Linking Electronic Health Records and In-depth Interviews to Uncover Barriers to Social Mobility and Health in a Declining Coal Mining Community

Statement of the Problem and its Importance

This research is situated at the nexus of poverty, social mobility, and health among low-income, racially diverse women in rural Pennsylvania. Poor health is a barrier to social mobility, and marginalized populations are both more likely both to experience poor health and to receive inadequate medical care. Yet the relationship between economic disadvantage and health is complex, and our awareness of the mechanisms that drive health attitudes and behaviors in poor communities is inadequate. Our research design is uniquely suited to uncover the mechanisms through which social inequalities of class, race, and gender shape women's health experiences and behaviors on the one hand, and how these experiences and behaviors compound poverty and reduce social mobility on the other (Murray 2006). Conducting this research is crucial to improving the physical and emotional well-being of poor women in poor communities.

While research in the social sciences documents disadvantaged people's health care challenges, this existing scholarship usually provides only the individual's perspective on their health and health care and may not be a reliable source of health data (e.g., healthcare utilization, medication prescribing and use, or diagnoses). In studies based only on medical health care data, in contrast, the voice of the patient is often missing, especially among marginalized groups, leaving the pathways through which social inequality and health experiences and outcomes interact unknown. Our research rectifies these omissions by developing an innovative mixed methods approach that links electronic health record (EHR) data from Central Health System, an integrated health system, with consented patients' own accounts of their experiences, worldviews, struggles, and obstacles to social, physical, emotional, and economic well-being.

Our study builds on previously funded research which links in-depth interviews with low-income white women to their electronic health record (EHR) data. Our data collection takes place in the anthracite coal region of Northeastern Pennsylvania, specifically in the rural counties of Schuylkill and Northumberland. Since the 1960s, mining jobs have been replaced by service jobs in education, health care, and retail that are largely non-union, pay low wages, and offer few benefits. Only 16% of the area's population holds a college degree in comparison to 20% at both the state and national level. The region reports an overall 14% poverty rate (American Community Survey 2012–2016). While Pennsylvania has historically been an overwhelmingly white state, with a minority of African-Americans in major cities, rural Pennsylvania is growing increasingly more ethnically and racially diverse (see, for example, Milofsky 2008). Over the last decade, rising housing costs, poverty, and crime have pushed black and Latino people out of urban economies and into the coal region, challenging long-standing boundaries of urban and rural, race and place. The counties of our research focus have a documented hyper-increase in the Latino population since the turn of the new century, increasing by 216% in Schuylkill from 2000 to 2014 and 177% in Northumberland during the same period (Pew Research Center 2014). These counties rank among the lowest in health indicators including poor physical and mental health days, as well as health behaviors such as teen births, preventable hospital stays, and incidences of violent crimes and injury deaths (Robert Wood Johnson 2019). Central Health System Health Center classifies both counties as "high-need communities" based on various socio-economic indicators, including income, educational attainment, insurance coverage, and English language barriers (Baker Tilly 2018).

Initial execution of this research (Stage 1, completed) resulted in interviews with 40 white rural women, 13 conducted in 2017–18 and 27 conducted in summer 2019. The qualitative

interviews probed respondents on their life histories, socioeconomic background, health concerns, and previous medical treatments. We linked these respondents' life history narratives to their individual EHRs, which contain their medical and treatment histories, including diagnoses, medications, treatment plans, and laboratory and test results. Stage 1 focused on developing a new methodology for integrating interview and EHR data. Our interdisciplinary team established new data-sharing protocols for merging data while maintaining participant confidentiality (see Appendix A) and novel approaches for analysis with a dataset that includes both interview and EHR data.

For Stage 2, we propose to apply these newly developed methods to a larger and more diverse dataset, to include the addition of 40 non-white participants and incorporation of free-text physician notes, as described below. Making novel connections across two under-utilized and rarely-accessible data sources — in-depth interviews and medical record data — we will uncover the economic, social, and cultural barriers that drive physical and psychological distress among white, black, and Latina low-income women, as narrated by the women themselves, while also situating these accounts within medical diagnoses, treatment plans, and physician's notes. This expanded effort using our refined methods with a larger, more diverse sample is key to understanding the pathways through which both economic and racial inequality impact health — and health impacts social mobility — with the goals of identifying and reducing structural barriers to opportunity and well-being in disadvantaged communities.

Principal Research Questions

1. What are the mechanisms, emerging from rural women's narratives of their experiences and behaviors, through which economic disadvantage and racial identity impact physical and emotional well-being?

a. How do these mechanisms vary by race and ethnicity?

2. What kinds of discrepancies exist between the formal medical record and patient narratives in terms of sources of poor health, diagnoses, and necessary treatment plans?

a. How do these discrepancies vary by race and ethnicity?

