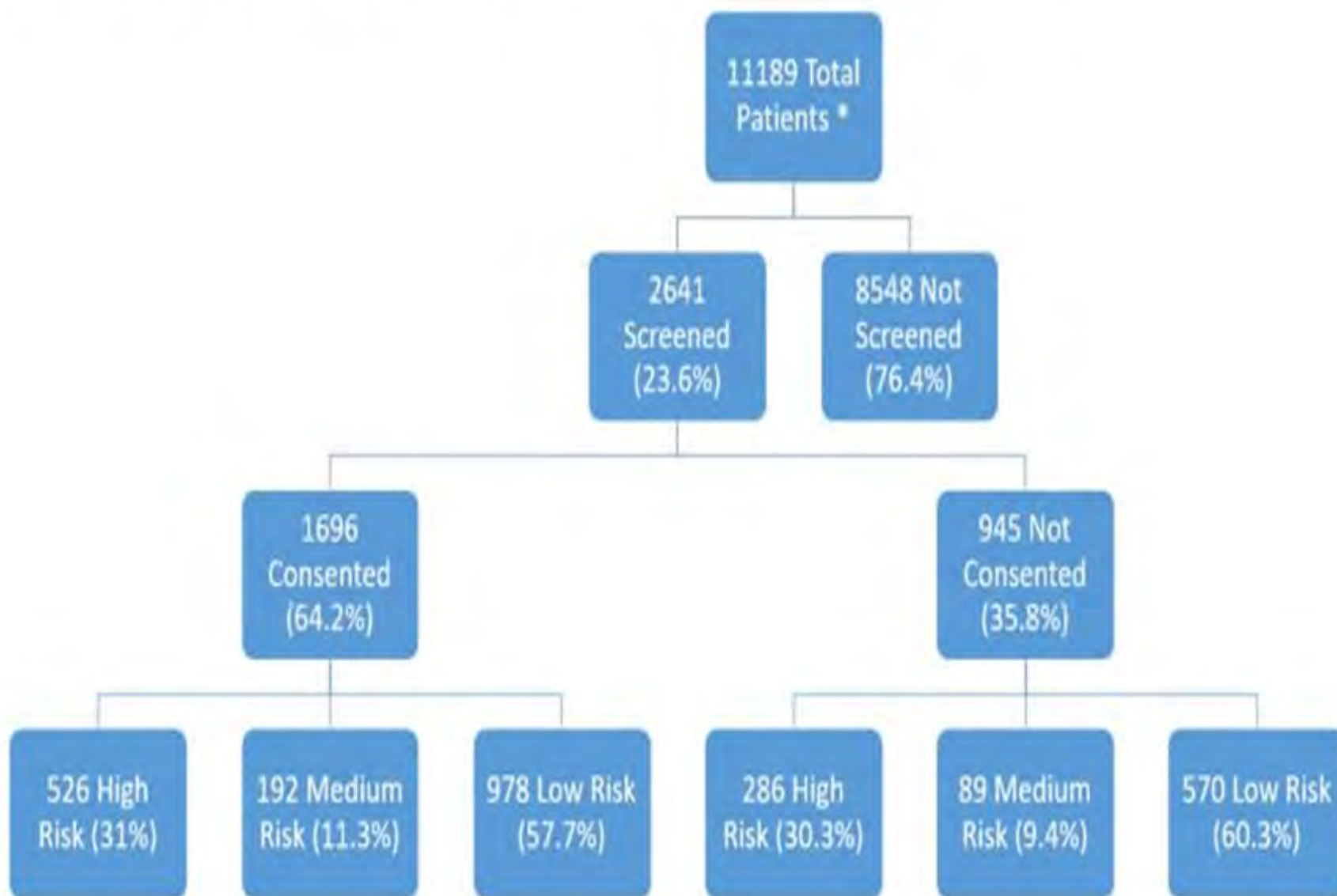
Workflow Analysis



Launch Marketing



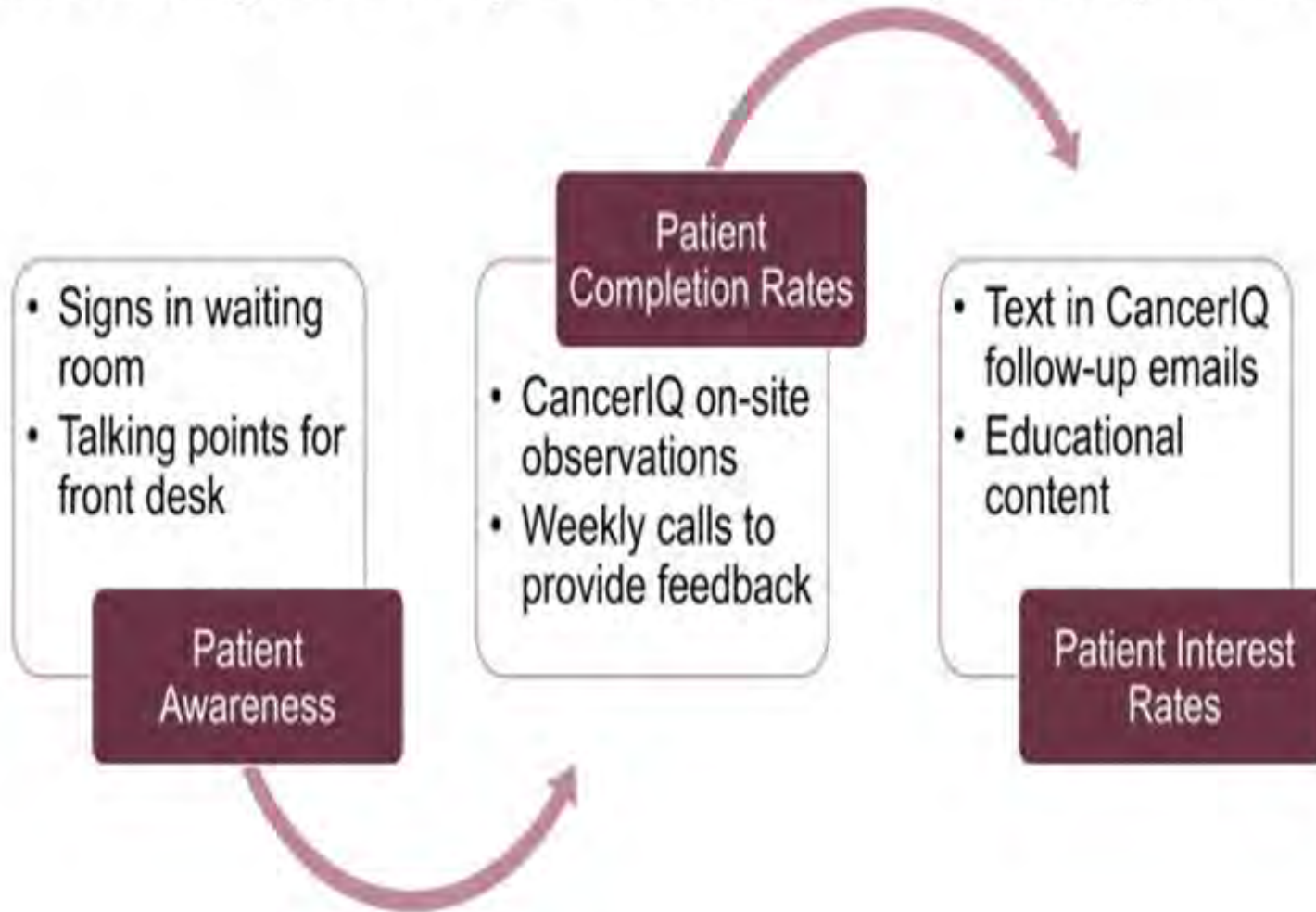
Referral Model Sample Weekly Outcomes



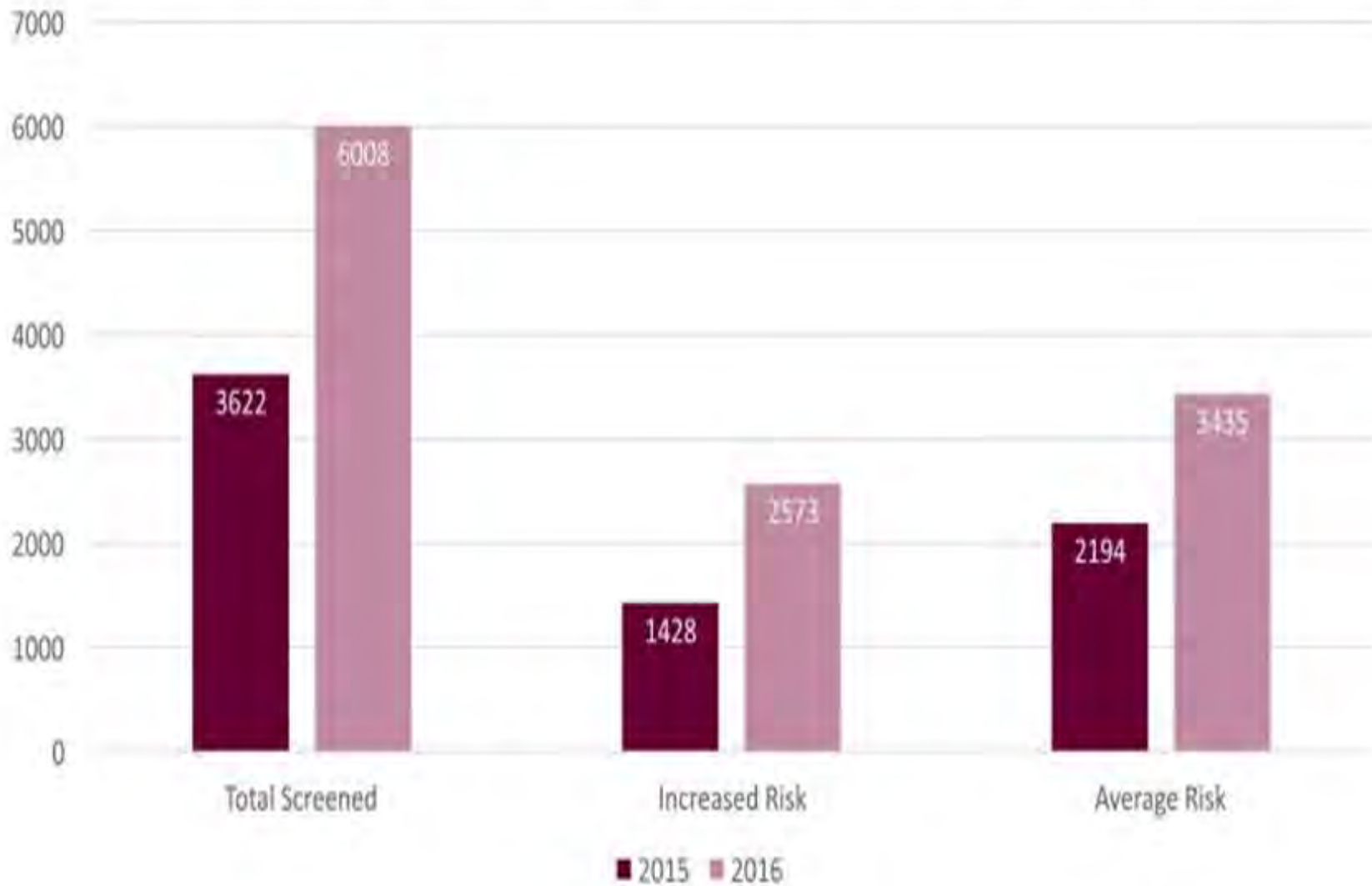
* This is as of 8/12/2015

Software Implementation/Planning

Used data generated by CancerIQ to identify & solve problems



2015 and 2016 Data – OSF HealthCare SFMC



Problem #2

**Hiring a Genetic Counselor so Patients
Could be Seen in a Timely Manner**

Problems Encountered

- Time consuming
 - Call all of the high risk patients
 - Lots of phone tag
 - Delay in contact
 - Potential loss of patients to follow
- Outside facility referral for genetic counseling
 - University center mainly focused pediatrics
 - Cancer center was overwhelmed referrals and prioritized affected patients



