

## BRIEF COMMUNICATION

# Tumor Specimen Biobanks: Data Gaps for Analyzing Health Inequities—the Case of Breast Cancer

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## Abstract

Biobanks are increasingly recognized to be vital for analyzing tumor properties, treatment options, and clinical prognosis, yet few data exist on whether they are equipped to enable research on cancer inequities, that is, unfair and unnecessary social group differences in health. We conducted a systematic search of global biobanks, identified 46 that have breast tumor tissue and share data externally with academic researchers, and e-mailed and called to obtain data on the sociodemographic, socioeconomic, and geospatial data included, plus time span encompassed. Among the 32 biobank respondents, 91% housed specimens solely from the Global North, only 31% obtained socioeconomic data, 63% included racial/ethnic data (of which 55% lacked socioeconomic data), 44% included limited geographic data, and 55% had specimens dating back at most to 2000. To enable research to address cancer inequities, including trends over time, biobanks will need to address the data gaps documented by our study.

In an age of ever-expanding biomarker, genomic, and other – omics data, biobanks are a vital resource for research on tumor properties, clinical treatment, and prognosis (1–4). Indicative of the keen interest in such data, the US National Cancer Institute is funding research to improve biobanks so as “to accelerate and/or enhance research in cancer biology, early detection and screening, clinical diagnosis, treatment, epidemiology, or address issues associated with cancer health disparities” (5).

Analysis of cancer health inequities, however, requires more than the biological specimens. Also needed are the social data used to characterize and quantify the inequities (6–8), that is, group differences in health that are unfair, unnecessary, and in principle preventable (8–10). For example, recent research in the United States has shown that understanding the etiology of, and temporal changes in, differences in breast cancer estrogen receptor status among US black and white women requires data on not only race/ethnicity and socioeconomic position but also time and place of birth in relation to the pre-1965 existence of legal racial discrimination (“Jim Crow”) in the District of Columbia and 21 of the 50 US states (11–15). The well-documented need for socioeconomic, sociodemographic, and geographic data (eg, neighborhood characteristics, urban vs

rural location) to analyze cancer inequities (6,7,16,17), however, remains largely unaddressed in the literature on minimum data sets for biospecimen repositories (1–3,18–21).

Motivated by our prior US-based research on assessing the feasibility of analyzing long-term trends in disparities in breast cancer biomarkers using archival tissue specimens (22,23), we sought to assess the feasibility of using tumor biobank data for research on cancer inequities and their trends over time. Our a priori hypotheses were that most biobanks 1) would not routinely collect socioeconomic, sociodemographic, or geographic data needed to quantify cancer inequities and 2) would primarily include specimens only from the Global North, with few specimens available before the 1990s.

We used the following international and US biobank directories to identify biobanks: specimencentral.com (24), IARC biobank membership (25), National Institute of Health (NIH) Cancer Specimens Search (26), and the NIH Cooperative Human Tissue Network (27). Inclusion criteria were that the biobanks had available breast cancer tumor tissue (not collected as part of randomized controlled trials) whose data they would share externally with academic institutions (ie, excluding tissue banking services that do not share data for research). We sent out initial

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Table 1. Cancer biobank data, on biobanks with breast cancer specimens that share data with academic collaborators