3. How do experiences within the healthcare system itself shape women's everyday approaches to their own health and well-being, as narrated by women themselves?

a. How do these experiences vary by race and ethnicity?

4. Can we identify possible patterns in diagnoses, prescribing of medications, and creation of treatment plans in the electronic health records that might either promote or hinder participants' ability to achieve economic and social well-being?

a. Are there differences by race and ethnicity?

Contribution to Existing Literature

Our project brings together research from sociology, economics, public health, and political science. Sociological studies of working-class Americans in rural settings have documented how stigma, isolation, and lack of effective mental healthcare and substance abuse treatment strengthen barriers to social mobility such as unemployment and low wages (Duncan 2015; Fitchen 1995) and contribute to the persistence of multigenerational poverty. Recent research has proposed that the disappearance of stable, good-paying blue-collar jobs has led to a culture of hopelessness among white Americans without a college degree, leading to rising mortality rates from "deaths of despair" (Case and Deaton 2015, 2017). These life expectancy losses have been particularly dramatic for white women with less than a college degree (Cherlin 2018).

While the specific mechanisms driving up deaths of despair are unknown, economists Case and Deaton (2015 and 2017) propose that working-class white people are turning to unhealthy coping mechanisms such as opioids, alcohol, suicide, and food (Harper et al., 2017) to manage economic and social dislocation. Lending support to this hypothesis, sociological studies

have documented that since the 1970s, rural working-class whites have become detached from mainstream institutions like work, marriage, religion, and politics, resulting in multi-generational poverty, vulnerability, and extreme isolation (Carr and Kefalas 2010; Duncan 2015; Gest 2016; Cramer 2016; Wuthnow 2018; Monnat and Brown 2017; Silva 2019). Yet little research has been done on the specific pathways that connect economic decline to psychological health; on the ways in which "despair" manifests biologically and behaviorally at the individual level; or on how whiteness interacts with economic and social distress at the level of individual narrative to produce unhealthy coping mechanisms (Brown and Tucker-Seeley 2018; Mezuk et al., 2013). Furthermore, we need more data on how the experience of poor health such as pain or depression may in turn affect people's ability to escape poverty (Krueger 2017).

Case and Deaton's research "unexpectedly positioned working-class Whites as the new face of disadvantage" (Brown and Tucker-Seeley 2018), spurring a flurry of media attention on working-class white Americans left behind in rural America. Yet the increased focus on the rural white working class tends to obscure two important trends: the increasing racial and ethnic diversity and the geographical flux in non-metropolitan areas (Lichter 2012; Lichter and Ziliak 2017). In the national context, nine out of 10 rural places experienced increases in diversity between 1990 and 2010, with racial and ethnic minorities moving to whiter areas, and white young adults moving to more diverse urban areas (Lee at al 2014). Today, twenty-one percent of rural America is Latino or non-white, and minorities accounted for over 80% of population increases from 2000 to 2010 (Johnson 2017). Scholars are uncertain whether newly-arrived ethnic and racial minorities will find increased opportunities for safety, work, community, and mobility in rural places in contrast to their previous places of residence (Carr, Lichter, and Kefalas; Jensen 2006; Weber et al., 2017), or whether hope will "turn sour" (Kefalas 2000;

Marrow 2017), compounding blocked opportunity, stigma, and social exclusion for the next generation (Eason 2017). Furthermore, past research has established that, despite higher risks of financial strain, stress exposure, morbidity, and mortality relative to whites, black and Hispanic people report lower rates of stress, anxiety, and depression — key indicators of despair — underlining the need for more research on the interplay between racial identity, structural barriers to mobility, and personal narratives of coping (Krueger 2017).

By using newly refined methods for examining the medical records in tandem with in-depth interviews of working-class white women and women of color in Pennsylvania coal country, our research design will provide novel insights into the relationship between poverty, racism, and mental and physical health in the 21st century. Our analysis will capture official medical diagnoses, healthcare utilization, medication usage, and treatment adherence through the EHR while simultaneously documenting the structural constraints such as poverty, racism, economic and social instability, and interpersonal or societal violence from interview transcripts. We will also witness and document how patients' experiences with medical institutions shape women's attitudes and behaviors about health.

Principal Research Objectives

1: We will interview 40 non-white female respondents, adding respondents and diversity to our qualitative dataset and allowing analyses that include race or/and ethnicity.

2: We will link Central Health System EHR data with patient interview data using our newly developed data-sharing protocol and data analysis techniques. We will continue to carefully examine patients' understanding of their diagnoses and required treatment

against Central Health System records on diagnoses, treatment, and outcomes to document emergent patterns, especially regarding race or/and ethnicity.

