

BMJ Open Community collaboration to improve access and outcomes in breast cancer reconstruction: protocol for a mixed-methods qualitative research study

Lily R Mundy,¹ Bryanna Stukes,² Moreen Njoroge,² Laura Jane Fish,^{3,4} Amanda R Sergesketter,² Sabrina M Wang ,² Valarie Worthy,^{4,5} Oluwadamilola M Fayanju,⁶ Rachel A Greenup,⁷ Scott T Hollenbeck^{2,4}

To cite: Mundy LR, Stukes B, Njoroge M, *et al.* Community collaboration to improve access and outcomes in breast cancer reconstruction: protocol for a mixed-methods qualitative research study. *BMJ Open* 2022;**12**:e064121. doi:10.1136/bmjopen-2022-064121

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-064121>).

Received 25 April 2022
Accepted 18 October 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Dr Lily R Mundy;
Mundy.lily@gmail.com

ABSTRACT

Introduction Breast reconstruction plays an important role for many in restoring form and function of the breast after mastectomy. However, rates of breast reconstruction in the USA vary significantly by race, ethnicity and socioeconomic status. The lower rates of breast reconstruction in non-white women and in women of lower socioeconomic status may reflect a complex interplay between patient and physician factors and access to care. It remains unknown what community-specific barriers may be impacting receipt of breast reconstruction.

Methods and analysis This is a mixed-methods study combining qualitative patient interview data with quantitative practice patterns to develop an actionable plan to address disparities in breast reconstruction in the local community. The primary aims are to (1) capture barriers to breast reconstruction for patients in the local community, (2) quantitatively evaluate practice patterns at the host institution and (3) identify issues and prioritise interventions for change using community-based engagement.

Ethics and dissemination Ethics approval was obtained at the investigators' institution. Results from both the quantitative and qualitative portions of the study will be circulated via peer-review publication. These findings will also serve as pilot data for extramural funding to implement and evaluate these proposed solutions.

INTRODUCTION

Breast cancer is the second most common cancer in women, with over 330 000 women diagnosed in the USA per year.^{1 2} After diagnoses of breast cancer, women must navigate the physical, emotional and financial impacts of undergoing cancer treatment. Cancer treatments, including chemotherapy, mastectomy and radiation, are influenced by tumour stage and patient preferences, and thus are highly variable and complex decisions.^{3 4} There are many women who elect not to pursue breast reconstruction for a variety of reasons. However, breast reconstruction continues to play an important role for many

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Study design and implementation is grounded in the needs of the community through community-based collaboration.
- ⇒ This study captures the experiences of black or African American women who are considering breast reconstruction.
- ⇒ The interview guide was designed to be comprehensive of factors surrounding breast reconstruction to best elucidate where barriers may arise.
- ⇒ This is a single-institution study, and findings may be generalised only to the study community.
- ⇒ Given the qualitative nature of the study, the findings may be biased by possible participant selection bias.

patients in restoring form and function following surgical resection of the breast.

In patients who elect to undergo breast reconstruction, the improvement in quality of life for many is substantial.⁵⁻⁷ As access to reconstructive breast care has increased in the USA, the rate of breast reconstruction following mastectomy has dramatically increased over the past 20 years.^{8 9} However, despite increasing overall rates of reconstruction, rates of breast reconstruction vary in different patient populations and due to different institutional structures.^{10 11} However, nationally in the USA, lower rates persist among minority patients and those of lower socioeconomic status.^{12 13} Similarly, the differences in rates of breast reconstruction by race and ethnicity at the investigators' institution and within the state of study are also significant. At the investigators' institution, after mastectomy, 33% of White women undergo breast reconstruction, compared with 16% of black and 15% of Hispanic women.¹⁴ This is in comparison to equal rates of reconstruction across race and ethnicity in other settings with adequate resources for

