Enhancing Population Health Assessment of Racially/Ethnically Diverse, Underserved Individuals in the Fox Chase Cancer Center-Temple Health Catchment Area

Nestor Esnaola, MD, MPH, MBA
Susan Fisher, MS, PhD
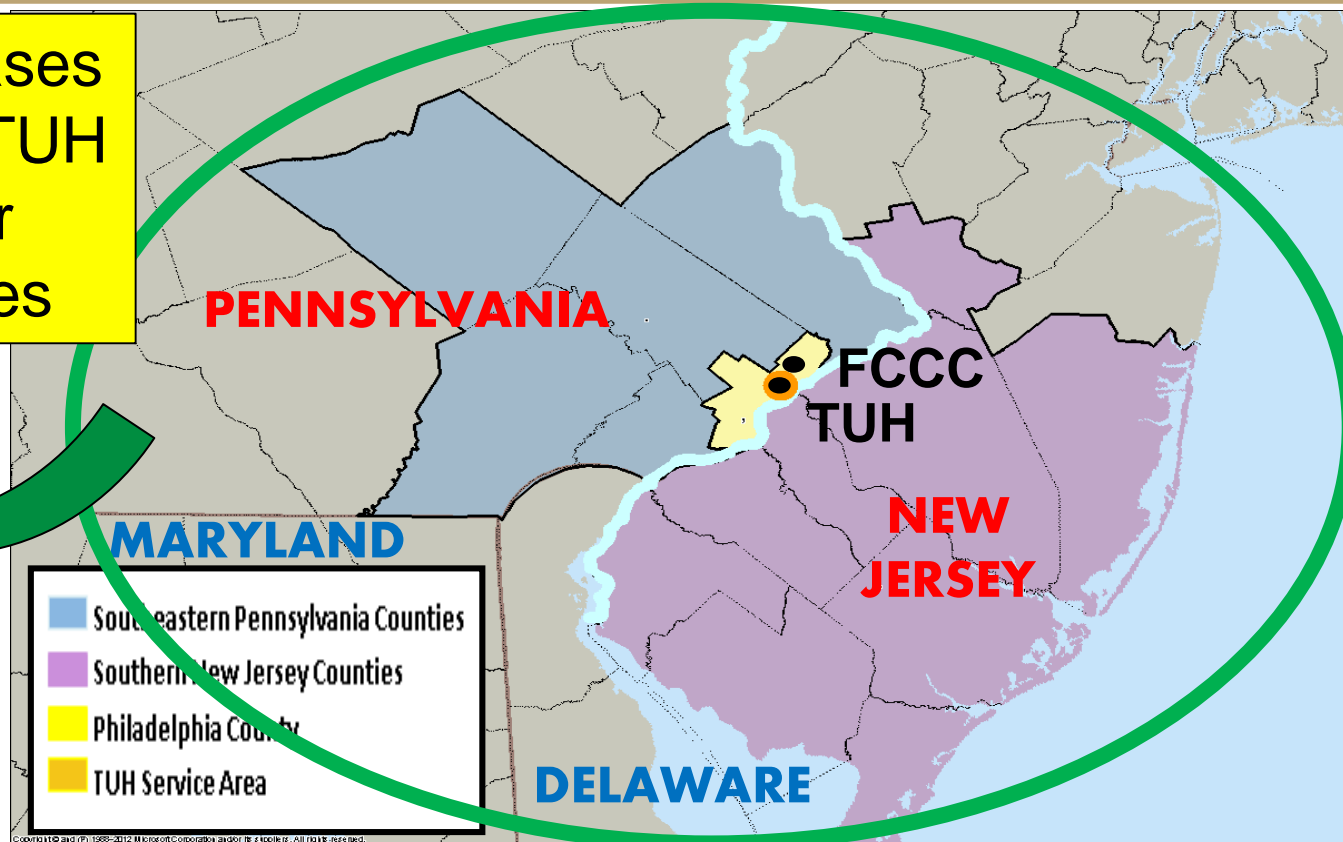**Shannon Lynch, PhD, MPH**

February 23, 2017

FOX CHASE CANCER CENTER
**TEMPLE HEALTH**

FCCC Catchment Area Sociodemographics

80% of cases in FCCC/TUH Cancer Registries

PENNSYLVANIA

FCCC TUH

NEW JERSEY

MARYLAND

DELAWARE

Legend:
- Southeastern Pennsylvania Counties
- Southern New Jersey Counties
- Philadelphia County
- TUH Service Area