3: We will focus on uncovering the barriers that drive gaps between formal health care and expected v. actual patient outcomes such as the often invisible reasons underlying missed appointments and not following a doctor's advice. Race or/and ethnicity will be key variables in our analysis.

4. We will trace how interactions with medical institutions shape participants' own understandings of health, well-being, and trust, focusing on how these interactions affect their ability to escape poverty and achieve upward mobility.

Research Methodology

We will continue our innovative mixed-methods research approach, relying on Central Health System EHR data and semi-structured interviews with economically disadvantaged women. The 40 white women we have already interviewed were recruited through the connections and relationships that Dr. Silva established while conducting fieldwork for her recent book *We're Still Here: Pain and Politics in the Heart of America.* We will add 40 black and/or Latina women to this sample. We chose to aim for a total sample size of 80, which is small enough to capture the depth of meaning and the vividness of the data (Lareau and Rao 2016) while large enough to establish patterns, look for cases that challenge our theoretical presumptions, and draw robust comparisons between the different groups (DeLuca et al., 2016; Ali and Cohen 2016).

We will continue to integrate electronic health record data with consented patients' own accounts of their experiences, worldviews, struggles, and obstacles to care. The interviews aim to

uncover patients' accounts of past medical issues, current medical issues, interactions with GHS, and existing diagnoses; their understanding of required treatment and barriers to compliance; their experiences of stress and economic deprivation; patients' social support systems; and their sense of self-efficacy and trust. Our analysis approach of the semi-structured interviews will employ open coding, in which we read each interview line by line to identify salient themes (See Appendix B for interview guide). We will then link EHR, including physician's notes, to interviews of patients' experiences of health care and their own understandings of their diagnoses and required care.

Central Health System is a health system that serves more than four million primary care patients across Pennsylvania and New Jersey. As one of the earliest adopters of the EHR system — and due to the low out-migration rate within this specific geographic area — Central Health System provides longitudinal health data like few others, capturing information on medical diagnoses and practices that inequality scholars rarely have access to. EHRs — capture in digital form — all inpatient, outpatient, and emergency department encounters, as well as diagnoses, laboratory tests, procedures, doctors' orders, medications, and other information that would be obtained from the clinical encounter (Swartz 2011). Central Health System's primary service area consists of a number of U. S. Department of Health and Human Services Health Resources and Services Administration-designated medically underserved areas (MUAs), including communities in Schuylkill and Northumberland counties. The Central Health System Family Plan is contracted with the Department of Human Services (DHS) to offer coverage to eligible Medical Assistance recipients living in 22 Pennsylvania counties. The Central Health System Clinic service area average household income ($60,378) is 15.3% lower than the US ($71,320);

13.1% have household income less than $15,000/year. The catchment area is one of the oldest and sickest in the nation in terms of multiple comorbidities.

To date, interviews with 40 white women have been completed. We propose to interview 40 women who identify as black and/or Latina and combine those data with the sample of white respondents. We will employ purposeful sampling, selecting cases that provide rich information on diagnoses of obesity and diabetes, reported smoking and drinking behavior, prescription history, and adherence to appointments. Each participant will have an EHR from Central Health System. (See Appendix B for interview guide.)

During the interview process, Drs. Silva and Durden and the research assistants obtain IRB consent from the study participants to access retrospective EHR data. Dr. Hirsch will provide a data pull request to Central Health System's Department of Biomedical and Translational Informatics for the EHR data using the name and date of birth of the consented individuals in the qualitative cohort. The following data elements will be extracted on all consented participants from the date of their first recorded encounter until December 31, 2016:

- Health system utilization: (1) Rates/counts of outpatient, inpatient, emergency department, and urgent care encounters; (2) rates/counts of prescription medication orders by indication and pharmacy class; (3) rates/counts of procedures.

- Health status: (1) Charlson Comorbidity Index — a widely used method of predicting mortality by classifying/weighting comorbid conditions; (2) status of intermediate risk factors for cardiovascular disease and diabetes such as glucose control, blood pressure, cholesterol, body mass index.

- Measure adherence: (1) Rates/counts of no-shows to scheduled appointments; (2) medication adherence as measured by rate of prescription fills (GHP data) for ordered

prescriptions (EHR) among individuals who both receive GC care and are GHP members.

- We will review and code free-text notes documented during the visit to identify themes not typically available in discrete data fields, including concerns regarding medication adherence, patient-reported stress, and social support.

In addition to these discrete data elements, Dr. Hirsch will request free-text physician notes from the EHR for each respondent, as these notes may contain details regarding patient experiences discussed during clinical visits that are not generally recorded in the discrete data fields of the EHR (e.g., financial challenges, family dynamics, etc.). We will amend the Stage 1 IRB to include free-text physician notes. No protected health information will be released from Central Health System. Rather, for each participant, Central Health System study staff will develop a de-identified narrative, based on the EHR data, that summarizes the participant's experience with the health system, a methodology developed during Stage 1 with the smaller sample.