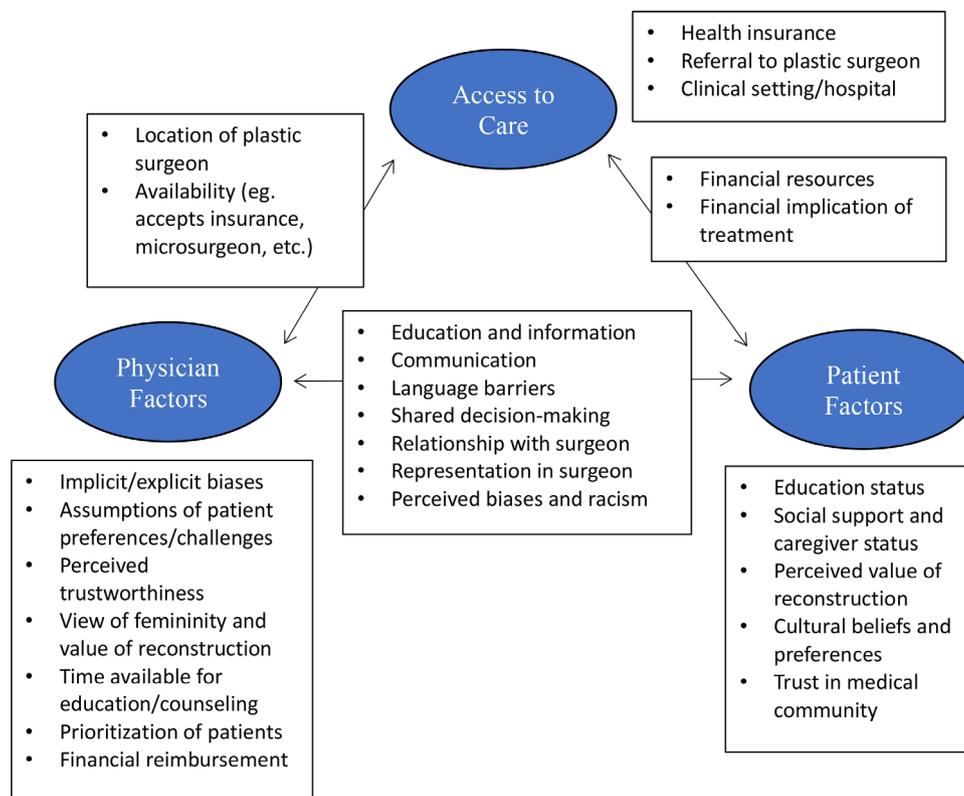


Figure 1 Preliminary conceptual framework of disparities in breast reconstruction.

traditionally underserved populations, suggesting opportunities for improvement.^{15 16}

The lower overall rates of breast reconstruction in non-white women and in women of lower socioeconomic status reflect complex interplay between patient and physician factors and access to care (Preliminary Conceptual Framework, [figure 1](#)). Pursuit of breast reconstruction is elective and has shown to be influenced by social and cultural norms, body image and identity, factors which may in turn be impacted by race and ethnicity.^{17 18} Furthermore, rates of reconstruction and patient satisfaction with surgical decision making is influenced by social and cultural history that may be outside of the control of an individual physician. This includes the presence of historical mistreatment and inadequate medical care, as well as perceived physician biases and racism.¹⁸ However, research to date exploring the barriers to reconstruction including the influence of race and ethnicity on receipt of breast reconstruction has focused on women from primarily northern USA and urban environments.^{17 19 20} The impact of race and ethnicity on rates of breast reconstruction in non-northern suburban, and rural areas is not well understood. Therefore, while significant disparities exist at the investigators' institution, it is unclear what factors are responsible for this finding.

The primary aims of this study are to (1) analyse barriers to breast reconstruction for patients in our local community, (2) quantitatively evaluate practice patterns at the host institution and (3) identify issues and prioritise interventions for change using community-based engagement. By identifying specific and actionable racial

health disparities in breast reconstruction to intervene on, we hope to improve the care of underserved patients in our community. Next steps will include the translation of any local success of this intervention to the national level. To achieve this goal, our team proposes a multipart, community-based collaborative approach ([figure 2](#)). Our hope is to ensure that all patients served by our health system who are interested in pursuing breast reconstruction are able to do so in an environment with sufficient education and preoperative counselling, in a process that is free of implicit bias.

METHODS AND ANALYSIS

This is a mixed-methods study combining qualitative patient interview data with quantitative practice patterns to develop an actionable plan to address disparities in breast reconstruction. The study enrolment period is targeted to run from March 2022 to March 2023 ([figure 3](#)).