	U.S.	FCCC Catchment Area	TUH Primary Service Area
Population	312,855,438	7,208,325	470,294
Non-White	25.9%	28.8%	74.9%
Hispanic or Latino	17.3%	9.5%	26.5%
Living in Poverty	14.1%	11.7%	35.7%

Source: U.S. Census, American Community Survey, 2008-2012

FCCC Catchment Area Sociodemographics
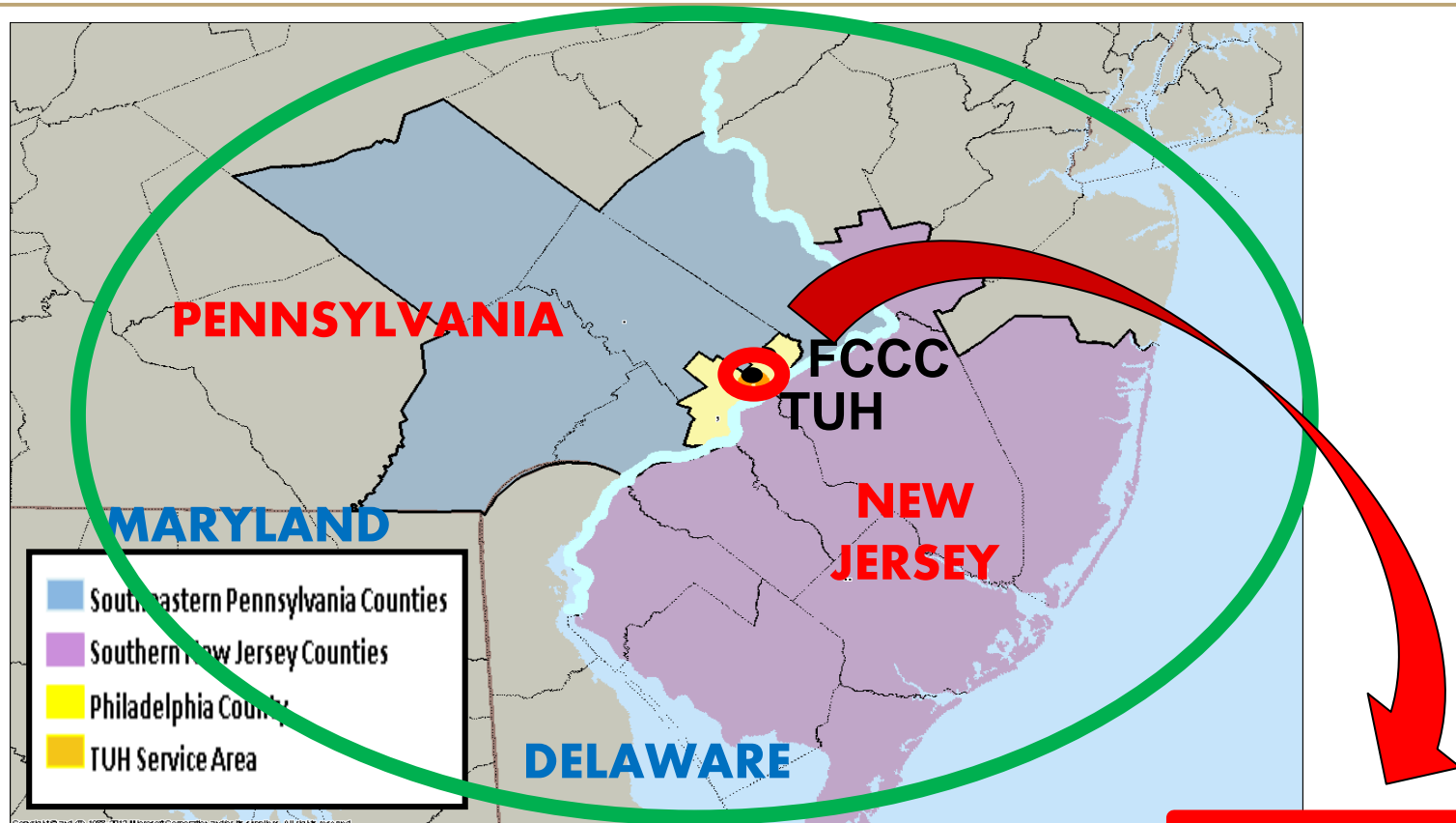
	U.S.	FCCC Catchment Area	TUH Primary Service Area
Population	312,855,438	7,208,325	470,294
Non-White	25.9%	28.8%	74.9%
Hispanic or Latino	17.3%	9.5%	26.5%
Living in Poverty	14.1%	11.7%	35.7%