Data analysis will occur in three stages. After the interviews are fully transcribed, Drs. Silva and Durden will carefully read through the transcripts and provide a thorough summary of the respondent's story, removing identifying data and pulling out key quotes and themes. Dr. Hirsch will simultaneously create a de-identified narrative of each EHR, highlighting the key medical prescriptions, the history of the patient with the Central Health System, and the medical recommendations provided. The summaries of the qualitative interviews and the EHR will then be read in tandem by the entire team. We will code events and diagnoses where the medical record and the patient narrative overlap (such as accounts of prescriptions taken or of visits) but also where they diverge - such as in discrepancies between formal diagnoses and patients'

understandings of their illnesses, and instances where the medical system did not register areas of respondents' concerns or experiences (such as domestic abuse or poverty). Rather than treat the medical record as the official, objective diagnosis compared with the subjective experience of this diagnosis in the interview, we aim to treat both the electronic health record and the narrative transcripts as two different stories being told, one by the health system and one by the patient. Moving back and forth between the electronic health records and the narrative transcripts, we begin with line-by-line coding that identifies patterns in how these two stories coexist.

Analysis Approach

Examples from Preliminary Data

For poor white women patients, we often found a dramatic difference between the EHRs and interview transcripts in understandings of causes for pain and disease, as well as strategies for healing. Specifically, formal diagnostic language seen in the EHR was rarely used in white women's interviews, which instead focus on social sources of suffering, especially poverty, trauma, and violent relationships. We also found that these women were frustrated and embarrassed by their lack of adherence to the physician's recommendations in the EHR. When they cannot afford to follow doctors' advice or have limited resources for healthy eating or returning to the doctor, they turn to self-treatment strategies such as eating, smoking, remaining in unhealthy relationships, and taking illegal drugs. The imperative to care for others makes caring for oneself too burdensome for these women in the face of financial constraints. The interviews uncover a sense of shame over these decisions, one that is magnified by their social interactions with employers, caregivers, and social service providers. Finally, we uncovered a

pervasive sense of distrust in the medical profession, which women view as over-prescribing medication and prioritizing profit over care.

To provide an example from Stage 1, the EHRs from Central Health System show that Bree (a pseudonym), a white female, first entered the system in 2004 at the age of 26. She was a smoker. Bree returned for care multiple times in 2004, including separate visits for an "unspecified mood (affective) disorder"; back pain diagnosed as a sprain; and an eye infection. She was prescribed Effexor, an antidepressant. Bree returned to Central Health System in 2011, where she was treated for generalized anxiety disorder and panic disorder. During the next five years, she suffered from chronic pain and mental health conditions. She was prescribed generic Xanax. Ultimately, she was referred to rehabilitation medicine and the neuropsychology department for chronic pain and was diagnosed with fibromyalgia. In 2012, Bree was prescribed three different antidepressants: amitriptyline HCL, duloxetine HCL, and citalopram hydrobromide. She received multiple prescriptions for pain, including oxycodone-acetaminophen (Percocet), opioid agonists (Tramadol HCL), glucocorticosteroids, NSAIDs medications, and muscle relaxants.

In her interview, Bree details a decade of low wages as a waitress and domestic abuse from a former husband. We do not know if Central Health System is aware of the sources of Bree's pain and anxiety, as she admits to being "embarrassed" about the domestic abuse. She describes: "My first husband did this to my teeth [she points to two gaps in her mouth where there should be canine teeth]. He bent me over the baby's crib with her in it backwards. I literally was in half, so I deal with that. I don't go to the doctor for it. They want to send me to this specialist, that specialist, a psychiatrist to deal with the pain, living with pain. I don't even go. I just don't even go, because, honestly, pain medication doesn't really help me." Bree states

simply: "my body is destroyed on the inside." The pain medication "tended to make me sleepy a lot, so I stopped taking it." She suspects she is "allergic" to the antidepressants she was prescribed: "They throw me off the reservation. They just make me real angry. It may even be in my chart that I'm allergic, because they've tried just about every single one for me." Bree is reluctant to return to Central Health System because "it almost seems like they give you a lot of things that you don't really need. Like, they send you to a lot of different doctors…" Another doctor prescribed both "Percocet and Dilaudid? They're both painkillers. Why do you need both? He just would just shove so much shit in my face. I asked for physical therapy and he got pissed off."