AIM 1: Capture barriers to breast reconstruction for patients in the local community. Purposeful sampling will be used to recruit a diverse sample of black or African American women who have undergone mastectomy for breast cancer, with consideration for diversity in socioeconomic status and receipt of breast reconstruction in Durham, NC. Eligibility criteria will include women age 18 years or older, who speak English or Spanish, and are able to consent and conduct an in-person, video or telephone interview. Eligible patients will have had a mastectomy for breast cancer, and either considered or pursued breast reconstruction surgery. Patients will

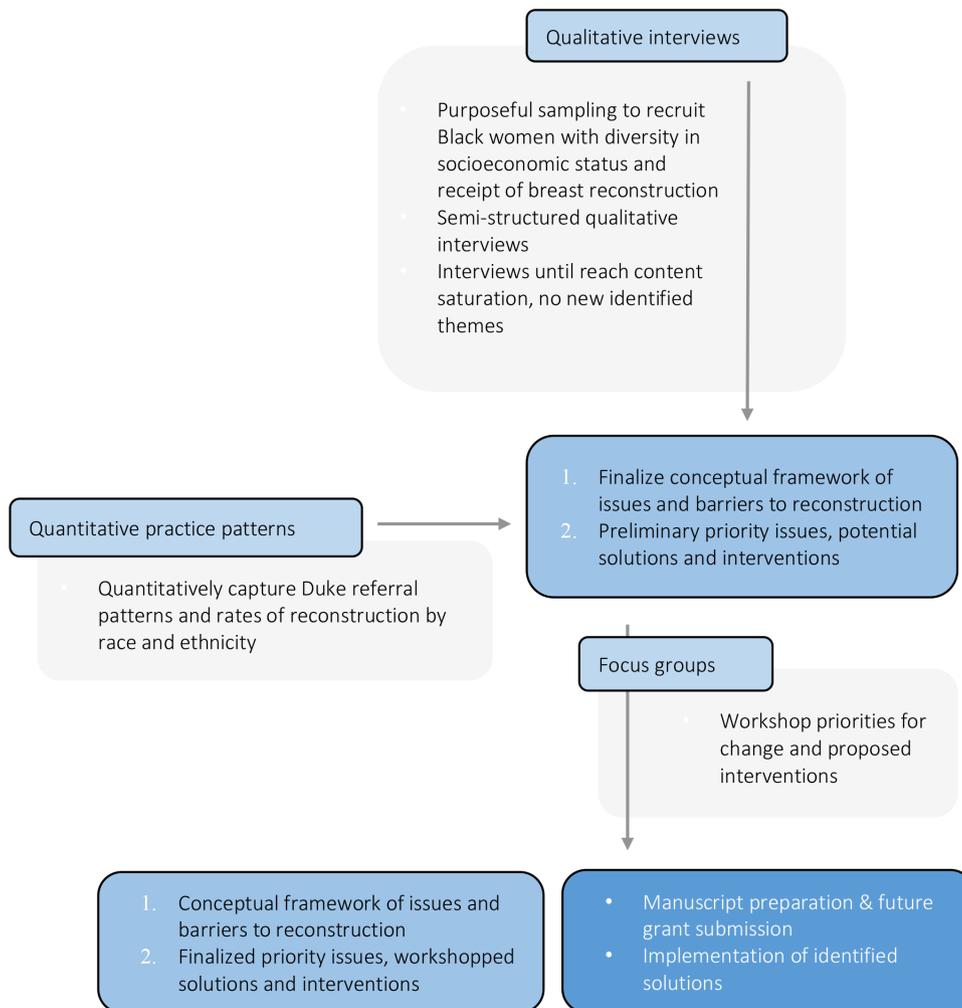


Figure 2 Study schematic.

be recruited through the breast oncology and plastic surgery clinics at Duke University, the statewide Duke Cancer Network, as well as through our community

partners. In addition, patients identified in the quantitative review in aim 2 will be potential patients for recruitment.