Source: U.S. Census, American Community Survey, 2008-2012

Cancer incidence rate ratios (IRR; compared to the US) across FCCC catchment area, Philadelphia county (Co.) and TUH CHNA area, by cancer site
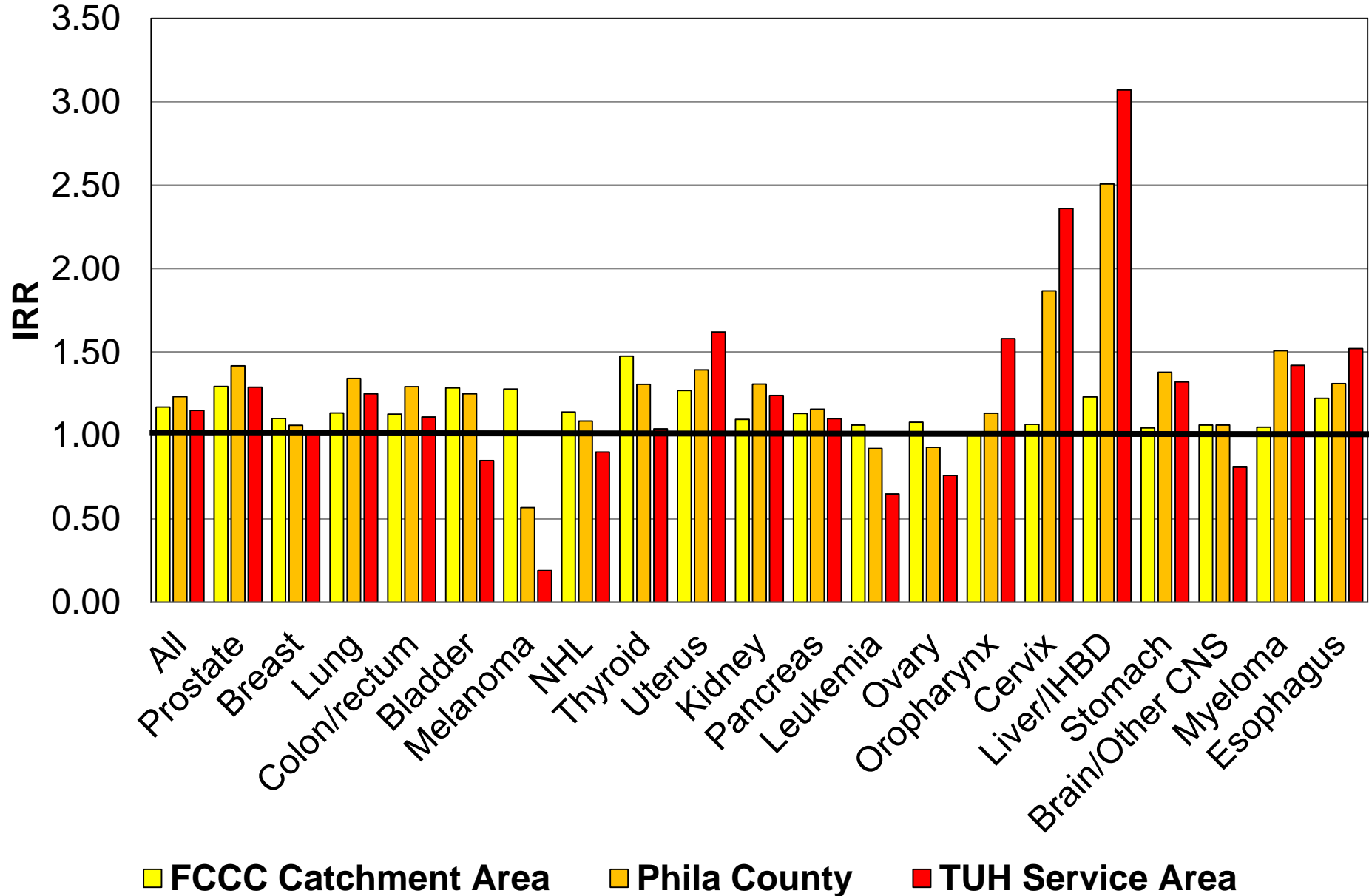
Figure 3. Existing Population Health Assessment Efforts

Existing Resource	Assessment
PA/NJ State Cancer Registries	Periodically analyze/compare incidence/morality rates at **county level** to U.S. to ensure outreach efforts & research enterprise align with cancer burden in our catchment area.

