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How Susan G. Komen's ShareForCures™ Research Hub will connect researchers with real-world data shared by breast cancer patients and survivors in the United States

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BACKGROUND

Optimizing care and improving outcomes for all breast cancer populations requires integrating data that represents the full diversity of individuals diagnosed. This encompasses clinical records, genomics, and other data types that capture the complete breadth of patient characteristics. Equally important is the collection of patient-reported outcomes and experience measures, which provide crucial insight into the overall picture. Unfortunately, datasets reflecting this necessary diversity are frequently scarce and fragmented across separate healthcare institutions, limiting our ability to leverage comprehensive information for improved care delivery.

To overcome these challenges, Susan G. Komen® (Komen) launched ShareForCures® (SFC), a direct-to-consumer, online, IRB-approved breast cancer research registry, designed to integrate real-world, longitudinal data from adults diagnosed with breast cancer in the United States and to make these data available for research. We created the SFC Research Hub to provide secure access to these data for academic researchers.

METHODS

A taskforce of research experts (clinical oncologists, translational scientists, and research advocates) provided guidance and feedback throughout the development of the SFC Research Hub by completing surveys, meeting with Komen staff, and engaging in user testing. Based on this feedback, we created the SFC Research Hub, which enables SFC data exploration, cohort creation, and applications for data access. To describe the SFC cohort to researchers, we analyzed data from participants who enrolled in SFC during the first two years.

CONCLUSIONS

Through SFC, Komen has created a real-world database that connects researchers with data contributed by participants with diverse backgrounds. The SFC Research Hub is expected to launch in 2026 enabling researchers to explore and use SFC data, build custom study cohorts, and request data access. These features enable researchers to make meaningful use of real-world breast cancer information to accelerate new findings and improve patient outcomes.

ACKNOWLEDGEMENTS

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RESULTS

Figure 1. The ShareForCures Research Hub provides secure access to integrated, deidentified participant data.

The SFC Research Hub was designed with researchers in mind, providing secure access to an interactive dashboard featuring demographic visualizations with hover-over details, a view of a researcher's latest projects, and quick, at-a-glance summary counts of available data.

1. The Research Hub Dashboard provides a high-level view of data collection status, participant demographics, and a researcher's project activity.
2. Researchers can create projects containing cohorts of interest. (See Figure 3.)
3. When signing up, researchers must **agree to a code of conduct**, and then submit a **data access application** outlining their project. Once this is approved by Komen, researchers must **acknowledge an institutional data use agreement** prior to accessing SFC data.
4. Researchers can submit feedback on data access, platform functionality, or dataset requests.
5. Notifications are utilized to alert researchers of new data available, data access application status, and responses to feedback.

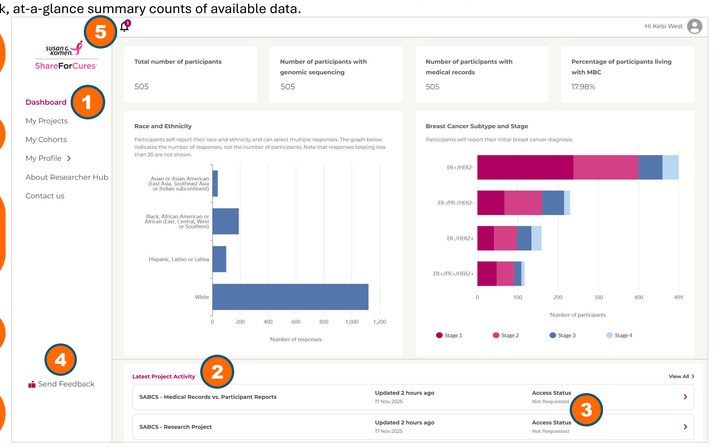


Figure 2. ShareForCures contains multi-dimensional data types.

All participants reported demographic and diagnostic information in the About You questionnaire. Whole genome germline sequencing (WGS) was requested for 15% of participants. Medical records were requested for 70% of participants, 33% were retrieved and curated. Data collection efforts are ongoing. Percentages on the graph represent the portion completed out of the total requested. Abbreviations: Quality of Life (QoL), Family Health History (FHH), Social Determinants of Health (SDoH).

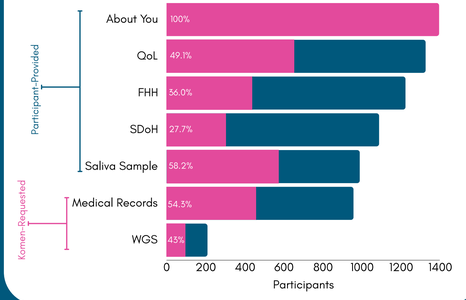


Table 1. Demographics of the ShareForCures cohort.