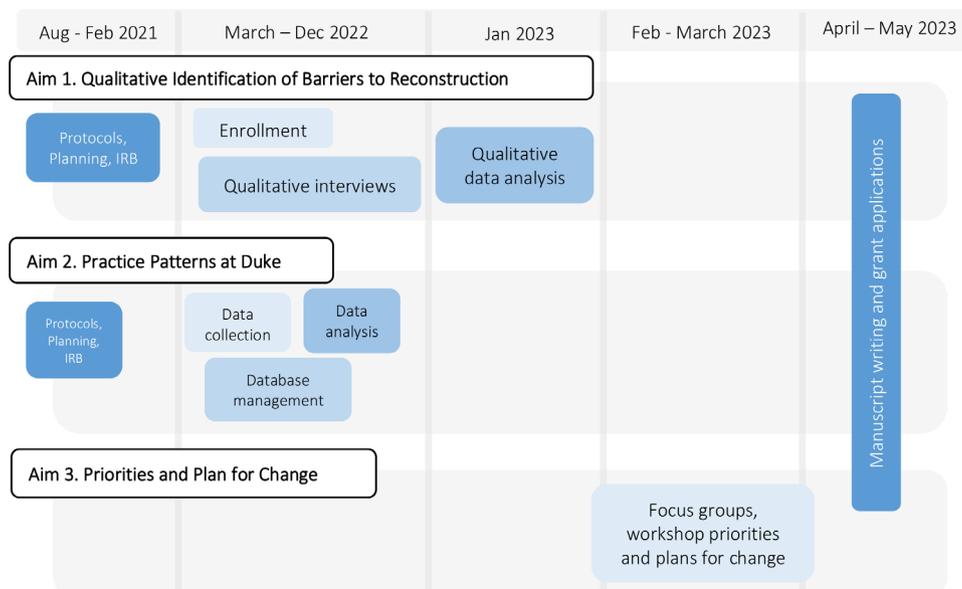


Figure 3 Interview guide.



Semistructured qualitative interviews, in English or Spanish, will be conducted to understand patient experiences, including barriers and issues faced while considering and pursuing breast reconstruction. An interpretive description approach will be used, combining theoretical knowledge from the literature with clinical knowledge from the research team to form a basis for the identification of key concepts and issues for the patient group.^{21 22} The interview guide is shown in online supplemental file 1. In patients who do not pursue reconstruction, the reasons behind this decision will be captured during the interview. Interviews will be conducted until content saturation is reached, that is, no new issues and barriers are identified.²³ Of note, establishing the point of content saturation has inherent subjectivity, as it is likely that with continued interviews, new issues and barriers would inevitably be revealed. However, content saturation will be reached when continued interviews add only marginal change to the overall conceptual framework of barriers faced by patients. We budgeted for 35 interviews, to ensure we had adequate funding to capture relevant barriers faced by women of varying race, ethnicity, class, geographical status and other socioeconomic factors, in addition to barriers influenced by medical or surgical complications. It is estimated that interviews will last approximately 30–90 min in length. Participants will be adequately reimbursed for their time and travel with a participation stipend.

Qualitative interviews will be recorded and transcribed. Inductive qualitative data analysis will be performed to identify common themes and issues, and to refine the preliminary conceptual framework (figure 1). Each interview will be coded line by line to identify common issues and themes. These will be categorised top down in domains, themes and then subthemes. Interviews will be coded by clinical team members (BS, MN, SMW and LRM) and qualitative methods expert (LJF) to ensure consistency, reliability and validity in coding. Coding discrepancies requiring additional expertise will be brought up with the senior clinical team members (STH, OMF and RAG). Statements describing multiple concepts and/or themes will be coded multiple times to adequately capture each unique concept/theme. Each concept/theme will only be coded once per subject, independent of how many times a subject repeats the same concept/theme. The refined conceptual framework and qualitative data will be used to create a preliminary set of interventions and priorities for change.

AIM 2: Quantitative evaluation of practice patterns at primary institution. Preliminary data demonstrates significant disparity in breast reconstruction rates at the primary institution,¹⁴ however, it is unclear what factors contribute to this discrepancy. We will perform a retrospective review of all breast cancer patients treated in the Duke Health System from 2018 until the present. Descriptive analysis will be used to understand current practice patterns, including current demographics of the breast cancer and breast reconstruction populations, racial

and ethnic differences in rates and utilisation of plastic surgery referrals, offered reconstruction, completed reconstruction, and reconstruction type and complications. In addition to race and ethnicity, we will evaluate the influence of insurance status, medical comorbidities, cancer stage and oncological treatment. Following the descriptive analysis, a multivariable analysis will be used to identify racial, ethnic, and socioeconomic factors associated with rate of referral and/or receipt of breast reconstruction.