She says heatedly: "I was going to a psychologist, whatever the hell that is. I was going to, um, a neurologist. Um, they had me going to a pain specialist, and then physical therapy, and then a psychiatrist, or a psychologist, to talk about my pain. I said, *let's talk about the gas money to get to [the specialist] every day*." When Bree's electricity was shut off last year, she and her children slept on her cousin's pull-out couch for three weeks while she saved up enough money to turn the heat back on. A severe lack of financial resources forces Bree to choose between having her garbage collected at $3 a bag or providing food for her family. She says desperately, "I gotta choose whether to feed my kids or get fined for my trash." Although she knows she needs to quit smoking — "if my mother died from this I will, so, like, if I don't stop soon…I mean, I'm almost 40" — it keeps her from "ending up in the loony bin."

As the case of Bree demonstrates, investigation of EHRs side by side with women's personal stories revealed areas of convergence and areas of divergence between medical diagnoses, doctors' advice, and patients' lived experiences. It is often the case that patients simply cannot afford to follow doctors' advice. We also see that Bree herself is overwhelmed by

the sheer number of medications she is prescribed, suggesting that reliance on drugs to treat social problems is a normalized part of her care. The integration of patient narrative thus offers the possibility of fusing clinical diagnoses and practices with social determinants of health such as poverty, despair, and isolation.

Potentials of Adding a Diverse Sample

Based on in-depth interviews with women of color who moved to the coal region, Silva (2019) chronicles how these black and Latina women leave behind traumatic histories — stories of early childhood abuse and neglect, poverty, extreme neighborhood violence, and drug abuse. Upon arrival, these women face accusations that they are unfit mothers, have poor work ethics, and are undeserving of government aid. These women encounter multiple predatory institutions waiting to take advantage of their optimism. Living a life of emotional turmoil, relationship flux, racial hostility, and poverty, however, leaves these women emotionally raw, deeply distrustful, and physically depleted. For Stage 2 of this research, we propose to reconnect with 40 of these non-white women to interview them about their health and request access from Central Health System for their medical records with the goal of understanding how race compounds economic disadvantage and poor health in the coal region.

The case of respondent Stephanie provides insights into how electronic health records and an additional round of interviews focused on poverty and health can achieve this goal. Stephanie Rivera, a twenty-three-year-old woman who identifies as black and Puerto Rican, spent the early years of her life in a public housing project in Brooklyn, New York. When Stephanie was ten years old, her mother decided to move west to rural Pennsylvania, which

promised more affordable housing, safety, and better jobs — "that's where everyone at the time was going, like everyone that wanted to get out of the city was going, and for her it was like, complete life-changing." Despite her mother's longing for peace and safety, their first apartment was "horrible"—"the landlord was this drug lord." She remembers: "A pipe busted and I don't remember if it was in the kitchen or the basement and we kept saying like our water bill was getting higher and higher and higher, and finally it burst, to a point where you stepped foot in the living room, your foot would go in the rug cause there was so much water. We couldn't live there." After high school, Stephanie got a job at a discount smoke shop that she could walk to, while her boyfriend got a job working in the shipping and receiving department at Walmart. The neighbors, however, "were like doing drugs there, and they caught a sofa on fire and it came into our house. It was horrible. And then we were homeless for three weeks cause we lost everything. I was three months pregnant. When I say we lost everything, the only thing we had was the clothes on our back, the phones cause we all sleep with our phones."

Stephanie's initial interview reveals how institutions, health, poverty, and race work together to shape life chances. When she was pregnant, she explains, she went to the local doctor and insisted something was wrong. At twenty-nine weeks "I kept saying I thought my water broke 'cause I had like fluid leakage. They said nope, it's not water, it's normal discharge. It was amniotic fluid coming out." It turned out she had preeclampsia, a serious and sometimes fatal complication. Stephanie finally went to a large hospital about twenty miles away with a more advanced maternity unit. She learned: "my preeclampsia was so severe. They explained to me what it was, high blood pressure during pregnancy. So I was high risk since I was twenty-nine weeks all the way to thirty-eight weeks and no one told me. And nobody said anything. I was working all the time. Always on my feet." To make matters worse, she adds, the doctors

"thought I was on drugs because of how small she [her daughter] was, but it was because they neglected my pregnancy. She wasn't getting the nutrients due to preeclampsia. She was born five pounds. Itty bitty little thing." Stephanie, who does not smoke or drink alcohol, continues with outrage: "They tested her without my permission for alcoholism and marijuana and all of that. So they came out, 'Oh yeah by the way she doesn't have alcoholism' and I was like wait, what? They said, 'Oh yeah, we tested her.'" Stephanie suspects that the hospital workers automatically assumed that she was a drug addict because she was poor and not white.