From July 1st, 2023 to October 31st, 2025, 1,389 participants enrolled in SFC from all 50 states, D.C., and 1 U.S. territory. Categories show response options from the About You questionnaire, with the largest in pink. Age categories were grouped for reporting purposes.

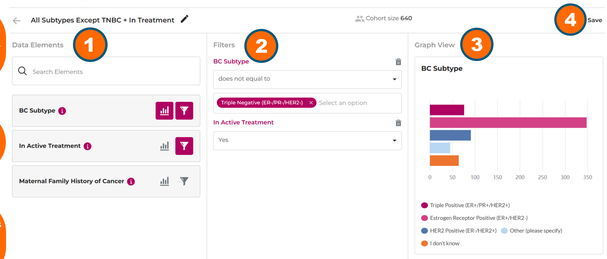
DEMOGRAPHICS	PERCENT
GENDER	
• Female	99%
• Male, Non-binary, Not Listed*	<1%
AGE	
• 20-39	8.3%
• 40-59	55.9%
• 60-79	34.7%
• ≥80	<2%
RACE AND ETHNICITY	
• Asian or Asian American	2.1%
• Black or African American	12.1%
• Hispanic or Latino	4.8%
• White	74.6%
• Multiple Options Selected	4.9%
• Other Race/Ethnicity, Not Listed*	<2%
AGE AT DIAGNOSIS	
• <30	2.8%
• 30-49	53.7%
• 50-69	40.1%
• ≥70	3.4%

*Some categories were combined to maintain privacy.

Figure 3. Researchers Can Create Cohorts Using Multiple Data Filters in ShareForCures Cohort Builder.

The SFC Research Hub Cohort Builder allows researchers to create cohorts of interest by selecting data elements (see orange table on right), filtering data by inclusion or exclusion criteria, viewing data, and saving the cohort.

1. The Cohort Builder allows researchers to select many different types of data elements from Medical Records and Participant-Reported Questionnaires. (See orange table on right.)
2. From the data elements selected, researchers can choose to filter for inclusion or exclusion of data features.
3. From the data elements selected, researchers can view graphs displaying the data available. In accordance with SFC data governance, data with <20 responses are hidden.
4. Researchers save and edit each cohort created before a project is submitted.

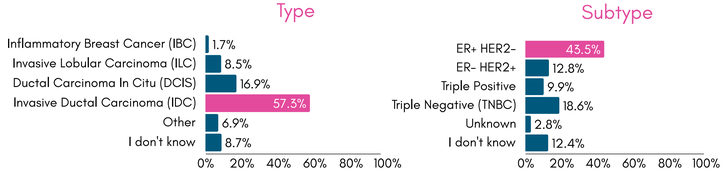


Participant-Reported Questionnaires	Medical Records
Year of First BC Diagnosis	Biomarker Genes Recorded
Gender Identity	Biomarker Gene Pathogenicity
Sex Assigned at Birth	Menopause
Sexual Orientation	Vital Status
Race/Ethnicity	Year of Death
BC Type	T Stage at Initial Diagnosis
BC Subtype	N Stage at Initial Diagnosis
BC Stage	M Stage at Initial Diagnosis
BC Recurrence	BC Procedure
Year of BC Recurrence	Radiation Therapy
Metastatic BC	Regimen Drugs
Year of Metastatic BC	Regimen Name
In Active Treatment	Clinical Trial Participation
Genetic Testing	Menopause
Annual Household Pre-Tax Income	Vital Status
Financial Stress	Year of Death
Health Insurance at Time of BC Diagnosis	T Stage at Initial Diagnosis
Health Insurance Coverage	N Stage at Initial Diagnosis
Location (Urban vs. Rural)	M Stage at Initial Diagnosis
Overall Quality of Life	BC Procedure
Physical Well-being	Radiation Therapy
Mental and/or Emotional Well-being	Regimen Drugs
Social Connectedness	Regimen Name
Religious or Spiritual	Clinical Trial Participation
Ashkenazi (European) Jewish Ancestry	
Genetic Counseling	
Maternal Family History of Cancer	
Paternal Family History of Cancer	
Twin	

*Future updates will include WGS data elements.

Figure 4. Initial breast cancer diagnosis self-reported by participants in ShareForCures.

Participants selected categories during onboarding via the About You questionnaire about their initial breast cancer diagnosis. Most reported invasive ductal carcinoma (57.3%) as their first breast cancer diagnosis, with 43.5% reporting ER+/HER2– disease.



18% Percentage of participants living with MBC.

15% Percentage of participants with Recurrence.

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