Existing Resource	Assessment
U.S. Census, American Community Survey	Catchment-area sex/race/ethnicity data periodically analyzed to benchmark Center-wide performance on inclusion of women/minorities in clinical research by **county/ ZIP code.**
Philadelphia Dept. of Public Health Community Health Assessment(CHA), including the Community Health Database (CHDB)	Includes Public Health Management Corporation (PHMC) household survey. Sections critical to cancer include: social factors, tobacco/ alcohol, obesity, HIV, cancer screening, access to care, and environmental health by **county/ZIP code**.

Existing Resource	Assessment
FCCC/TUH Community Health Assessments (CHNA) w/ PHMC Collaboration.	Systematic reviews of community health needs (FCCC/TUH service areas) allow us to develop strategies/ implementation plans to address gaps in service & optimize benefit to populations served by **county/ZIP code.**

Existing Resource	Assessment
FCCC/TUH Cancer Registry data and OnCore Enterprise Research System Data	Analyzed quarterly to assess campus-level cancer case sociodemographic data, refine clinical trial portfolios, and track/optimize accrual of women/minorities into treatment and interventional trials.

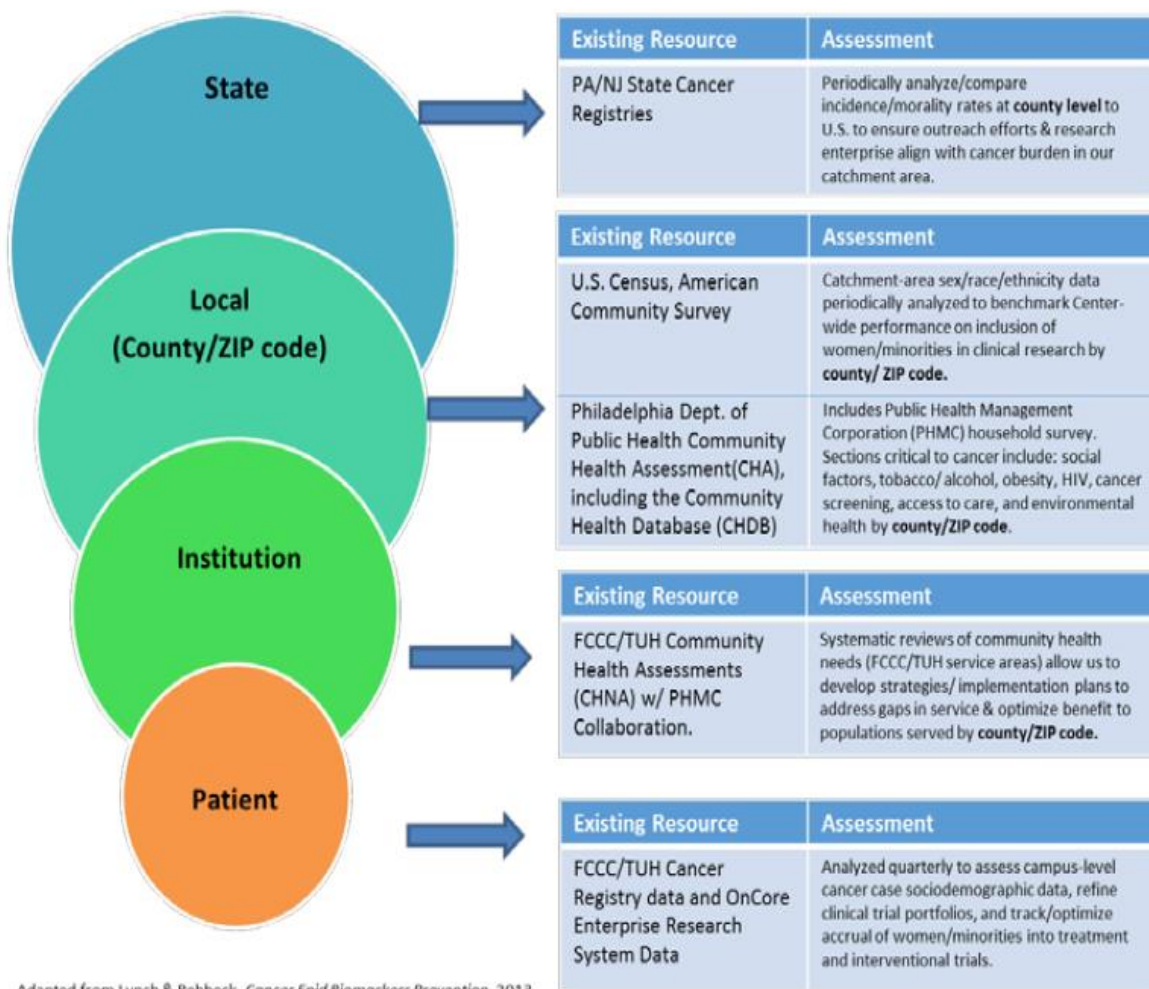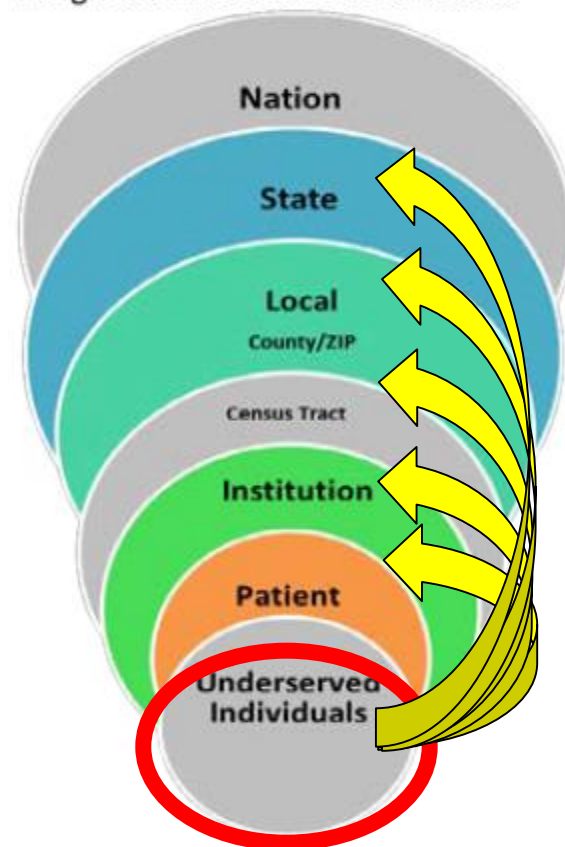Adapted from Lynch & Rebbeck, *Cancer Epid Biomarkers Prevention*, 2013.