AIM 3: Determine issues and barriers, prioritise and workshop interventions for change using community-based engagement. Integrating the qualitative and quantitative data collected in the first two aims, the preliminary conceptual model will be revised. Using both the quantitative and qualitative data, a preliminary prioritisation of issues and potential interventions and solutions will be developed. We hypothesise that these community-based and system-based solutions will be multifaceted and include interventions to improve education, counselling, communication, community outreach and physician cultural bias training. A series of two to three focus groups with patients and community partners will be conducted to workshop the preliminary prioritisation of issues and potential solutions. The focus groups will be conducted by a member of the research team, with a second member of the team taking notes on participant perspectives and ideas. After each session, the issues and solutions will be revised, with the revised set of issues and solutions being presented to the next group. In between the revisions, the results of the focus group will be discussed with members of the healthcare team to evaluate for feasibility and possible implementation issues. The focus groups will continue until there are no significant changes to the proposed list of issues and initial solutions. It is estimated that this will take two to three focus groups. The goal will be for there to be 5–10 patients and/or community members at each focus group. This process will ensure our targeted interventions are grounded in the needs of the community we strive to serve. Extramural funding will be sought to implement and evaluate the proposed solutions for change.

In addition to the study aims, the data and analysis generated from this project will facilitate an evaluation of the internal processes at our institution from the perspective of the breast oncology and reconstructive plastic surgeons. Patient data generated will help our multidisciplinary surgical team evaluate our current multidisciplinary practices, role of shared decision-making in clinical encounters, level of informed consent and early versus delayed reconstruction among others.

Patient and public involvement

The study was designed in partnership with multiple community partners that represent both patient and community interests and needs.

ETHICS AND DISSEMINATION

Institutional review board (IRB) approval was obtained at Duke University, Durham, NC. This is a low-risk study. For aims 1 and 3, the risks are related to privacy of personal health information as well as the emotional impact of undergoing qualitative interviews. For aim 2, the risk is related to privacy of personal health information. To mitigate this risk for aims 1 and 3, patients will be offered support and mental healthcare if needed, as a result of the psychological impact of the interviews. For aims 1 and 3, patients are consented by a member of the study team via telephone. The consent process ensures that all efforts are made to maintain confidentiality. Patients are informed that personal information will be shared with members of the research team as necessary for analysis, collaboration, funding purposes and study regulation. Patients are informed that if they choose not to participate, then there will be no changes to their routine medical care.

All data collected will be stored and transferred using secure, IRB approved storage locations and transfer methods. Audio of the interviews will be transcribed by a Health Insurance Portability and Accountability Act (HIPAA) compliant, IRB approved transcription service that generates deidentified transcripts of the interviews.

The results of the qualitative and quantitative analyses, as well as finalised conceptual framework, priorities for change and workshopped proposed solutions will be circulated via peer-review publication (figure 3). In addition, findings will be circulated to our community partners using lay summaries. These findings will also serve as pilot data for extramural funding to implement and evaluate these proposed solutions.

Author affiliations

¹Department of Plastic and Reconstructive Surgery, Johns Hopkins University, Baltimore, Maryland, USA

²Division of Plastic and Reconstructive Surgery, Department of Surgery, Duke University, Durham, North Carolina, USA

³Department of Family Medicine and Community Health, Duke University, Durham, North Carolina, USA

⁴Duke Cancer Institute, Duke University, Durham, North Carolina, USA

⁵Triangle Chapter, Sisters Network, Raleigh-Durham, North Carolina, USA

⁶Department of Surgery, University of Pennsylvania, Philadelphia, Pennsylvania, USA

⁷Department of Surgery, Yale University, New Haven, Connecticut, USA

Twitter Bryanna Stukes @BryannaStukes

Contributors BS, MN and LRM were responsible for study planning and design, manuscript writing, development of figures and editing. LJF, SMW, ARS, RAG, OMF, VW and STH were responsible for study planning and design and editing.

