

Project Life and Research

Lesley Glenn- Patient Advocate
Dr. Mya Roberson - Researcher (Vanderbilt)



Voice your experience:

Reimagining cancer care delivery for people living with metastatic breast cancer

Overview

- Participate in a research study on care delivery for people living with MBC
- Engage in a 60-minute individual interview through phone or Zoom
- \$50 Visa gift card compensation for completion of interview

Eligibility

- Adult (18 years or older)
- Identify as living with de novo or recurrent metastatic breast cancer
- Have a way of being contacted (phone or e-mail)
- Ability to conduct interview in English
- Consenting to being involved in the study

Contact Us

- Study Principal Investigator (PI): Mya Roberson, PhD
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- Phone: (615) 875-2979
- Vanderbilt University Medical Center
- VUMC IRB #:

VANDERBILT UNIVERSITY
MEDICAL CENTER

[Link to information sheet and eligibility survey.](#)



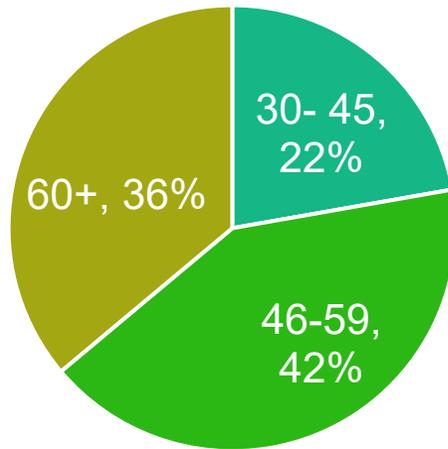
- Patient-partnered with Project Life and GRASP
- Goal: Understand key issues affecting people with MBC and the role of patient-created initiatives
- Funded by the Susan and Luke Simons Discovery Award for Health Equity

Research Objectives

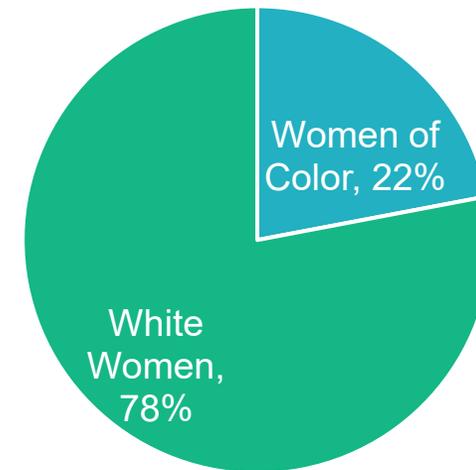
- Characterize how the COVID-19 pandemic affected MBC care delivery
- Describe how people living with MBC would reimagine care delivery
- Evaluate MBC patients experiences with Project Life, a patient-led online wellness community

