



# Brandeis University

Human Research Protection Program



IRB Office Use Only

## Initial Research Protocol

Use this form for non-exempt research involving data collection.

Healthcare Mistreatment Among Individuals Experiencing Homelessness				
<b>Project Title</b>				
Saadoun	Mayada	The Heller School for Social Policy and Management	781 736-3821	mayada@brandeis.edu
<b>PI Last Name</b>	<b>First Name</b>	<b>Dept.</b>	<b>Phone</b>	<b>E-mail</b>
Lepson	Joshua	Undergraduate	(617) 797-0446	jlepson36@brandeis.edu
<b>Student Researcher Last Name</b>	<b>First Name</b>	<b>Status</b>	<b>Phone</b>	<b>E-mail</b>
Minimal	May 2018	Decemeber 2018	This study does not qualify as an NIH Clinical Trial	
<b>Estimated Level of Risk</b>	<b>Anticipated Start Date</b>	<b>Anticipated End Analysis Date</b>	<b>NIH Clinical Trials</b>	
Funded	Rich/Collins Community Leadership and Impact Fellowship, Department of Community			
<b>Funding Status</b>	<b>Sponsor</b>	<b>Sponsor ID</b>	<b>Account #</b>	<b>Grant PI</b>
Rich/Collins Community Leadership and Impact Fellowship Grant, Spring 2018				
<b>Grant Title</b>				

### 1. Purpose of the Research

- Class Assignment  
  Thesis/Dissertation  
  Presentation  
  Evaluation/Assessment  
  Publication  
  Other:

Describe the overarching goal of what you seek to discover from the research, as well as its expected benefits.

This project aims to educate the Greater Boston Community (Brandeis University and Waltham included) on the extreme barriers to healthcare access and treatment for individuals experiencing homelessness. We plan to detail the barriers to healthcare that individuals experiencing homelessness face, and reduce the stigmas these individuals face from physicians as well. Ultimately, we hope to educate the community such that “homelessness” does not become an individual’s main identity when receiving care. Ideally, this educationally based research will improve the relationship between individuals experiencing homelessness in the Greater Boston Community and healthcare providers at local hospitals.

### 2. Personnel

List the PI’s qualifications – including CITI training in human subjects research and academic, professional, and/or volunteer activities – with regard to the research. (Note: we do not need your entire CV.) For student-initiated research, describe the PI’s professional qualifications to oversee the student project. If applicable, describe any necessary support services and facilities that exist to support the research.

This is a student-initiated project supervised by Dr. Mayada Saadoun. Dr. Saadoun brings eight years of work experience in strengthening public health practices in the Middle East as a trained emergency physician, and as a Senior Research Associate and Lecturer at the Heller School for Social Policy and Management at Brandeis University. In Sudan, she worked with the World Health Organization to evaluate the preparedness and response to one of largest yellow fever outbreaks. At the Schneider institute at Brandeis, she analyzed the cost-effectiveness of fitness programs in residential services for adults with chronic moderate-to-severe acquired brain injury in Massachusetts. Currently, Dr. Saadoun is examining the impact of early use of treatment modalities of complementary and integrative medicine for low back pain management in the U.S. military. She is also examining predictors of post deployment opioid use and long-term opioid use among army active duty soldiers. Dr. Saadoun also has experience researching the health outcomes of individuals experiencing homelessness, and her expertise in this field as well as emergency medicine, makes her an excellent choice as a PI for this project investigating health attitudes for individuals experiencing homelessness in eastern Massachusetts health systems.

List the student researcher's qualifications – including relevant courses taken, CITI training in human subjects research, professional and/or volunteer activities, and additional experiences or skills – with regard to the research.

Not Applicable

Joshua Lepson is a third year undergraduate at Brandeis University studying Biology. He will be the primary student researcher responsible for this project. Joshua has served on the board of the Community Day Center of Waltham, a local homeless shelter in Waltham for over one-and-a-half years. He has experience working with vulnerable populations, particularly those experiencing homelessness for four years. Joshua serves as a co-coordinator for Brandeis University's Hunger and Homelessness service organization within Waltham Group and the Department of Community Service. Additionally, he has completed the Brandeis University CITI training in human subjects research. Specifically, he completed the Social & Behavioral Research Investigators module required for "IRB Reference Resource."

Sankirth Madabhushi is currently a junior (undergraduate) at Brandeis University studying Health: Science, Society, and Policy and Biology. He will also be a

student researcher for this project, and has worked as an Associate in Research in Clinical Research at Baystate Medical Center (UMass Medical School-Baystate Campus) during the summer of 2017 in Springfield, MA. As a result, he has completed the Collaborative Institutional Training Initiative (CITI) certification program for Baystate Medical Center, and will be completing the training for Brandeis University. Additionally, he has previously been involved in community service at the St. Francis Day Shelter in Boston, MA as a volunteer. As a member of the Leadership in Health and Medicine Leader-Scholar community, he conducted a research project investigating the prevalence and opinions regarding influenza vaccinations on college campuses while presenting the results at the experiential learning symposium at Brandeis.