Funding This work was supported by a US\$20 000 grant from the Kenan Institute of Ethics at Duke University, Durham, North Carolina, USA (grant number N/A).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been

peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Sabrina M Wang <http://orcid.org/0000-0001-9225-585X>

REFERENCES

- Breast cancer statistics | how common is breast cancer? Available: <https://www.cancer.org/cancer/breast-cancer/about/how-common-is-breast-cancer.html> [Accessed Mar 26 2022].
- Cancer data and statistics | CDC. Available: <https://www.cdc.gov/cancer/dccpc/data/index.htm> [Accessed Aug 5 2022].
- Alderman AK, Hawley ST, Wajee J, *et al*. Understanding the impact of breast reconstruction on the surgical decision-making process for breast cancer. *Cancer* 2008;112:489–94.
- Morrow M, Li Y, Alderman AK, *et al*. Access to breast reconstruction after mastectomy and patient perspectives on reconstruction decision making. *JAMA Surg* 2014;149:1015–21.
- Mundy LR, Rosenberger LH, Rushing CN, *et al*. The evolution of breast satisfaction and well-being after breast cancer: a Propensity-Matched comparison to the norm. *Plast Reconstr Surg* 2020;145:595–604.
- van Bommel ACM, de Ligt KM, Schreuder K, *et al*. The added value of immediate breast reconstruction to health-related quality of life of breast cancer patients. *Eur J Surg Oncol* 2020;46:1848–53.
- Eltahir Y, Werners LLCH, Dreise MM, *et al*. Quality-Of-Life outcomes between mastectomy alone and breast reconstruction: comparison of patient-reported BREAST-Q and other health-related quality-of-life measures. *Plast Reconstr Surg* 2013;132:201e–9.
- Sergesketter AR, Thomas SM, Lane WO, *et al*. Decline in racial disparities in postmastectomy breast reconstruction: a surveillance, epidemiology, and end results analysis from 1998 to 2014. *Plast Reconstr Surg* 2019;143:1560–70.
- Fu RH, Baser O, Li L, *et al*. The effect of the breast cancer provider discussion law on breast reconstruction rates in New York state. *Plast Reconstr Surg* 2019;144:560–8.
- de Ligt KM, van Bommel ACM, Schreuder K, *et al*. The effect of being informed on receiving immediate breast reconstruction in breast cancer patients. *Eur J Surg Oncol* 2018;44:717–24.
- Schreuder K, van Bommel ACM, de Ligt KM, *et al*. Hospital organizational factors affect the use of immediate breast reconstruction after mastectomy for breast cancer in the Netherlands. *Breast* 2017;34:96–102.
- Soni SE, Lee MC, Gwede CK. Disparities in use and access to postmastectomy breast reconstruction among African American women: a targeted review of the literature. *Cancer Control* 2017;24:1073274817729053.
- Kamali P, Ricci JA, Curiel DA, *et al*. Immediate breast reconstruction among patients with Medicare and private insurance: a matched cohort analysis. *Plast Reconstr Surg Glob Open* 2018;6:e1552.
- Fayanju OM, Yenokyan K, Ren Y, *et al*. The effect of treatment on patient-reported distress after breast cancer diagnosis. *Cancer* 2019;125:3040–9.
- Enewold LR, McGlynn KA, Zahm SH, *et al*. Breast reconstruction after mastectomy among department of defense beneficiaries by race. *Cancer* 2014;120:3033–9.
- Wang MM, Warnack E, Joseph K-A. Breast reconstruction in an underserved population: a retrospective study. *Ann Surg Oncol* 2019;26:821–6.
- Alderman AK, Hawley ST, Janz NK, *et al*. Racial and ethnic disparities in the use of postmastectomy breast reconstruction: results from a population-based study. *J Clin Oncol* 2009;27:5325–30.
- Rubin LR, Chavez J, Alderman A, *et al*. 'Use what God has given me': difference and disparity in breast reconstruction. *Psychol Health* 2013;28:1099–120.