Hiring an APN vs. a Genetic Counselor

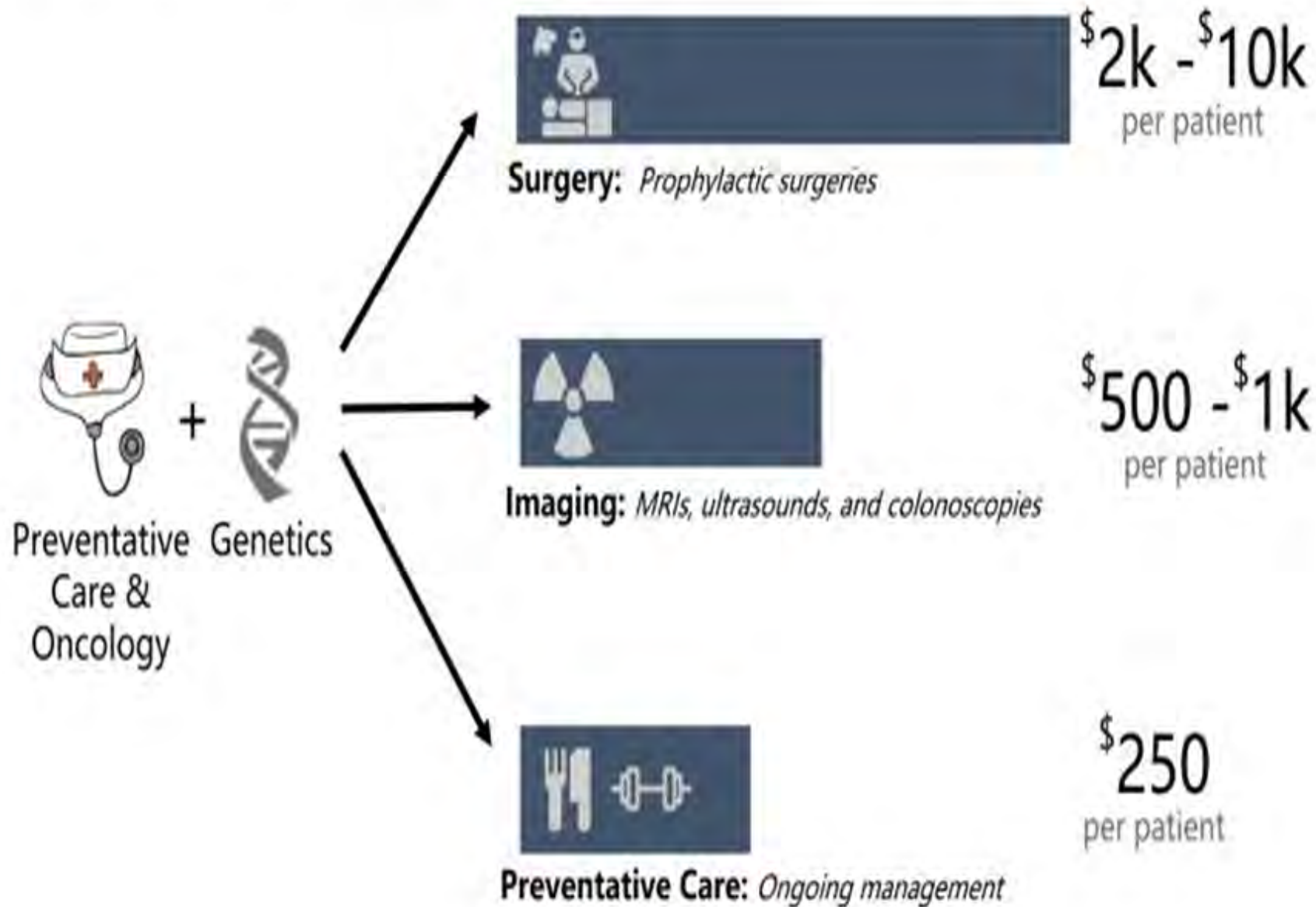


- Offer pre-test counseling
- Interpret testing results
- Offer post-test counseling
- **Difficult to recruit, hire, and retain**



- Offer pre-test counseling
- Interpret testing results
- Offer post-test counseling
- **Bill for E&M services**
- **Offer comprehensive care**
- **Take management off the plate of the PCP**