List all other personnel who will be taking part in the research, their institutional affiliation, role in the research, CITI training in human subjects research, and relevant experience with regard to the research.

Not Applicable

Executive Director of the Community Day Center of Waltham (CDCW) Carolyn Montalto and CDCW head Case Manager Christina Lordi will assist in the recruitment of human subjects for this study. Executive Director Carolyn Montalto and head Case Manager Christina Lordi will not assist in this study beyond simple recruitment of subjects. They will provide locations within the CDCW day shelter to conduct **the online survey** and will help ensure complete anonymity of human subjects. **Here, anonymity refers to the ability for human subjects to take the online survey that this study will employ alone in a private room in order to protect their privacy.**

### 3. Collaborations

Describe any additional collaboration or subcontract with an outside institution or vendor.

Not Applicable

Human subjects will be recruited through the Community Day Center of Waltham (CDCW) day shelter in Waltham, MA. Findings of this study will be shared with the CDCW with the aims of improving relationships between healthcare providers and individual experiencing homelessness. There are no subcontracts involved with this study.

### 4. Conflicts of Interest

List any external or internal funding for the research and describe any possible real or apparent conflicts of interests any research personnel or collaborator may have with the sponsor or any other organization involved in the research. (If PHS funded and a significant financial interest exists confirm that all necessary SFI disclosure forms have been submitted.)

This research study is supported by the the Rich/Collins Community Leadership and Impact Fellowship (R/C CLIF) within the Department of Community Service of Brandeis University. The R/C CLIF is a “mini-grant program” that provides students with the opportunity to implement a community based impact project over one academic year. The R/C CLIF provides financial support to enable completion of the project. No conflicts of interest are stated at this time.

#### 5. Study Location

Outline where the proposed research will be conducted.

Home Institution (e.g. Brandeis campus)

Survey style collection of data will be conducted at the Community Day Center of Waltham (CDCW), which is located at 16 Felton St., Waltham, MA 02453. Specifically, human subjects participating in the survey will be provided a private room within the CDCW to complete the **online** survey anonymously. **Here, completing the survey anonymously indicates that data obtained from human subjects via the online survey will be separated from the subject's name. Any names collected will be coded using a random combination of characters (j3l14) and the list that links name with name code will be entirely separated from data as described in "12. Procedures" of this document.** Data analysis will occur through Brandeis University qualtrics and **data will be stored using Brandeis Box as described in "17. Data Storage" of this document.**

#### 6. Results of previous related research

Discuss past research undertaken by others and/or by yourself that places the proposed research in context and explain how it fits within the literature of your field. (Please keep this brief, 1-2 pages max.)

Although individuals experiencing homelessness are a diverse group, their unstable circumstances indicate that they would benefit from specific approaches in health care services. Overall goals are that we, as well as previous researchers, should enable homeless individuals to have higher quality care in health systems and improved access to the range of services that exist with less stigma, thereby decreasing their need for specialized services (Institute of Medicine (U.S.), 1988).

Prior research studies and literature review have explored the experiences of individuals experiencing homelessness in the health care delivery system.

Studies have shown that providers were sympathetic to the homeless and viewed them as entitled to social and health services and that stigma was not seen as a problem. However, from the perspective of individuals experiencing homelessness, they stated that sometimes they felt like part of an experiment while in the health care system “like they were animals or research subjects” (Martins, 2008). They often felt invisible, ignored, or not noticed while in the health care system, and worse, sometimes prematurely discharged (Martins, 2008). Furthermore, researchers across various large tertiary care health centers discovered through a cross-sectional study that in the emergency room, negative attitudes and beliefs about homeless people are more prevalent among teachers (attending providers) than learners (residents and students) (Fine, Zhang, & Hwang, 2013). Clearly this discrepancy in attitudes between providers and individuals experiencing homelessness is a concern that needs to be addressed in order to ensure that both parties are satisfied with care and receiving proper treatment to avoid more fatal and costlier complications in the future. Whatever the reason may be, it is crucial to educate the parties on issues individuals experiencing homelessness face, and work on training providers such that these barriers can be mitigated.

Previous research has investigated this discrepancy in different healthcare models that have a variety of strengths and weaknesses. The Institute of Medicine (US) states that stationary clinics are able to provide more sophisticated technology (e.g., x-rays and electrocardiograms [ECGs]). On the other hand, such clinics might be viewed as too threatening for clients, especially if these individuals have had negative experiences with emergency rooms or clinics in the past.