Study Population

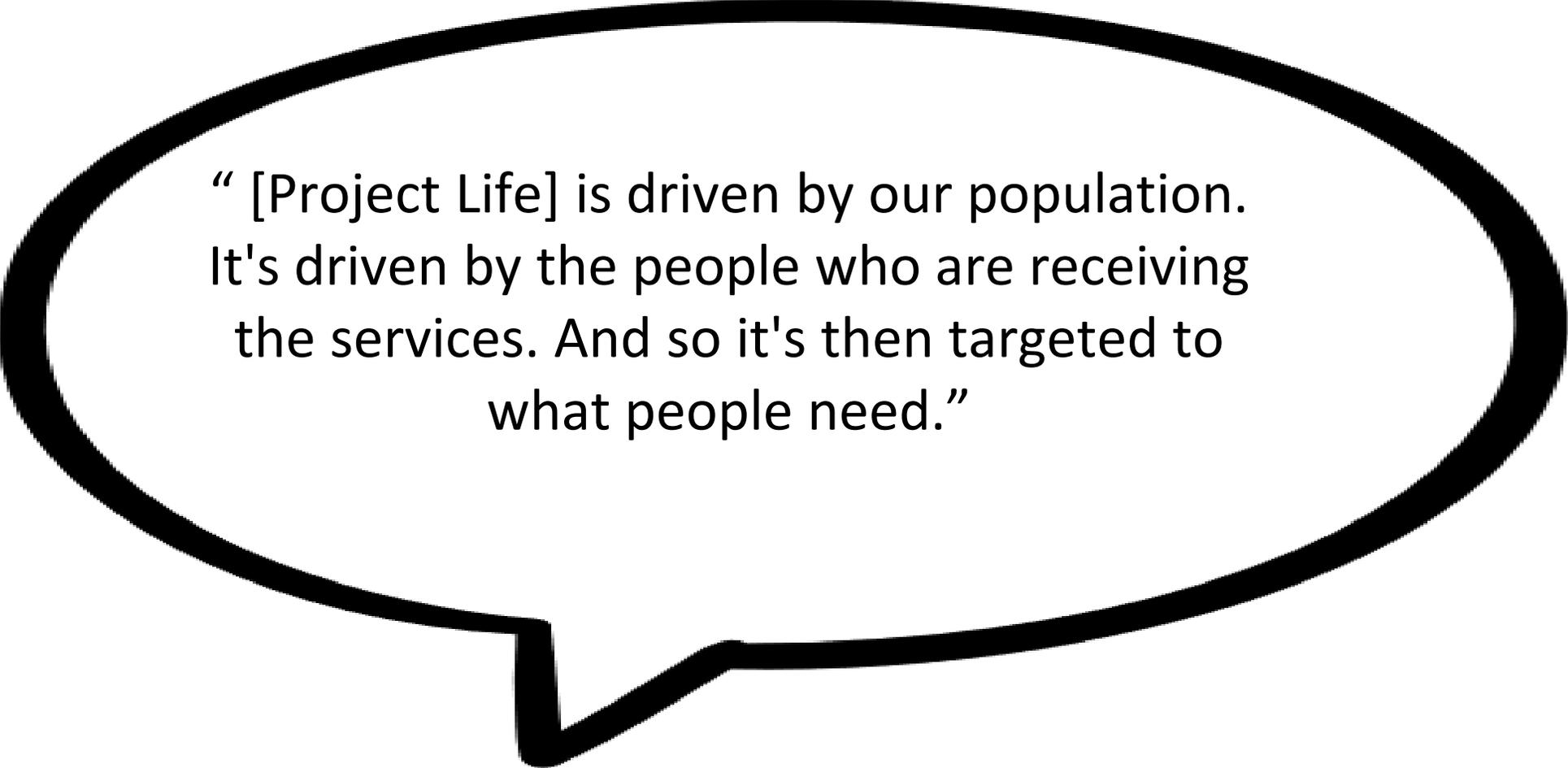
Age Distribution of Study Population (n=36)



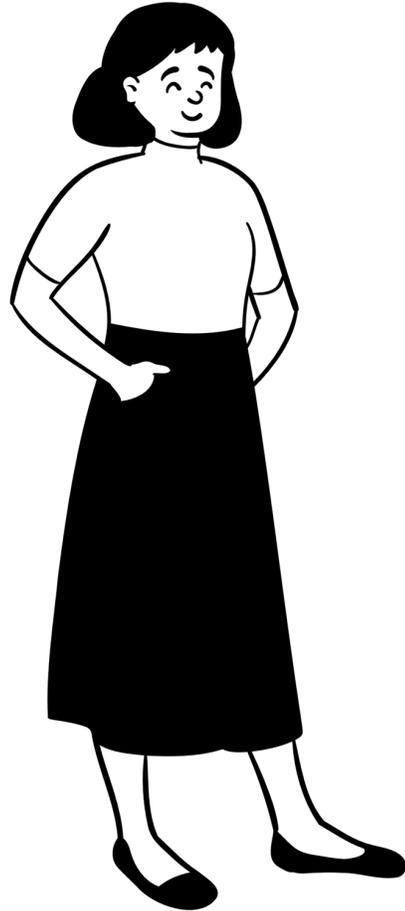
Demographic Distribution of Study Population (n=36)



The value of Project Life



“ [Project Life] is driven by our population. It's driven by the people who are receiving the services. And so it's then targeted to what people need.”



“Being around other people who are going through the same thing as me and to just the focus on, How do we live with this? Not, ‘The oh my gosh, we're all dying.’ But hey...It's just the focus on living.”

“We are a community. This is the shittiest club with the most amazing people. So we are extraordinary community who are there for each other.

So whenever something big like this, like, I think what Lesley did with Project Life is something beyond words, and it's so helpful for especially new diagnosed patients and caregivers that when someone is going to do something big like being is, we are all for it.”