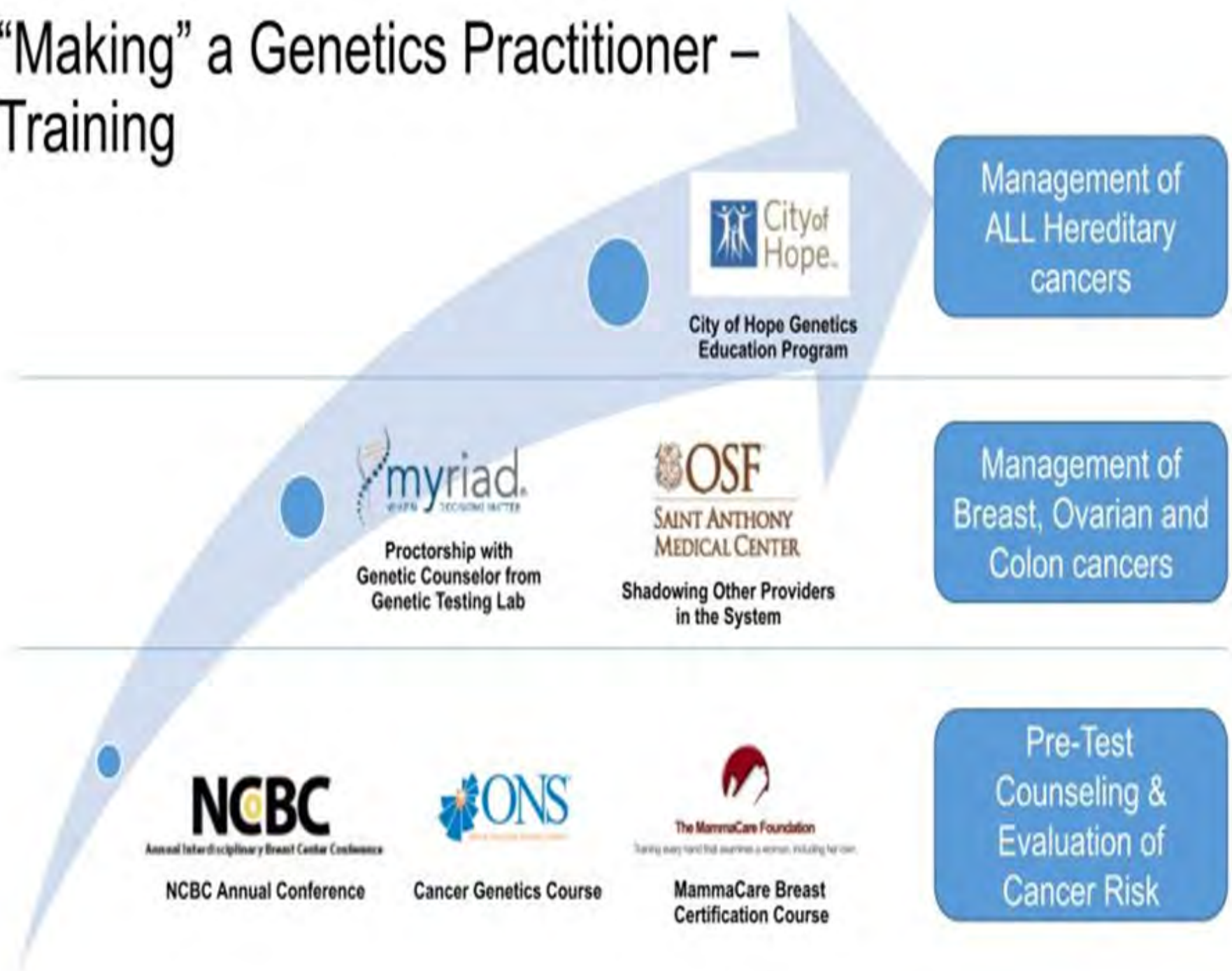
“Making” a Genetics Practitioner – Business Justification



“Making” a Genetics Practitioner – Job Description

- Meets with patient
 - Reviews personal and family history
 - Calculates risk assessment models
 - Genetic Counseling/Testing
- Follow-up appointment for results disclosure
 - Develop personalized cancer prevention plan of care
- Ongoing care management
 - Annual clinical breast exams
 - Management of preventative therapies
 - Ordering MRIs

“Making” a Genetics Practitioner – Training



Management of ALL Hereditary cancers

Management of Breast, Ovarian and Colon cancers

Pre-Test Counseling & Evaluation of Cancer Risk

How? Marketing the Program

- **Referring Physician Marketing**

- Physician group meetings to introduce the program
- 1-page referring physician "guide"
- Fax-ready referral letters at outside provider offices

- **Patient Marketing**

- TV/Radio spots on all local networks
- Social Media and website marketing
- Community Health Fairs



OSF HEALTHCARE Women's Health

Breast Cancer High Risk Assessment

Women's Health

- Programs & Services
- Resources
- Classes & Events
- Community Based Services
- Health Library
- Prevention Clinics
- Self Assessments
- Breast Cancer
- 1200 W. Third St
- Urbana
- 800.848.8484

OSF HealthCare's Health of Women Program, Breast Cancer Risk Assessment (BCRA) is a risk factor medical history and questionnaire that helps identify women at high risk for breast cancer.

With no known changes to breast cancer screening guidelines, it is for all women with average risk. The following steps should be followed:

The BCRA is designed to evaluate your risk for breast cancer, whether you already know your mammography results or not. Your response to the BCRA will determine your next steps.

How Do Breast Cancer High Risk Assessment Work?