Figure 4. Value added (in gray) includes data collection on individuals from understudied/ underserved areas and the creation of an integrated multilevel data resource.

Adapted from Lynch & Rebbeck, *Cancer Epid Biomarkers Prevention*, 2013.

Aim 1. Improved characterization of FCCC catchment area

- Focus: <u>Underserved/understudied</u> populations

- Development of a novel, multilevel data resource relevant to local/regional/state/national cancer surveillance efforts.

Aim 2. Enhance Center capacity to gather state-of the-art, local, individual-level, sociodemographic data **linked (via geocoding** to potentially actionable local data regarding

- cancer knowledge/attitudes
- cancer information access/usage
- risk behaviors
- cancer screening knowledge/access/usage, and
- knowledge/attitudes regarding
  - genetic testing,
  - clinical research/trials, and
  - biobanking research.

Aim 3. Through geocoding,

- Integrate de-identified primary data collected from **Aim 1** with geocoded, already-existing, de-identified
  - regional (i.e., Community Health Database [CHDB])
  - state/national data resources (e.g., HINTS, NHIS, BRFSS)

  data resources → multilevel data resource → future geospatial analyses.

- Identify common data elements from
  - the proposed local *convenience* sample (**Aim 1**),
  - regional *population-based* samples/surveys, and
  - state/national *population-based* samples/surveys

  to allow for
  - local vs. regional/state/national comparisons
  - assess bias, error, coverage, and reliability of this/similar local data collection projects.