Project Life Specific Programming

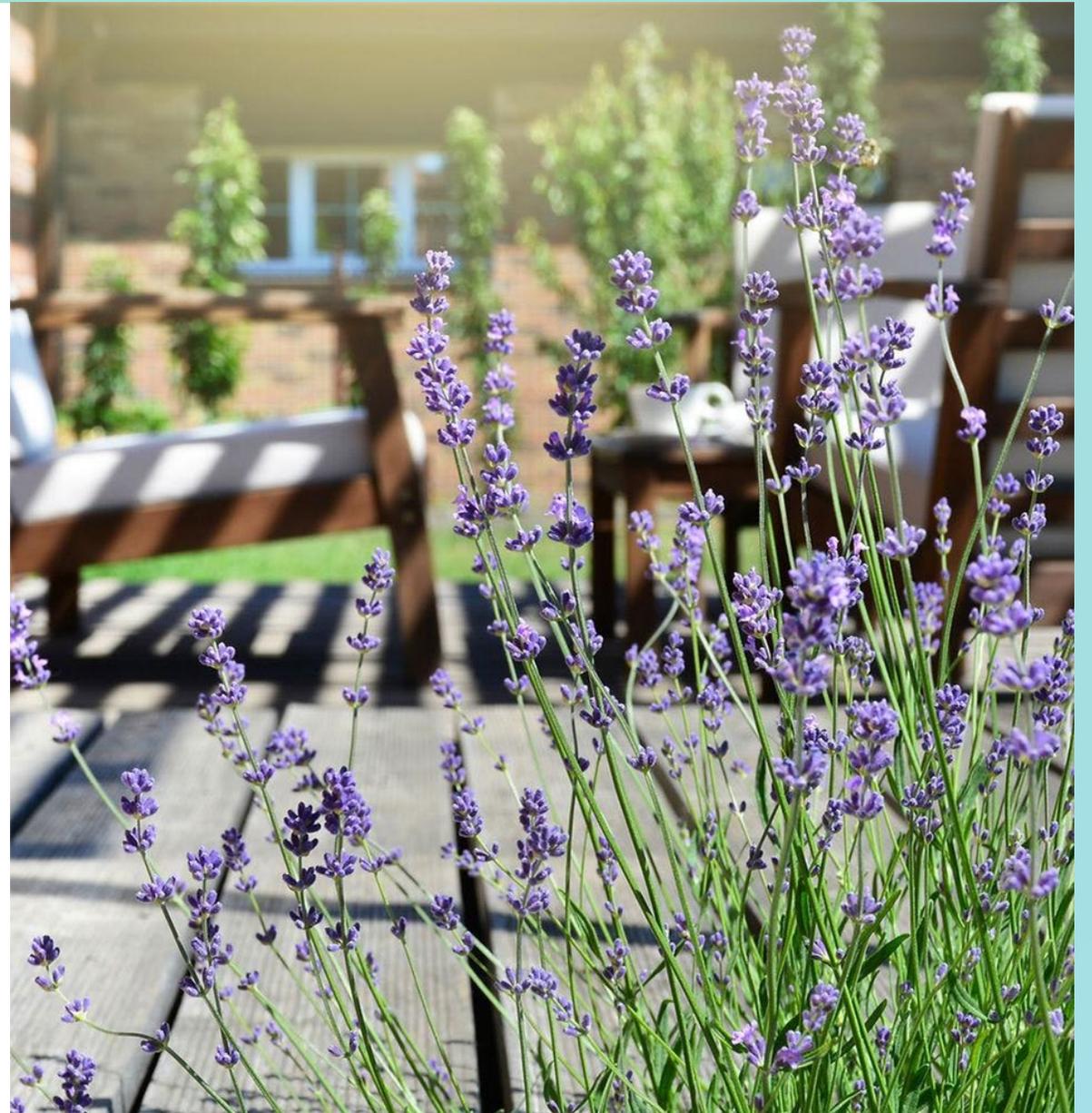


“While I do [therapeutic art] for surviving, but I also do it because I love it. And it's something that I can put my just my mind on my project, and I just forget about everything. “

“Abigail's legal class is so impactful because like her knowledge base is like [whoa], she gives like the resources, like it's like she's like a like a Google inside and she knows answer. So she knows how it could pertain to you, how to make it better and how we think about things I didn't think about as far, especially my estate planning. “



“The healing circles piece has been most helpful, not just because it moved me into an activity that I can then allow me to give back, but also. Because it, it fills my cup. I mean, there's purpose to it, there is opportunity, whether I'm hosting it or participating in if there's opportunity to take a deeper dive.”



Access to precision medicine and clinical trials



“So I did ask [my oncologist]... so for almost two years, I was taking letrozole and it really wasn't doing its job. Why wouldn't the insurance cover a liquid biopsy of some sort?”



“[Clinical trials] should be introduced as a treatment option when we're diagnosed. And so, I have to admit that wasn't immediately offered. It was like, ‘Hey, we're going to try this traditional chemotherapy.’”

...

“So in speaking with my peers, they had similar experiences where they were not provided with all of the options until they advocated for themselves.”

Next Steps:

- *interview patients who are not members of the wellness house
- *simple way to get resources into the hands of MBC patients at the moment of diagnosis.
- *Continue to focus on the whole person.

Contact Information.

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