- 19 Tseng JF, Kronowitz SJ, Sun CC, *et al.* The effect of ethnicity on immediate reconstruction rates after mastectomy for breast cancer. *Cancer* 2004;101:1514–23.
- 20 Rosson GD, Singh NK, Ahuja N, *et al.* Multilevel analysis of the impact of community vs patient factors on access to immediate breast reconstruction following mastectomy in Maryland. *Arch Surg* 2008;143:1076.
- 21 Thorne S. *Interpretive Description: Qualitative Research for Applied Practice*. Routledge, 2016.
- 22 Vindrola-Padros C, Johnson GA. Rapid techniques in qualitative research: a critical review of the literature. *Qual Health Res* 2020;30:1596–604.
- 23 SAGE Reference - The SAGE Encyclopedia of Qualitative Research Methods. Available: <https://sk.sagepub.com/reference/research/n456.xml> [Accessed Aug 5 2022].

Breast Reconstruction Interview Guide: Understanding Barriers to Care

The purpose of this interview is to understand the experiences of women who have had breast cancer, and what it was like to pursue breast reconstruction. I am interested in hearing your thoughts and feelings about breast reconstruction as well as what this experience has been like for you. We're interested in talking about any challenges you may have faced that made breast reconstruction difficult for you. Our goal is to use this information to develop a program to help make it easier for women who want breast reconstruction to get it.

1. Please tell me about your experience when you were referred to the plastic surgeon to discuss breast reconstruction. *PROBE: What were your priorities? What did you want to discuss with your doctor? What came to mind as your biggest concerns?*

Education/Information:

2. Please tell me about the conversations you had about breast reconstruction with your plastic surgeon? *PROBE: What stood out to you the most about your conversation with the plastic surgeon? PROBE: Did you feel emotional support, empathy and respect?*
3. Thinking back now, what other information would have been helpful when you were making the decision to have breast reconstruction? *PROBE: what was the thing you felt the least prepared for?*

Communication and bias:

Next we're interested in your communication and interactions with your plastic surgeon.

4. Please tell me about your relationship with your surgeon. *PROBE: communication, trust, time spent, understanding, bedside manner, barriers to communication, clear information? What do you like? What don't you like?*
5. Looking back, what would you like to have done differently during that appointment?
6. Some women feel a strong connection with their plastic surgeon and others don't feel very connected at all. Please tell me about the connection you had with the plastic surgeon? *PROBE: good/bad, emotional connection, intellectual connection, spiritual connection, listened to, respected, heard, supported, empathetic? Connection and involvement with your family?*
7. Some women have a strong connection with their surgeon for most things, but there are some things they don't feel comfortable about discussing with their surgeon. *PROBE: feeling whole, intimacy, sexuality, dating?*
8. Some women feel that they are treated differently because of their race, ethnicity or other parts of their identity? what was your experience in the course of your breast

reconstruction/breast cancer treatment? *PROBE: treatment of your religious or spiritual perspectives?*

9. For some patients, it's important that they have a surgeon who is like them in terms of gender, language, and/ or race. How important was this for you? *PROBE: what about when you are discussing more intimate things, such as sexuality, or body image?*

Decision making:

10. Please tell me about the process you went through to decide about having breast reconstructions. *PROBE: What factors were important to you? PROBE: friends, family, social network, religious community, physician's opinion, time off work, cost*

Access to care:

11. We are interested in your experience finding a plastic surgeon. How did you choose the plastic surgeon that did your reconstructive surgery? *PROBE: logistical challenges, access to fast and reliable care, referral challenges, insurance, continuity of care between your other doctors and surgeons?*

12. Breast reconstruction can impact many patients financially, both directly and indirectly. What was your experience?

PROBE:

- *Out of pocket expenses?*
- *Time lost from work, or change in employment?*
- *Caregiver missing work?*
- *Hospital bills? Co-pays? Ability to afford cancer care?*
- *Childcare?*
- *Change in savings?*
- *Ability to afford the basics?*
- *Ability to afford other healthcare needs?*
- *Concern about future financial problems?*
- *Impact on your family?*
- *Did you anticipate these expenses?*
- *Did you have any control over the expenses?*
- *Do you feel in control of your financial situation?*
- *How did you cope with the financial impact?*
- *What resources did you rely on while undergoing reconstruction?*
- *Who helped to take care of you during this time?*

Conclusion:

13. Is there anything else that is important for us to understand about undergoing breast reconstruction? *PROBE: barriers, bias*
14. What could we improve about breast reconstruction and the access to breast reconstruction for patients? *PROBE: improved from perspective of hospital, surgeon, in the community, resources available outside of your clinic visits?*