Individually survey 1000 adult persons residing in our catchment area (in-person > by phone; English & Spanish-speaking)

- ≥ 50% of the individuals surveyed will reside in the TUH Primary Service Area

- ≥ 75% of the individuals surveyed *across the catchment area* will satisfy at least one of the following criteria of being historically underserved

  - 1) Live in medically underserved areas (HRSA)

  - 2) Have low literacy

  - 3) Have low income

  - 4) Be uninsured/subsidized health insurance coverage

- 1) We will identify/recruit subjects who reside in the TUH Primary Service Area by expanding Temple Health Block-by-Block's (THB3) already-planned, third wave of data collection
  - Re-contacting families already participating in THB3
- 2) We will identify/recruit (historically underserved and "non-underserved") subjects *across the entire catchment area (both within and outside the TUH Primary Service Area)*
  - Via future community outreach/cancer screening efforts scheduled/conducted by FCCC's Office of Community Outreach (OCO)
  - Through the OCO's and the Health Communication and Community Engagement (HCCE) Facility's community partners
  - Re-contacting individuals who previously participated in research studies conducted by the HCCE Facility

Temple Health: Block-by-Block Project Goals

…establish a multigenerational urban neighborhood health partnership to enrich minority research participation, optimize the institutional research portfolio, and contribute to the health improvement of our community.

- Provide a sustainable cohort of community participants engaged in individual and community health improvement across the life cycle through research;
- Provide investigators access to descriptive health data from urban populations for research purposes;
- Enhance participation of minorities in clinical research through improved education, access, and empowerment;
- Provide a venue for a community voice in new research initiatives.

Temple Health: Block-by-Block Recruitment Goals

- 1,000 subjects per year
- Ages ≥ 18 years (children to be included in Year 3)
- Multiple individuals within each household
- Maintain retention >80%
- Minimum goal of 5,000 subjects accrued and retained

Temple Health: Block-by-Block Methods

- Collect descriptive, longitudinal data every 6 months related to:
  - Demographic and social characteristics
  - Anthropometric & biologic parameters
  - Health behaviors
  - Health outcomes
- Specific data "themes" for each bi-annual assessment
- Integration of data collection/interventions for independent research studies

- 1) We will identify/recruit subjects who reside in the TUH Primary Service Area by expanding Temple Health Block-by-Block's (THB3) already-planned, third wave of data collection

  - Re-contacting families already participating in THB3

- 2) We will identify/recruit (historically underserved and "non-underserved") subjects *across the entire catchment area (both within and outside the TUH Primary Service Area)*

  - Via future community outreach/cancer screening efforts scheduled/conducted by FCCC's Office of Community Outreach (OCO)

  - Through the OCO's and the Health Communication and Community Engagement (HCCE) Facility's community partners

  - Re-contacting individuals who previously participated in research studies (+/- conducted by the HCCE Facility)

- 1) We will identify/recruit subjects who reside in the TUH Primary Service Area by expanding Temple Health Block-by-Block's (THB3) already-planned,

  ~ Population-based sample

  - Re-contacting families already participating in THB3

- 2) We will identify/recruit (historically underserved and "non-underserved") subjects *across the entire catchment area (both within and outside the TUH Primary Service Area)*

  - Via future community outreach/cancer screening efforts scheduled/conducted by FCCC's Office of Community Outreach (OCO)

  - Through the OCO's and the Health Communication and Community Engagement (HCCE) Facility's community partners

    Convenience samples

  - Re-contacting individuals who previously participated in research studies (+/- conducted by the HCCE Facility)
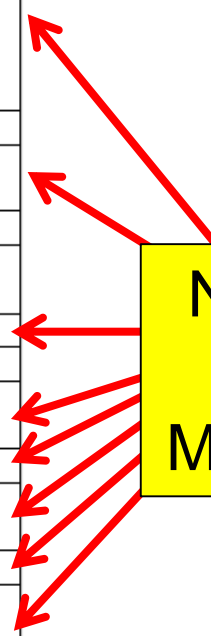
PENNSYLVANIA