Stephanie mostly stays in the house and takes care of her daughter. "I don't really go out besides work. Would I walk around at night? No. No," she says firmly. "There's a lot of drunk people around here, just stupid things. One time when I was trying to drive away, is when they was doing the fireworks [during the Fourth of July], I had a crowd of people around my car yelling the n-word and all this at me. My daughter's crying in the backseat, 'cause she didn't understand what's going on. It was horrible. It was the worst. I cried, I never cried so hard in my entire life." Stephanie's skin color clearly marks her as an unwelcome outsider in her rural community, increasing her isolation and fear in ways that could impact her health. Stephanie connects her fear of walking outside to her recent weight gain: "I just can't stop gaining weight." Stephanie's original interview suggests that both poverty and racism shape women of color's health experiences and behaviors on the one hand, and that negative interactions with the medical profession may increase distrust and isolation, stymieing potential opportunities for escaping poverty. Pulling the electronic health records and re-interviewing Stephanie more specifically about her health and mobility offers the possibility of deeper understanding of how the dual mechanisms of economic disadvantage and racial identity impact women's physical and emotional well-being. Furthermore, a nonwhite sample will allow us to explore possible racial

patterns in medical treatments; for instance, while we see Bree prescribed multiple opioid medications, Stephanie is suspected of drug addiction in her medical encounters; both experiences affect their sense of trust, behaviors, and well-being in different ways.

Project Work Plan

This proposed research will be conducted over two years (January 2020 – December 2021).

Pre-Award Research Activities **(September 2015 – August 2019)**

- May 2015 – December 2016: Forged community connections in Central Pennsylvania and conducted 120 in-depth interviews with poor and working class residents, both male and female.

- June 2017 – May 2018: Conducted 13 semi-structured interviews with white women in Central Pennsylvania exploring experiences, worldviews, and formal barriers to health care (research funded by Bucknell Central Health System Research Initiative 2017).

- January – December 2018: The development of a new methodology for the integration of interview and EHR data. New data-sharing protocols were established, in collaboration with administrators from Central Health System and Bucknell, to merge data from both study teams while maintaining participant confidentiality (see Appendix A). The interdisciplinary team also established novel approaches to analyzing a dataset that includes both interview and EHR data. Initial analysis conducted, linking narratives with electronic health records.

- May 2019: Preparation of data collected — 13 transcribed interviews and 13 electronic records decoded.

- May – August 2019: Conducted, and to conduct an additional 27 interviews with white women, and collected additional electronic data, including free-text physician notes (research funded by Bucknell Central Health System Research Initiative 2019).

- August – December 2019: Additional interviews to be transcribed and electronic health records pulled and decoded.

Year One **(January 2020 – December 2020)**

Silva, Durden, and Hirsch will oversee data collection for the sample of 40 black and Latina women and analyze data for the combined sample of 80 women. Ongoing research will be presented at academic conferences and submitted for publication.

- January – August 2020: Semi-structured interviews to be conducted with 40 non-white female respondents.

- March – December 2020: Interview subjects will be linked with their electronic health records; newly collected interviews will be transcribed; data from discrete electronic health record fields to be extracted — diagnosis codes, medication orders, medical procedure codes, etc.; extraction and summary of free text clinician notes will be documented during clinical encounters.

- August 2020: Conference paper to be submitted and presented at the American Sociological Association Annual Meeting in San Francisco.

- November 2010: Article to be submitted to *American Sociological Review* on research involving Stage 1 collected data.

Year Two **(January 2021 – December 2021)**

- January – November 2021: Interview data and electronic health records will continue to be analyzed, with particular attention paid to the role of race in economic disadvantage, physical well-being, and health care responses.

- August 2021: Conference paper to be submitted and presented at the American Sociological Association Annual Meeting.

- November – December 2021: Book proposal and sample chapter prepared for advance contract with press.

Qualifications and Responsibilities of Researchers

This team is uniquely equipped to complete the proposed research. **Dr. Jennifer Silva** is an assistant professor at the O'Neill School of Public and Environmental Affairs at Indiana University. She has extensive experience conducting qualitative research. Her first book, *Coming Up Short: Working-Class Adulthood in an Age of Uncertainty* (Oxford, 2013), examines the transition to adulthood for working-class youth. Her new book, *We're Still Here: Pain and Politics in the Heart of America* (Oxford 2019), investigates how working-class residents in rural Pennsylvania respond to the decline of the American Dream. Additional scholarship has appeared in the *American Sociological Review, Social Forces*, and the *Journal of Consumer Research*. **Dr. T. Elizabeth Durden** is an associate professor of sociology at Bucknell University. Her research encompasses race and ethnic inequalities within the United States, the sociology of immigration, and medical sociology. Her research has been supported by a Fulbright Hays Faculty Research Award and the National Endowment of Humanities, and has been published in the *International Migration Review*, *Journal of American Ethnic History*, *Journal of Immigrant and Minority Health*, *Social Science and Medicine,* and other scholarly

books and journals. **Dr. Annemarie Hirsch**, associate professor, focuses on novel applications of health system data to measure health outcomes, health care quality, medication adherence, and the epidemiology of chronic conditions such as diabetes and obesity. Dr. Hirsch secured a $3 million grant from the CDC to evaluate the role of social and community factors in type 2 diabetes incidence and control. Her research has been published in *Health and Place*, *JAMA*, *American Journal of Preventive Medicine,* and *Medical Care Research and Review,* among others.