Name	Country	Collection years	No. of cases	Preservation type*	Organization type	Racial/ethnic data	Socioeconomic data	Geospatial information	Vital status	Treatment received
1) Australian Breast Cancer Tissue Bank <a href="https://www.abctb.org.au/abctbNew2/default.aspx">https://www.abctb.org.au/abctbNew2/default.aspx</a> 2) Biobank Graz <a href="http://biobank.medunigraz.at/">http://biobank.medunigraz.at/</a>	Australia  Austria	2004+  1985+	8149  462 881 (includes noncase biopsy samples)	FFPE  FFPE	Academic  Academic	No  No (reported "99% Caucasian")	No  Yes (education, occupation, birthplace, "confession," marital status, income)	No  Yes (birthplace)	Yes  Yes	Yes  Yes
3) Biobank of Hospital Clinic—IDIBAPS <a href="http://www.clinicbiobanc.org/qui-som/sobre-el-biobanc/en_index.html">http://www.clinicbiobanc.org/qui-som/sobre-el-biobanc/en_index.html</a>	Spain	2008+	Data not shared†	FFPE	Academic	No	No	No	Yes	Yes
4) Breast Cancer Family Registry <a href="http://www.bcfamilyregistry.org/">http://www.bcfamilyregistry.org/</a>	Australia, Canada, USA	1995+	Current data not shared† (4293 as reported in 2004‡)	FFPE	Academic	Yes (black, white, Native, Filipino, Japanese, Chinese, Vietnamese, other East Asian, South Asian, Middle Eastern, Hispanic)	Yes (education, marital status, language, and English proficiency)	Yes (country of birth, years in current country)	Yes	Yes
5) CHTN/NCI Breast (Prospective Procurement) <a href="https://www.chtn.org/">https://www.chtn.org/</a>	USA	1987+	Temporally dynamic§	Frozen tumor tissue	Academic	Yes (categories not shared)†	No	No	Yes	Yes
6) CHTN/NCI Specialized Tissue Microarray Resource Stage I, II, III Breast Prognostic TMAs <a href="https://www.chtn.org/">https://www.chtn.org/</a>	USA	1985+	Stage I: 590 Stage II: 398 Stage III: 181	TMA	Academic/governmental	Yes (categories not shared)†	No	No	Yes	Yes
7) Duke Cancer Institute and Dept. of Pathology Biobank <a href="https://pathology.duke.edu/core-facilities-services/biorepository-precision-pathology-center">https://pathology.duke.edu/core-facilities-services/biorepository-precision-pathology-center</a>	USA	1967+	Data not shared†	FFPE	Academic	Yes (categories not shared)†	Yes (occupation)	No	Yes	Yes

(continued)

Table 1. (continued)

Name	Country	Collection years	No. of cases	Preservation type*	Organization type	Racial/ethnic data	Socioeconomic data	Geospatial information	Vital status	Treatment received
8) East-West Biopharma <a href="http://ewbiopharma.com/en">http://ewbiopharma.com/en</a>	Switzerland	2005+	17	FFPE	Private	Yes (categories not shared)†	Yes (occupation before surgery)	No	Yes	Yes
9) Hawaii Tumor Registry <a href="http://www.uhcancercenter.org/research/shared-resources/hawaii-tumor-registry">http://www.uhcancercenter.org/research/shared-resources/hawaii-tumor-registry</a>	USA	1992+	>6000	FFPE	Academic	Yes (white, black, American Indian/Alaska Native, Asian, Chinese, Filipino, Japanese, Native Hawaiian/Pacific Islander, other, multiracial, Hispanic) No	No	Yes (birthplace, census tract of residential address at diagnosis)	Yes	Yes
10) Interdisciplinary Center for Biobanking-Lübeck <a href="https://www.uni-luebeck.de/en/biobank.html">https://www.uni-luebeck.de/en/biobank.html</a>	Germany	Data not shared†	Data not shared†	FFPE	Academic	No	No	No	Yes	Yes
11) Iowa Residual Tissue Repository <a href="https://uihc.org/iowa-residual-tissue-repository">https://uihc.org/iowa-residual-tissue-repository</a>	USA	1973+	11 064	FFPE	Academic	Yes (white, black, American Indian/Alaska Native, Asian, Chinese, Filipino, Japanese, Native Hawaiian/Pacific Islander, other, multiracial, Hispanic) No	No	Yes (birthplace, census tract of residential address at diagnosis)	Yes	Yes
12) Karolinska Mammography Project for Risk Prediction of Breast Cancer <a href="https://karmastudy.org/sources/">https://karmastudy.org/sources/</a>	Sweden	2011+	70 877	FFPE	Academic	Yes (European/not European, nativity) No	Yes (education)	No	Yes	Yes
13) Los Angeles Residual Tissue Repository <a href="http://uscnorriscancer.usc.edu/Core/TransPath/">http://uscnorriscancer.usc.edu/Core/TransPath/</a>	USA	1970+	9972	FFPE	Academic/governmental	Yes (white, black, American Indian/Alaska Native, Asian, Chinese, Filipino) No	No	Yes (birthplace, census tract of residential address at diagnosis)	Yes	Yes