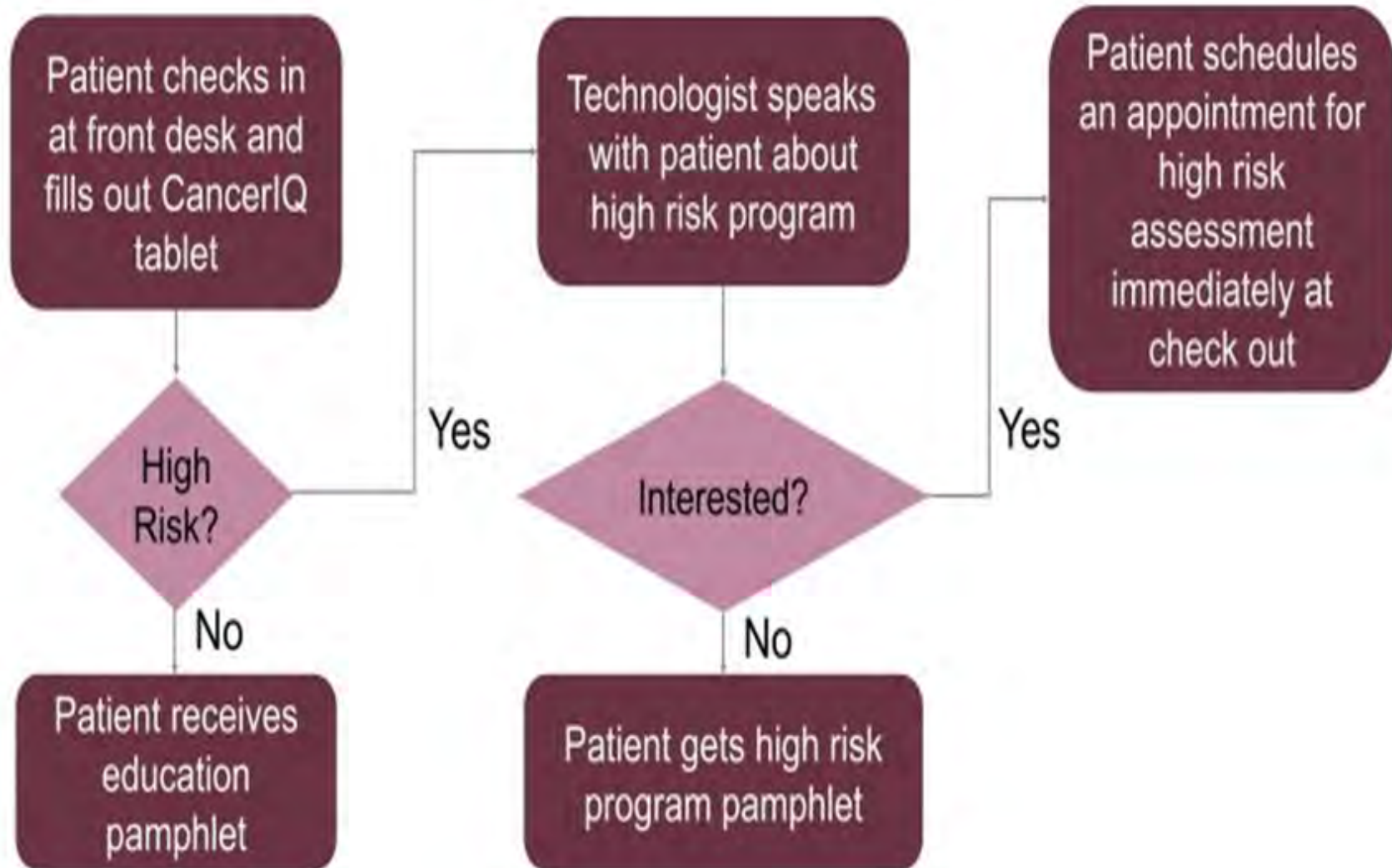
During your mammogram appointment, you will be asked to take the BCRA. The assessment only takes a few minutes to complete.

As a private area, you will be asked to answer a series of questions on a secure tablet or computer.

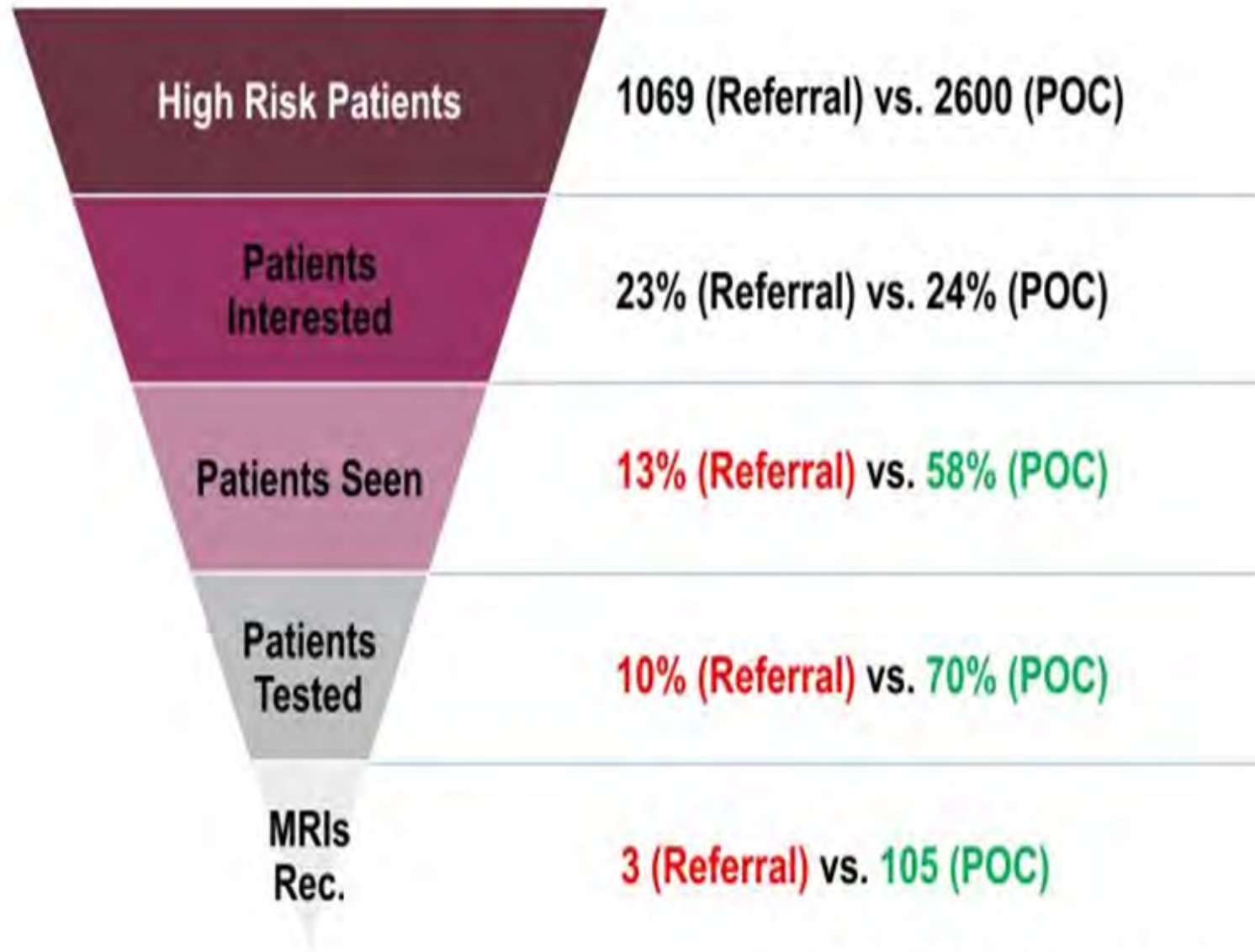
The questions are designed to calculate your risk for breast cancer. You will receive your results immediately.