The proposed research falls within the scope of scholarship and expertise for each investigator. Successful working relationships have already been established from previous funded research and demonstrate our ability to collaborate. Durden and Hirsch collaborated on research which illustrated the key roles of community resources and socioeconomic deprivation in influencing the effectiveness of formal health care, recently published in *Diabetes Care*. Silva, Durden, and Hirsh collaborated (2017–18 and 2019–20) for a pilot of the research proposed here that successfully established (1) new data-sharing protocols, in partnership with administrators from Central Health System and Bucknell, to merge data while maintaining participant confidentiality (see Appendix A); and (2) novel approaches to analyzing a concatenated dataset that included interview, EHR, and physician free text data.

Responsibilities of this project will be shared by all three co-principal investigators. Drs. Silva and Durden will take the lead on collecting the qualitative interviews while Dr. Hirsch will gather the EHR and physician notes. As previously discussed (see Research Methodology), all three collaborators will be involved in the analysis of the data and the writing of academic articles and manuscripts. In regards to a public release of the data, as detailed in "Transparency & Reproducibility," the investigators request that Russell Sage consider an exception for this

project due to the nature of the data (both qualitative and medical records). This research, which explores barriers to social mobility and health in a declining coal mining community, will be reported and shared at professional meetings, by peer-reviewed journal articles, and in book format.

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Appendix A: IRB Approval Process

Previous Grant Support: This research has previously been funded by two grants from the Bucknell Central Health System Research Initiative (2017–18: $20,000 and 2019–2020: $78,380).

The proposed research design, informed consent process, and data collection instrument was approved by IRBs at Bucknell University and Central Health System in December 2017 and renewed in May 2019. The IRBs at both the university and the hospital system have required us to adhere to Health Insurance Portability and Accountability Act (HIPAA) Health Information Technology for Economic and Clinical Health Act (HITECH Act) regulations. For Stage 1, we went through a six-month approval process that resulted in the creation of a data use agreement between Bucknell and Central Health System. For the Stage 2 research being proposed, we will modify the existing IRB to allow for 40 additional women to be interviewed. Our data use agreement between the hospital system and the university specifies the following procedures:

Step 1: Researchers at Bucknell University sends the names, dates of birth, and transcribed interviews of interviewees who consented to release their Central Health System data.

Step 2: Central Health System pulls de-identified medical record data on these patients.

Step 3: Central Health System merges the de-identified medical record data with the corresponding interview transcript.

Step 4: Central Health System replaces patient identifiers originally provided by the university with a randomly generated patient ID.

Step 5: Central Health System sends the university a completely de-identified dataset that merges medical record and interview data.

Step 6: Bucknell University researchers do not make any attempt to link the de-identified dataset back to any identifiable information that they may have collected during their interviews.

Appendix B: Interview Guide

Introduction/Background Questions
1. Would you tell me a little bit about yourself? How old are you, and where did you grow up? Where were you raised?
2. What did your parents do for work? Mother? Father? Other?
3. When you were growing up, were your parents married (or: never married, divorced, living with new partner, re-married)? If divorced, when? Whom did you live with? If partnered/remarried, when and to whom? How did your life change after the divorce/remarriage/new partner?
   – Probe: less attention from parent, financial hardship, adjusting to step-family.
4. Can you remember times when your parents seemed to struggle economically? Was there a time when they couldn't pay the bills, or worried about money? How did they talk about this? What did they do about it?
5. How would you compare yourself to your own parents? Do you think you will end up like they did?
   – Probe: financially but also as a person.
Current Life Questions
6. Can you walk me through a typical day in your life (from when you get up to when you go to bed)?
7. What jobs have you had, and where have you worked? How did you get those jobs?
8. Where would you say are the best opportunities around here for work? Why?
9. How competitive are these jobs? What stands in your way of getting them, if applicable?
10. Do you know people who have or have you ever left the area for better opportunities?
11. What keeps you here (in the area you currently live in)?