(continued)

Table 1. (continued)

Name	Country	Collection years	No. of cases	Preservation type*	Organization type	Racial/ethnic data	Socioeconomic data	Geospatial information	Vital status	Treatment received
14) LBIH Biobank <a href="https://www.liverpool.ac.uk/translational-medicine/research/lbih/about/">https://www.liverpool.ac.uk/translational-medicine/research/lbih/about/</a>	UK	1993+	Data not shared†	FFPE	Academic/governmental	Japanese, Korean, Native Hawaiian/Pacific Islander, other, multiracial, Hispanic) Yes (categories not shared)†	Yes (occupation)	No	Yes	Yes
15) Lifelines Cohort Study <a href="https://www.lifelines.nl/researcher/biobank-lifelines">https://www.lifelines.nl/researcher/biobank-lifelines</a>	Netherlands	2006+	167 000 (cases and noncases)	FFPE	Academic	Yes (white [East and West European, Mediterranean, or Arabic], Black, Asian)	Yes (employment, work, harassment, structure, social support)	Yes (longitudinal data + baseline GIS data on air pollution, noise exposure)	Yes	Yes
16) MRC Brain Banks Network <a href="https://www.mrc.ac.uk/research/facilities-and-resources-for-researchers/brain-banks/">https://www.mrc.ac.uk/research/facilities-and-resources-for-researchers/brain-banks/</a>	UK	2013+	25	FFPE	Academic	Yes (Arab, Bangladeshi, black other, black African, black Caribbean, Chinese, Indian, other, Other Asian, multiracial, Pakistani, white European, white other, Asian)	No	No	Yes	Yes
17) National University of Singapore Tissue Repository <a href="http://medicine.nus.edu.sg/tissue/">http://medicine.nus.edu.sg/tissue/</a>	Singapore	2002+	613	FFPE	Academic	Yes (racial categories not shared but collects nationality)	No	Yes (place of death)	Yes	Yes
18) NHS Grampian Biorepository <a href="http://www.biorepository.nhsgrampian.org/">http://www.biorepository.nhsgrampian.org/</a>	UK	2016–2020	<100	FFPE	Academic/governmental	No	No	Yes (postal code at diagnosis)	Yes	Yes

(continued)

Table 1. (continued)