NEW JERSEY

FCCC
TUH

MARYLAND

Baltimore

DELAWARE

Invasive Cancer Incidence
Rates by County
All Sites, 2007 - 2011

	478.9 − 499.5
	499.6 − 510.2
	510.3 − 527.2
	527.3 − 539.3
	539.4 − 564.4

Catchment Area Rate: 520.9
U.S. Rate: 458.1
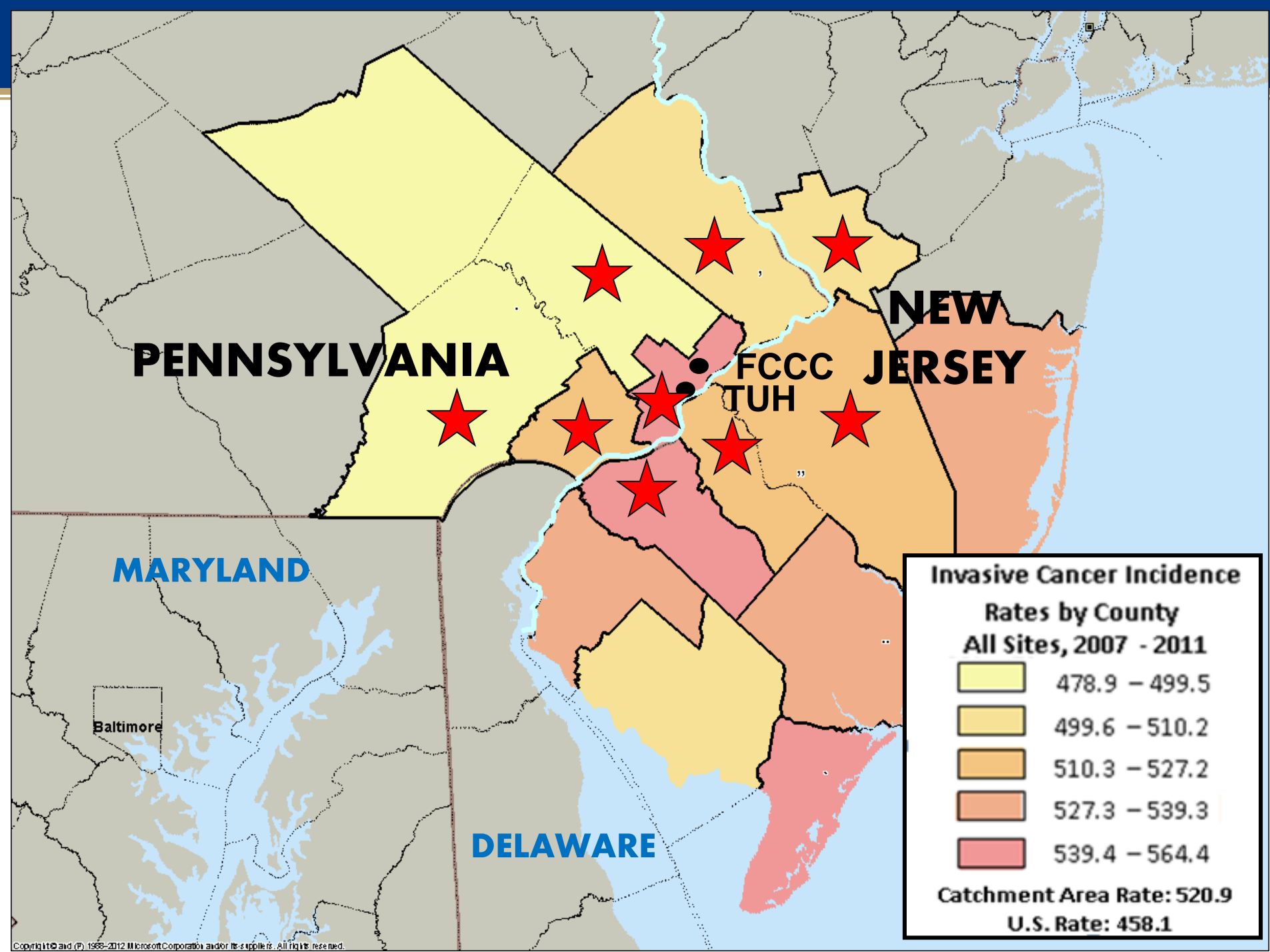
Population Health Assessment: Key Constructs

Table 1. Data and key constructs for proposed data collection project.