If the BCRA determines you have a higher risk for developing breast cancer and other types of cancer, you can call for follow-up counseling with one of our advanced genetic testing experts. Specialists for this service are available at our OSF sites.

Current Implementation – Point of Care Scheduling



Results



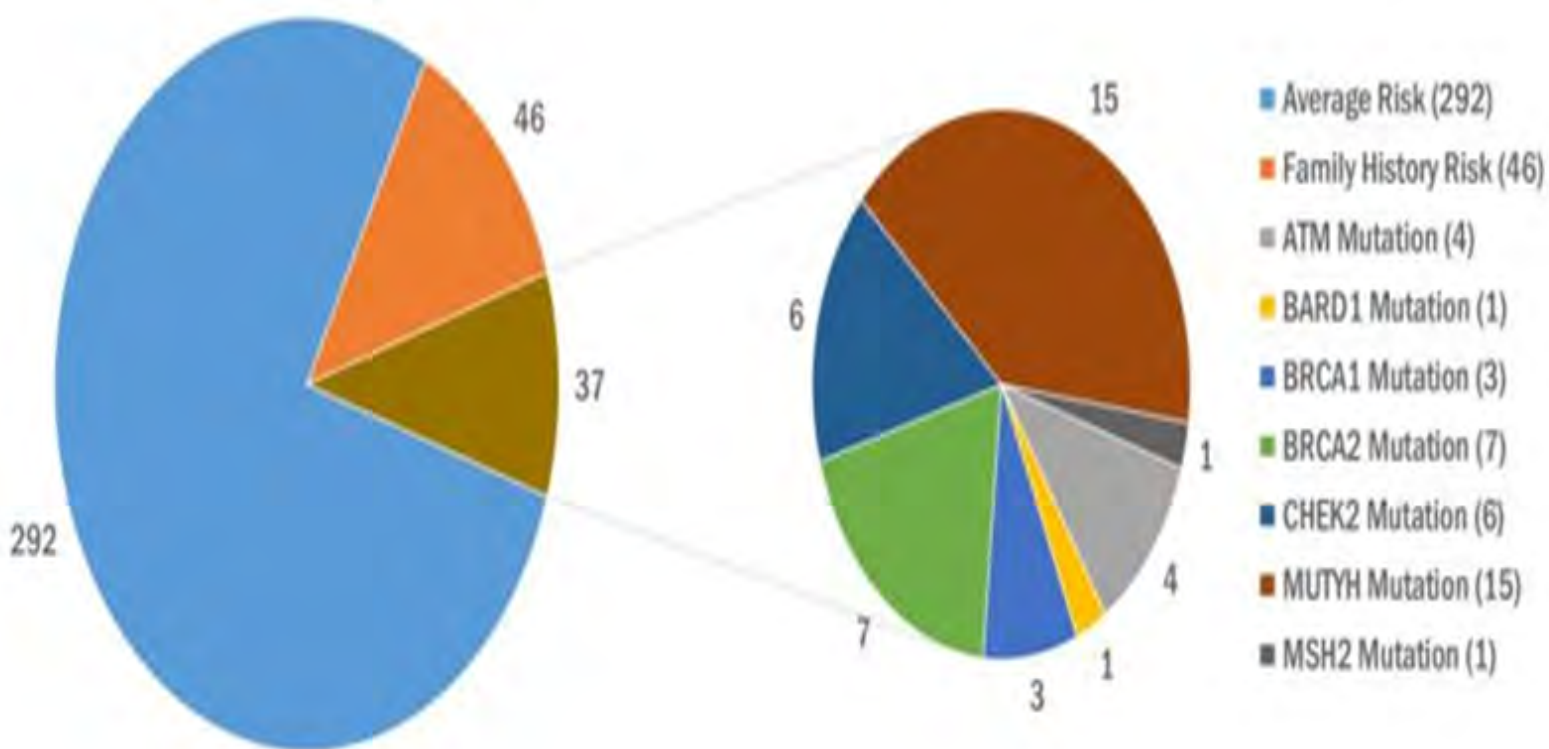
*Results are from 8 months prior to 8 months following APN hire

