

Carolina Breast Cancer Study: Frequently Asked Questions

Thank you for your interest in the Carolina Breast Cancer Study: Phases I, II, and III. Here are the answers to the common questions we get from researchers making data sharing requests.

Question	Answer
How many breast cancer cases are there?	<p><u>CBCS Phase 1</u>: 861 <u>CBCS Phase 2</u>: 1450 (include CIS cases) <u>CBCS Phase 3</u>: 2998</p> <p>Total N = 5309</p>
Over what years were these cases diagnosed?	<p><u>CBCS Phase 1</u>: 1993-1996 <u>CBCS Phase 2</u>: 1996-1999 <u>CBCS Phase 3</u>: 2008-2013</p>
<p>Race/Ethnicity:</p> <p>What percentage of your breast cancer cases are...</p> <p> White? African American? Hispanic?</p>	<p>There are 2 race/ethnicity questions on the baseline survey.</p> <p>1.) What race would you describe yourself as? White – 52.9% (N=2806) African American – 45% (N=2389) Hispanic – 0.5% (N=27)</p> <p>2.) Are you Hispanic? Yes – 1.5% (N=77) No – 98.5% (N=5232)</p>
What is the distribution of breast cancer cases' age at diagnosis?	<p>Age was a randomized recruitment variable: 50% of the data is under age 50; 50% is age 50 or greater.</p> <p>Median = 50 1st quartile = 44 3rd quartile = 61 Range = 23-74</p>
<p>What is the geographic spread of the breast cancer cases?</p> <ul style="list-style-type: none"> • How many institutions contributed data? • Which states? • Which countries? 	<p>Eighty-one facilities in the 44-county study area in North Carolina, USA, contributed data.</p> <p>Data are housed at University of North Carolina at Chapel Hill, North Carolina, USA.</p>

<p>Geographical Detail:</p> <p>Do you share patient home location by... Home address? Census tract? Zip code? County?</p>	<p>We can share county information. Other data will need IRB and study PI approval.</p>
<p>Insurance types:</p> <p>What percentage of your cases are... Uninsured? Private insurance? Medicaid? Medicare?</p>	<p>This data is only available in CBCS, Phase III, and then only from the baseline survey.</p> <p>Uninsured – 6% (N=179) Private insurance – 69.2% (N=2075) Medicaid – 15.8% (N=473) Medicare – 21.6% (N=646)</p>
<p>Available Data from Central Cancer Registry:</p> <p>Does your data include... Date of diagnosis? Subtype? Stage? Recurrence? Date of death?</p>	<p>This data is not from the NC Registry. It is <i>medically abstracted</i>.</p> <p>Date of diagnosis, Stage, Recurrence are abstracted from medical records.</p> <p>Subtype is derived from clinical record or from central lab results.</p> <p>We have date of death data for CBCS 1 & 2, censored at 12/31/2016.</p> <p>Currently, date of death data is very limited for CBCS3 because patients are being followed by medical record and have not been linked to National Death Index. When we receive medical reports of deaths, we confirm these with the NDI.</p> <p>Access to the date of diagnosis and death required IRB approval because these are considered PHI.</p>
<p>Available data: Electronic Health Records</p> <p>Does your data include... Encounter (dates, times, types)? Clinical Notes? Pathology reports? Radiology reports?</p>	<p>Yes.</p> <p>Access to dates require IRB approval because these are considered PHI.</p>

<p>Available data: Administrative (claims)</p> <p>Does your data include... Insurance claims?</p>	<p>A linkage with Blue Cross Blue Shield and Medicare claims data is underway but not yet ready for sharing.</p>
<p>Available data: Other</p> <p>Does your data include... Molecular? Genomic? Transcriptomic? Proteomic? Metabolomic?</p>	<p>RNA expression via a custom Nanostring array is available for the majority of patients; a small (n≈100) subset of these also have RNASeq data.</p> <p>Targeted sequencing of DNA is underway.</p> <p>Germline SNP data has been collected in association with the AMBER consortium and the BCAC consortium.</p>
<p>Available data: Images</p> <p>Does your data include... Historic images?</p>	<p>Yes.</p>
<p>Available data: Patient-reported</p> <p>What types of patient-reported data do you have?</p>	<p>We have survey data reported by patient on demographics, family history, pregnancy/lactation history, and other potential breast cancer risk factors.</p>
<p>Available data: Clinical Trials</p> <p>Does your data include... Clinical trials enrollment figures?</p>	<p>No.</p>
<p>How many publications have used your dataset?</p> <p>A.) # of total publications B.) # breast cancer specific publications C.) # disparities specific publications in breast cancer (defined as research regarding the effect of race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location on breast cancer prevention screening, diagnosis, treatment, or survivorship)</p>	<p>As of January 21, 2022...</p> <p>A) 209* B) 209* C) 209</p> <p>*This does not include some recent consortium projects that are not disparities focused.</p> <p>Go to https://unclineberger.org/cbcs/for-researchers/ for links to a full list.</p>