Data/Key Construct	Instrument
Sociodemographics (e.g., age, gender, marital status, race, ethnicity, preferred language, education, income, urban/rural status, insurance status, etc)	U.S. Census [1]*, HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*
Reactions to race	BRFSS [4]*
Social context (e.g., work, finances, etc)	BRFSS [4]*
Social networks	HINTS [2]*
Chronic health conditions/ functional status	BRFSS [4]*, HINTS [2]*
Health care access	HINTS [2]*, BRFSS [4]*
Health status/HRQOL	BRFSS [4]*, SF-12 [5]
Cancer perceptions/knowledge	HINTS [2]*
Cancer communication	HINTS [2]*
Cancer-related risk behaviors	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*
Cancer risk attitudes	HINTS [2]*
Cancer screening	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*
Family history/genetic testing	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*, 13-item Attitudes Toward Genetic Research and Testing [6]
Knowledge/attitudes regarding medical research/clinical trials	HINTS [2]*, 17-item Likelihood of Participation Scale [7]
Knowledge/attitudes regarding biobanking research	BANKS [8]*

*, denotes selected items; HINTS, Health Information National Trends Survey; NHIS CCS, National Health Interview Survey Cancer Control Supplement; BRFSS, Behavioral Risk Factor Surveillance System; SF-12, 12-Item Short Form Health Survey; BANKS, Biobanking Attitudes and Knowledge Survey.

NCI PHA "Core Measures"

Table 1. Data and key constructs for proposed data collection project.

Data/Key Construct	Instrument
Sociodemographics (e.g., age, gender, marital status, race, ethnicity, preferred language, education, income, urban/rural status, insurance status, etc)	U.S. Census [1]*, HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*
Reactions to race	BRFSS [4]*
Social context (e.g., work, finances, etc)	BRFSS [4]*
Social networks	HINTS [2]*
Chronic health conditions/functional status	BRFSS [4]*, HINTS [2]*
Health care access	HINTS [2]*, BRFSS [4]*
Health status/HRQOL	BRFSS [4]*, SF-12 [5]
Cancer perceptions/knowledge	HINTS [2]*
Cancer communication	HINTS [2]*
Cancer-related risk behaviors	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*
Cancer risk attitudes	HINTS [2]*
Cancer screening	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]
Family history/genetic testing	HINTS [2]*, NHIS CCS [3]*, BRFSS [4]*, 13-item Attitudes Toward Genetic Research and Testing [6]
Knowledge/attitudes regarding medical research/clinical trials	HINTS [2]*, 17-item Likelihood of Participation Scale [7]
Knowledge/attitudes regarding biobanking research	BANKS [8]*

*, denotes selected items, HINTS, Health Information National Trends Survey; NHIS CCS, National Health Interview Survey Cancer Control Supplement; BRFSS, Behavioral Risk Factor Surveillance System; SF-12, 12-Item Short Form Health Survey; BANKS, Biobanking Attitudes and Knowledge Survey.

NCI PHA "Core Measures"

Of special interest to Programs & investigators at FCCC

Table 1. Data and key constructs for proposed data collection project.

Data/Key Construct	Instrument

Communication Tool

- Developed by NCI GMap Region 4 investigators
- Focused on
  - Cancer research/clinical trials
  - Biospecimens & biobanking
- Pilot tested in 100, randomly selected, English-speaking participants *throughout catchment area* (pre/post testing)

Toward Genetic Research and Testing [6]

Knowledge/attitudes regarding medical research/clinical trials	HINTS [2]*, 17-item Likelihood of Participation Scale [7]
Knowledge/attitudes regarding biobanking research	BANKS [8]*

*, denotes selected items, HINTS, Health Information National Trends Survey; NHIS CCS, National Health Interview Survey Cancer Control Supplement; BRFSS, Behavioral Risk Factor Surveillance System; SF-12, 12-Item Short Form Health Survey; BANKS, Biobanking Attitudes and Knowledge Survey.

- Survey
  - Being finalized/user-tested
  - Creating REDCap database
- IRB protocol/application
  - Being finalized → submit 1-2 weeks
- Timeline for fielding
  - Start recruitment/data collection within 1-2 months
- Data collection
  - Completed within 3-6 months

- Enhancing Center's ability to more effectively define cancer problems relevant to our catchment area

- More <u>granular</u>, <u>potentially actionable</u> data

  - ➡ **Guide the Center's research enterprise**

  - Focus & refine

    - ➡ Community outreach (e.g., cancer screening) and education efforts

    - Cancer prevention and control efforts,

      – Preliminary data for investigators

      – ➡ <u>Targeted</u> interventions

      – ➡ Enhance inclusion of minorities in

        » (<u>Clinical & research</u>) Precision medicine initiatives

        » Clinical research & trials

        » Biobanking research

- Geospatial characterization of our catchment area → linkage to similar regional/state/national data resources

  - Resoruce for Center programs/investigators

  - Of interest/value to other NCI designated/comprehensive cancer centers serving underserved populations.