Name	Country	Collection years	No. of cases	Preservation type*	Organization type	Racial/ethnic data	Socioeconomic data	Geospatial information	Vital status	Treatment received
19) NHS Greater Glasgow & Clyde <a href="http://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/biorepositories-and-tissue-services">http://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/biorepositories-and-tissue-services</a>	UK	2005+	Data not shared†	FFPE	Academic/governmental	Yes (categories not shared)†	Yes (categories not shared)†	Yes (categories not shared)†	Yes	Yes
20) NHS Tayside Biorepository <a href="http://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/biorepositories-and-tissue-services">http://www.nhsresearchscotland.org.uk/research-in-scotland/facilities/biorepositories-and-tissue-services</a>	UK	2006+	<1000	FFPE	Academic/governmental	Yes (categories not shared)†	No	No	Yes	Yes
21) Northern Ireland Biobank <a href="http://www.niobank.org/">http://www.niobank.org/</a>	UK	2011+	Data not shared†	FFPE	Academic/governmental	No	No	No	Yes	Yes
22) OHSU Knight Biobrary <a href="http://www.ohsu.edu/xd/health/services/cancer/research-training/knight-biobrary/index.cfm">http://www.ohsu.edu/xd/health/services/cancer/research-training/knight-biobrary/index.cfm</a>	USA	2011+	Data not shared†	FFPE	Academic	Yes (categories not shared)†	No	Yes (categories not shared)†	Yes	Yes
23) Ontario Tumour Bank <a href="https://ontariotumourbank.ca/">https://ontariotumourbank.ca/</a>	Canada	2004+	666 tumor, 201 normal adjacent	FFPE	Nonprofit	No	No	No	Yes	Yes
24) Sapien Biosciences <a href="http://sapienbio.co.in/">http://sapienbio.co.in/</a>	India	1997	8000	FFPE	Private	No	No	Yes (residential address at treatment)	Yes	Yes
25) Southwest France Tumour Bank <a href="http://www.biobank-gso.org/">http://www.biobank-gso.org/</a>	France	1987+	17 709	FFPE	Academic/governmental	No	No	No	Yes	Yes
26) Taiwan Biobank <a href="https://www.twbiobank.org.tw/new_web/">https://www.twbiobank.org.tw/new_web/</a>	Taiwan	2016+	Data not shared†	FFPE	Hospital consortia	Yes (categories not shared)†	Yes (education, occupation)	Yes (birthplace, current address)	Yes	Yes
27) Tumor Bank of Provence <a href="http://tumorpacamarseille.inserm.fr/">http://tumorpacamarseille.inserm.fr/</a>	France	2015–2016	3419	FFPE	Academic/governmental	No	No	No	Yes	Yes
28) University of Alabama Breast SPORE Tissue Repository <a href="http://www.uab.edu/medicine/tcbf/sporebb-tpsfsi.debar">http://www.uab.edu/medicine/tcbf/sporebb-tpsfsi.debar</a>	USA	1991+	<1000	Frozen tumor tissue	Academic	No	No	No	Yes	Yes

(continued)

Table 1. (continued)

Name	Country	Collection years	No. of cases	Preservation type*	Organization type	Racial/ethnic data	Socioeconomic data	Geospatial information	Vital status	Treatment received
29) University of Arizona Cancer Prevention & Control (CPC) Biorepository <a href="http://uacc.arizona.edu/research/programs/cpc">http://uacc.arizona.edu/research/programs/cpc</a>	USA	2006+	Data not shared†	FFPE	Academic	Yes (categories not shared)‡	No	No	Yes	Yes
30) BioServe <a href="https://www.bioserve.com/human-samples/">https://www.bioserve.com/human-samples/</a>	International	1999+	1271	FFPE and frozen tumor tissue	Private	Yes (Arab, Asian, Hispanic/Latino, Black/African American, American Indian/Alaskan Native, Czech, Eastern European, Filipino, Greek, Jewish, Native Hawaiian/other Pacific Islander, Russian, Vietnamese, Katu, white/Caucasian)	Yes (occupation)	Yes (clinic location at treatment or biopsy, birth country, parents' birth country)	Yes	Yes
31) Victorian Cancer Biobank <a href="https://viccancerbiobank.org.au/">https://viccancerbiobank.org.au/</a>	Australia	1999+	Data not shared†	FFPE	Government	Yes (categories not shared)‡	No	Yes (state, county)	Yes	Yes
32) Wales Cancer Bank <a href="http://walescancerbank.com/">http://walescancerbank.com/</a>	UK	2005+	1400	FFPE	Academic/governmental	No	No	No	Yes	Yes

\*Preservation type: FFPE, TMA, CHTN = Cooperative Human Tissue Network; FFPE = formalin-fixed paraffin-embedded; IDIBAPS = Institut d'Investigacions Biomèdiques August Pi i Sunyer; LBIH = Liverpool Bio-Innovation Hub; MRC = Medical Research Council; NCI = National Cancer Institute; NHS = National Health Service; OHSU = Oregon Health & Science University; SPORC = Specialized Program of Research Excellence; TMA = tumor microarray.

†Data not shared indicates that the biobank did not provide the requested information.

‡See reference 36 (John et al, 2004).