12. Would you move to a city for better jobs? To Lewisburg, to Philly?
13. Do you have a pension, disability pension?
14. Are you able to pay your bills? What kinds of bills do you have to pay?
    – Probe: income security, debt, do they get benefits like health insurance, and for how much?
15. How would you define your current standard of living? Do you have any assets like a house or a savings account?
16. Who do you live with? How long have you lived there? How did you make the choice to live there?
    – How does it compare to the neighborhood where you grew up?
    – Can you get everything you need nearby?
17. Do you feel like you can make ends meet? How do you do it? Do you ever worry about making it to the end of the month?
18. Would you say your income fluctuates substantially over the course of a year? Would losing your job, getting sick, or breaking up with your partner force you to dramatically reduce your assets, and/or significantly re-adjust your living standards?
19. How do you feel about your standing at work? Why? Do you think there are opportunities for promotion?
20. Have you ever received any kind of assistance like WIC (women, infant, children) or SSI (supplemental security income)? How did you find out about these? How do you feel about getting this kind of support?
    – Probe: SSI, food stamps, Section 8 housing.
    –Are you eligible for the EITC (earned income tax credit)? Do you claim it?.
21. Have you ever been arrested? Convicted?
22. Thinking about all we just discussed — when you were younger, did you imagine your life turning out this way?

Health Questions
23. Can you tell me about your physical health? What kinds of health issues are you currently experiencing? – Probes (diabetes, obesity, blood pressure, back pain).
    a. Who helps you with these health issues? Family, friends, church doctors?
24. Are you in pain right now? What hurts?
25. What have you been diagnosed with? Who diagnosed you? When were you diagnosed?
26. Tell me about your history of health issues. Have you had any major health issues?
27. When you have pain, does it prevent you from working?
28. How would you rate your mental and emotional health? Are you stressed out?
    a. How do you cope with stress?
    b. Do you take medication for stress?
    c. What do you think is causing your stress?
    d. Who do you turn to for help with your stress? Family, friends, church, doctors?

29. Can you tell me about the last time you went to the doctor?
    a. Where did you go?
    b. Why did you go?
    c. What doctor did you see? Have you seen this doctor before? How did you choose what doctor to see?
    d. How did you feel about the visit?
    e. How did you get to and from the appointment?
    f. How did the doctor explain your health to you?
    g. What did the doctor do for you? Prescribe a medication? Send you to another doctor? Talk about smoking, exercise, eating?
    h. Did you take their advice? Why or why not?
    i. Did they spend enough time listening to you?
    j. Do you trust your medical doctor?
30. Have you ever been unable to get an appointment with a doctor you thought you needed to see?
31. Have you ever been unable to pay for what you needed in terms of health care?
32. (If applicable.) What was your experience with Central Health System like when you were pregnant? How was your experience giving birth?
33. Do you smoke? Do you drink? Do you have a history of using illegal drugs?
    a. Why do you do it? What does it do for you?
    b. Do you tell your doctor this information?
34. Do you receive health care outside of Central Health System? Why or why not?
35. How do you think your experience with doctors and Central Health System compares to what you have heard from your family and friends? Have family and friends had good/bad experiences getting care?
36. How do you pay for medical care? (If on governmental assistance: how long? Where did you get it? How were you treated?)
37. Have you ever experienced violence (either in an intimate relationship or childhood)? Did you feel like you were able to get the help you needed?
    a. Did you stay in the relationship?
    b. Did a doctor ever ask you about this experience, if applicable?
38. What would you like to change about your personal health? Do you feel like you are in control of your health?
39. What would you like to change about your health care/the way you receive healthcare?
40. Do you worry about your children's health?
41. Do you trust the health care your child receives?
42. Whose responsibility is it to manage your health? (The government, you, your employer…)
43. Do you have people in your life that you trust? That you could rely on for rides, childcare, or to sleep on their couch? How about to borrow $30?

44. Do you trust social institutions, like the government? The police? Schools? Why/why not?
45. Do you feel hopeful about your future? Do you think there is opportunity for your children to achieve a good life?

Perceptions of Education Questions (specific to college experience that relocates)
46. Is/was going to college at a four-year school (that relocated you, like Bloomsburg, Wilkes, Bucknell) ever in your plans?
    – Follow-up: what would make going to college possible for you? If in your plans, what has stood in the way of you attending college or completing a degree?
47. Do you know anyone (family members, neighbors, friends?) from your community who went to a college where they had to leave their hometown area? How well did you know them before they started school? How far away did they go? Did they come back after they finished college?
48. What do you think college should do for people? If you received a degree, what changes would you expect to see in yourself and your life? Thinking back to the person(s) you described in the previous question, what changes, if any, did you see in them after they went to college?
    – Probe: How they interact with others, who they interact with, ways they speak.
49. What value do you see in obtaining a college degree? Is it worth the debt?
50. If you (or your child) got a college degree from somewhere like Bloom, Bucknell, or Wilkes, would you want to come back to get a job in this area? Or do you see college as something that would allow you to move you somewhere else? What would moving somewhere else mean to you? How connected do you feel to your 'home' area, wherever that is?
51. Have you ever had to move away from home for a time? Why did you have to move away? What was your experience like coming back?
    a. Follow up: if this (where you are now) is your temporary location, how do you feel about returning?