Problem #3

Managing Patients Over Time

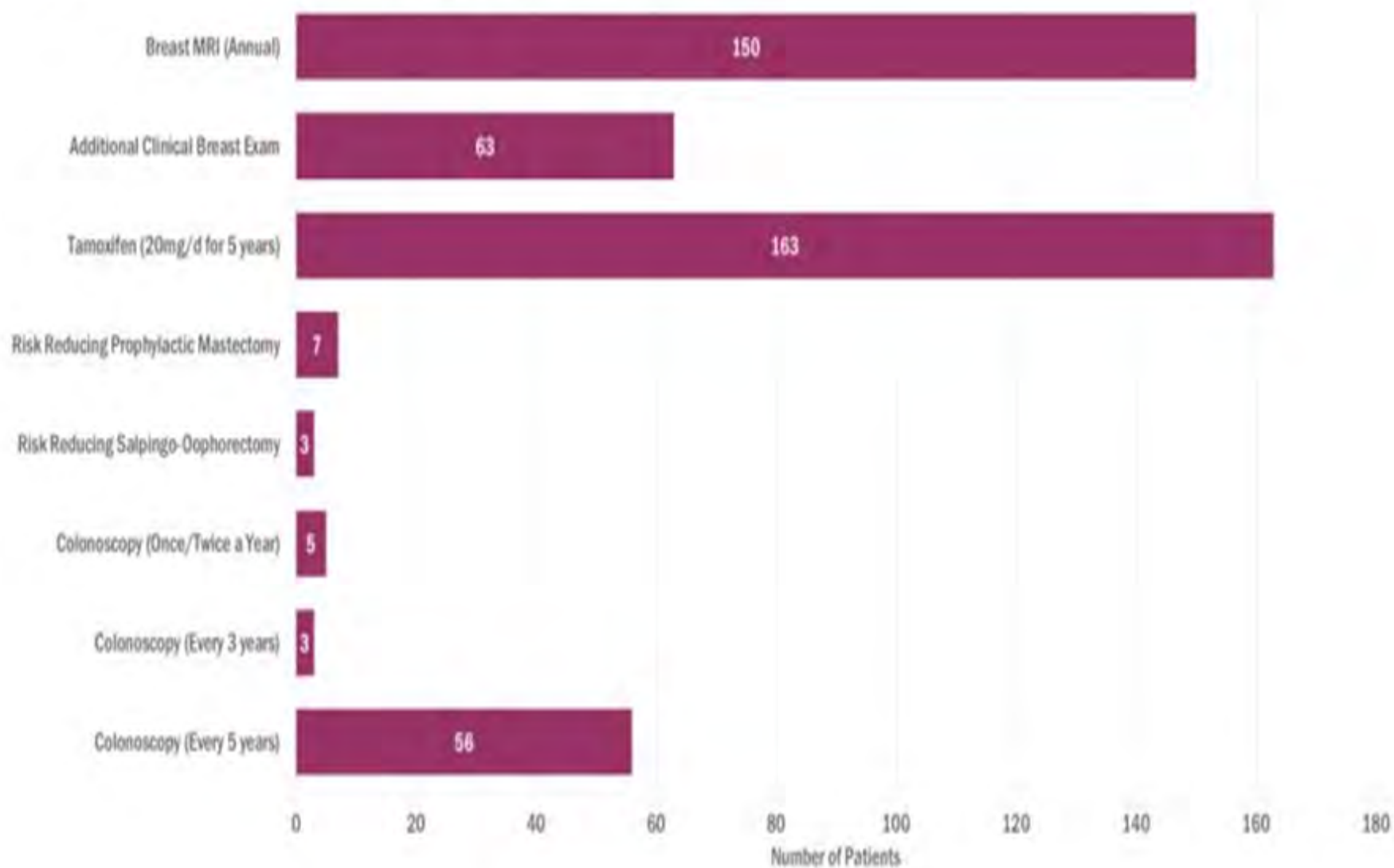
Genetic Evaluation Outcomes

Genetic Testing Outcomes




Recommended Changes in Medical Management

Breakdown of Medical Management Changes Recommended




Name	Care Plans	Due 
Electra Natchios	Breast MRI (Annual) 	27 days ago
Margot Robbie	Exercise and Wellness Program 	17 days ago
test test	Breast MRI (Annual) 	2 days ago
Sinai Demo	Breast MRI (Annual) 	Today
Wonder Woman	Tamoxifen (20mg/d for 5 years) 	2 days
Meryl Streep	Breast MRI (Annual) 	69 days
RWJBarnabas Demo	Breast MRI (Annual) 	683 days
Jamie Doe	Other 	N/A
Cheryl Crowe	Genetic Counseling 	N/A
Super Woman	Tamoxifen (20mg/d for 5 years)	N/A











Margot Robbie

Date of Birth: 01/01/1971
Cell Phone: +1 (000) 765-4321



Care Plans

- Tamoxifen (20mg/d for 5 years)   
- Exercise and Wellness Program 
- Nutrition Counseling 
- Breast MRI (Annual)   

Case Study-Mary

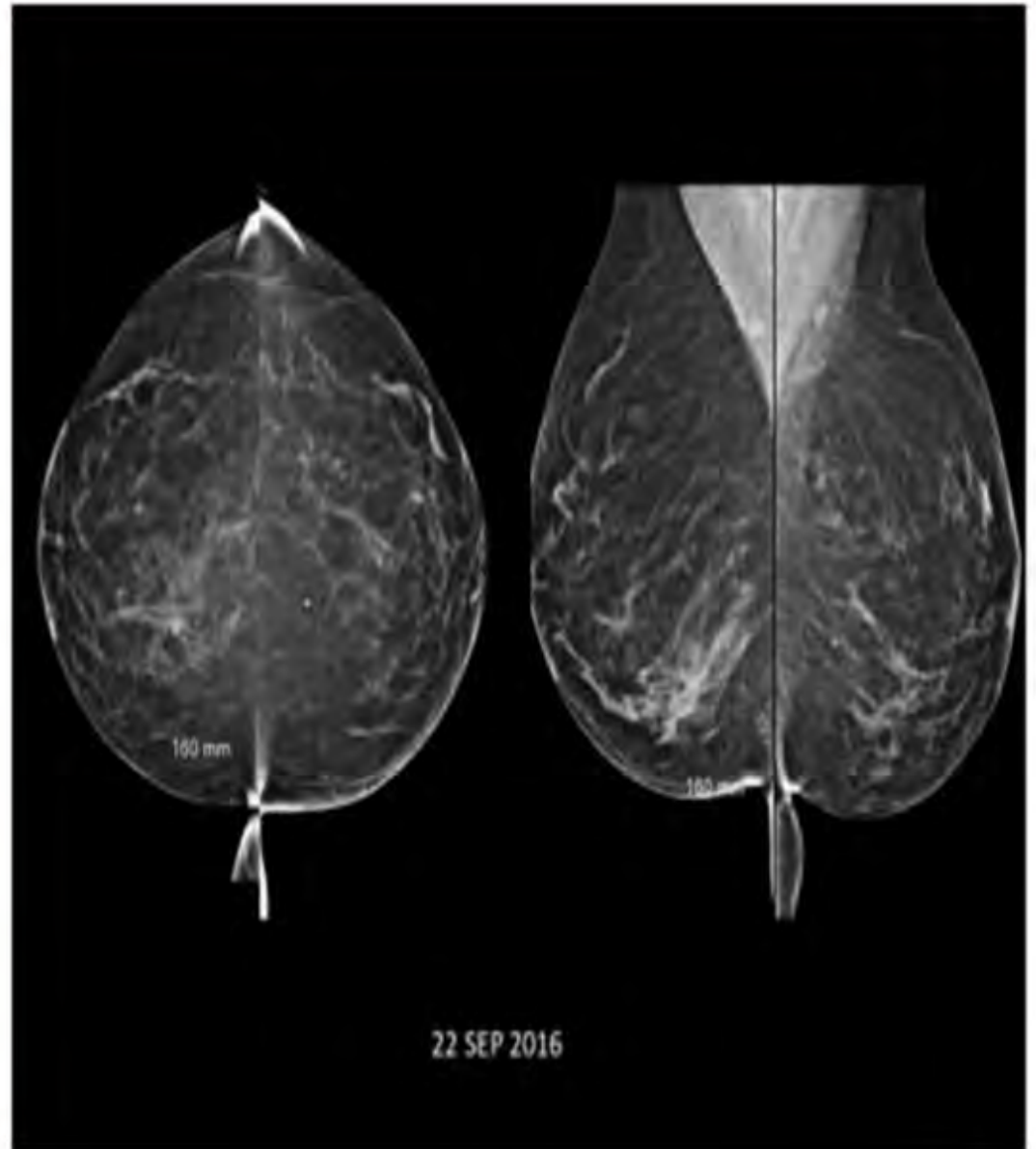
Patient Information:

- Female, Age 42
- Premenopausal
- Menarche: age 15
- Gravida: Para 1
 - Age at first birth 34

Baseline Mammogram

- Normal Result

Patient took Cancer IQ
Risk Assessment Tool



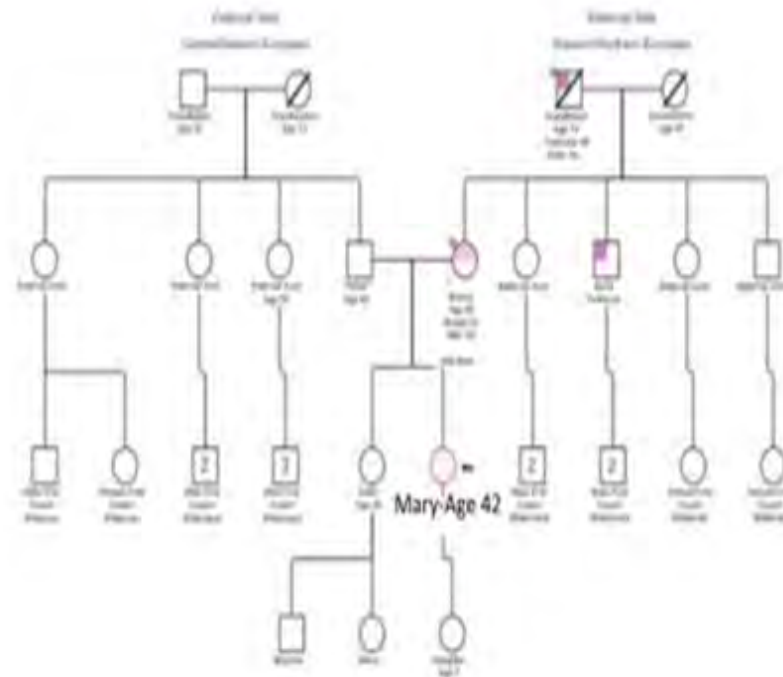
Case Study-Mary

Patient reports:

- BSE: Occasionally
- CBE: Annually
- Pelvic exam: annually, normal

Family History:

- Mother: Breast CA age 52 and 60 (bilateral)
- Maternal Grandfather: Testicular CA Age 66
- Maternal Uncle: Testicular Age Unknown



○ Breast Cancer

○ Breast (Both Breasts)

□ Testicular

Case Study-Mary

Risk Models:

- Gail Model 5 yr: 1.22%
- BCSC 5 yr: 1.46%
- Claus Lifetime: 9.87%
- Tyrer-Cuzick Lifetime:
31.33%

NCCN Guidelines:

- Mom with bilateral
breast cancer

**Meets Criteria For
Testing**



Case Study-Mary



Recommendations:

- Breast Exams
- Mammography
- Breast MRI
- Preventative Surgery Options
- Yearly Pelvic Exam
- Colonoscopies
- Comprehensive Physical Exams
- Mutation testing for family members

Case Study-Mary

- Patient was referred to Breast Surgeon to discuss options
 - CBE, preventative surgery, Chemo-prevention medication
- Bilateral Breast MRI completed 6 months post mammogram
- Bilateral suspicious enhancing lesions-Biopsies recommended



Case Study-Mary

Biopsy Results:

Right: Atypical papillary
lesion
(High Risk Lesion)

Left: Ductal Carcinoma In
Situ
Stage 0-Early Breast Cancer

Plan of Care:

- **Bilateral Mastectomies with reconstruction**
- **No Additional Treatment Needed for Cancer**
- **Continue surveillance for other cancer**

Case Study-Mary

- Missed Opportunity
 - Genetic Testing completed sooner than age 42, before breast cancer occurred
 - Patient's family history could have been evaluated earlier with mom
- Personal Impact/Outcome
 - Early Breast Cancer Diagnosed-Great Survival Rate
 - Increase Surveillance-Proactive in her Health
 - Education Provided for Risk Reductions
- Family Impact:
 - Testing Recommended for Family
 - Proactive Screenings



If you had a chance to change your fate...would you?

-Merida

Conclusions

- **This program has successfully helped patients take control of their health**
 - Innovative web based survey
 - Complex Care planning created by an APN
 - Continued patient education and counseling
 - Reducing the chance of patients developing a hereditary cancer



Acknowledgements

- OSF Team
 - Mindy Thompson, Lindsay Vlaminck-RN Breast Health Navigators
 - Danette Doubet-Coordinator
 - Cindy Martin-Director of Women's Services
 - Vicki Shanklin-Manager OSF Centers for Breast Health
 - Technologists
- Cancer IQ
- Myriad Genetics Laboratory



Thank you for your
attention....
Questions?