§The CHTN banks specimens prospectively, and they are provided to investigators on a first come, first served basis, resulting in a temporally dynamic number of specimens.

inquiries by e-mail in July 2017, e-mailed nonresponders twice (September and October 2017), and attempted to call once (October 2017). We asked about data collected for year of diagnosis and death, specimen preservation, race/ethnicity, socioeconomic position, and residential address/geographic information. No institutional review board (IRB) review was needed, as no human subjects were involved.

Of the 46 initial eligible biobanks we identified, 32 had specimen data available online or responded to e-mail or phone calls. We excluded 12 biobanks (10 from the United States and Europe, one from Iran, one from China) because they either did not respond ( $n = 10$ ) or would not provide information without a formal data request and IRB approval ( $n = 2$ ). The Global North included Europe, North America, Australia, New Zealand, and Japan; other countries comprised the Global South (28).

Table 1 presents results for the 32 included biobanks, listed in alphabetical order. Virtually all (94%) housed specimens solely from the Global North (North America [United States: 9; Canada: 2]; Western Europe: 16; or Australia: 3); two encompassed multiple countries, and three respectively included specimens from India, Singapore, and Taiwan. All 32 biobanks included data on age at diagnosis, treatment, and mortality. Among the 21 biobanks that shared data on their number of specimens (primarily cases but also some noncase biopsies), the range was from 25 to approximately 463 000. Among the 30 biobanks reporting preservation type, 29 (97%) stored formalin-fixed paraffin-embedded (FFPE) specimens, three had frozen tissue, and one had tumor microarray (TMA) specimens.

Only 10 (31%) of the 32 biobanks included any socioeconomic information, mainly education and occupation. Among the 20 biobanks (63%) with racial/ethnic data, 12 (60%) did not share the categories employed, the rest employed diverse categories (with two [10%] using the category “Caucasian”), and 11 (55%) lacked socioeconomic data. Only 14 of the 32 biobanks (44%) included any geographic information, primarily pertaining to birth place, with only eight (25%) having residential location at time of diagnosis.

Among the 31 biobanks providing the dates of their specimens, the number (and percentage) whose earliest dates of diagnosis by decade were: 1960s = 1 (3%); 1970s = 2 (6%); 1980s = 4 (13%); 1990s = 7 (23%); 2000s = 10 (32%); and 2010s = 7 (23%). Thus, the majority (55%) had specimens dating back at most to 2000, that is, less than two decades.

Supporting our a priori hypotheses, few biobanks included the social and geographic data required to analyze cancer inequities and their trends (6–8,11–17,29–31). Raising concerns about continuing the racialization of cancer data (6–8,32), among the 32 biobanks we surveyed with breast cancer tissue specimens available for use in research studies, 63% obtained racial/ethnic data (with two using the scientifically invalid and discredited spurious category of “Caucasian” [32–35]), only 31% had socioeconomic data, and only 28% had both racial/ethnic and socioeconomic data. The majority (>55%) also lacked geographic data. Additionally, these biobanks overwhelmingly (94%) contained specimens solely from countries of the Global North, primarily from the past two decades.

Our study has several strengths and limitations. First, we employed a systematic and replicable approach to identifying, contacting, and requesting information from eligible biobanks. Nevertheless, among the 46 eligible biobanks, we were unable to obtain information from 12 (of which only two were countries in the Global South), and among the 32 that provided information, not all provided information on all variables. As there is no a priori reason to believe that nonrespondents would obtain

more or better-quality data than the respondents, our findings thus likely provide conservative estimates of data deficiencies.

In summary, for biobanks to enable research to address cancer inequities (6–8,11–17,29,32), the social data gaps we document require remedy. Greater expansion of the time frame also warrants support, given evidence of long-term trends and variations in the magnitude of cancer inequities (12,14,28–31).

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## Note

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Contributions: NK conceived the study, designed and supervised the analyses, and drafted the manuscript; JJ obtained the data and contributed to the manuscript; both authors reviewed and approved the final version prior to submission.

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