Researchers at the Institute of Medicine (US) found that the most effective health care and other services for homeless people are those that recognize the special needs and characteristics of the homeless. With this in mind, the committee recommends that the following general strategies be adopted. Services should be provided on a voluntary basis, respectful of individual privacy and dignity, with appropriately skilled and trained health care professionals to link clients to and provide continuity of services in community-based health care centers. Health care providers should be trained in the special problems of patient engagement and communication and follow-up of those conditions that are especially prevalent among individuals experiencing homelessness. Finally,

techniques should be developed to address the particular difficulties homeless people have in maintaining medication or dietary regimens; and ways should be developed for homeless patients to obtain needed medicines, medical supplies, or equipment. The goal of improving such relations between providers and individuals experiencing homelessness is to identify those in need of treatment and to encourage intervention at the earliest appropriate time in order to avoid unnecessary deterioration in their health status through primary care services (Institute of Medicine (U.S.), 1988). While this previous research is applicable on a large scale, we want to learn about the specific needs and barriers for individuals experiencing homelessness to receive quality-care in eastern Massachusetts health systems, where we will be working with the local populations to report and hopefully improve these attitudes.

#### 7. Existing Data

Yes  No Does the proposed research involve the use of existing data, documents, records, or pathological or diagnostic specimens?

#### 8. Subject Details:

- Adults ( $\geq 18$ )    Minors ( $< 18$ )    Cognitively Impaired    Minorities    Students  
 Economically Disadvantaged    Educationally Disadvantaged    Prisoners    Elderly/Aged  
 Other: homeless

Approximately how many subjects do you plan to enroll (including controls)? (Note that a modification request will need to be submitted before you may exceed this number.) 30

Describe your subjects – explain any inclusion and exclusion criteria you plan to employ.

Inclusion criteria for subjects to be recruited as research participants include the following:

- Individual has attended the Community Day Center of Waltham (CDCW) day shelter at least once during the past month.

- Individual has experienced homelessness at least once in the past year.

Homelessness is defined according to the U.S. Department of Housing and Urban Development NOTICE PIH 2013-15 (HA).

“Category 1: An individual or family who lacks a fixed, regular, and adequate nighttime residence, meaning: a. An individual or family with a primary nighttime residence that is a public or private place not designed for or ordinarily used as a regular sleeping accommodation for human beings, including a car, park, abandoned building, bus or train station, airport, or camping ground; or 3 b. An individual or family living in a supervised publicly or privately operated shelter designated to provide temporary living arrangements (including congregate

shelters, transitional housing, and hotels and motels paid for by charitable organizations or by federal, state, or local government programs for low-income individuals); or c. An individual who is exiting an institution where he or she resided for 90 days or less and who resided in an emergency shelter or place not meant for human habitation immediately before entering that institution; Category 4: Any individual or family who: i. Is fleeing, or is attempting to flee, domestic violence, dating violence, sexual assault, stalking, or other dangerous or life-threatening conditions that relate to violence against the individual or a family member, including a child, that has either taken place within the individual's or family's primary nighttime residence or has made the individual or family afraid to return to their primary nighttime residence; and ii. Has no other residence; and iii. Lacks the resources or support networks, e.g., family, friends, and faith-based or other social networks, to obtain other permanent housing." (Henriquez, 2013)

Exclusion criteria for subjects to be recruited as research participants include the following:

- Individual has never experienced homelessness.
- Individual has not experienced homelessness at least once in the past year.

Justify the use of any special/vulnerable populations for this research.

Not Applicable

This study entails the recruitment of individuals experiencing homelessness as research subjects. Individuals are considered a vulnerable population mainly due to their economically disadvantaged status. Because this study examines the barriers to healthcare individuals experiencing homelessness in the Waltham area face, the recruitment of individuals experiencing homelessness is crucial for the operation of this study. Results of this study will shed light into key areas local hospitals are neglecting in providing adequate healthcare to individuals experiencing homelessness. These key areas will be shared with local hospitals such as Newton-Wellesley Hospital with the goal of improving healthcare for this vulnerable population. Ultimately, any data collected from individuals experiencing homelessness will be used to improve their healthcare experience and to educate the Greater Boston Community on the extreme barriers to

healthcare access and treatment for individuals experiencing homelessness. All data collected will be anonymous to protect the privacy of individuals experiencing homelessness. Additionally, each research subject will be provided with an informed consent statement to ensure they understand the goals of this project.

#### 9. Identifiers to be Collected:

- |  |  |
|--|--|
| <input checked="" type="checkbox"/> Names  | <input checked="" type="checkbox"/> Gender   |
| <input type="checkbox"/> Addresses   | <input checked="" type="checkbox"/> Race   |
| <input type="checkbox"/> Phone/Fax #s  | <input type="checkbox"/> Ethnicity   |
| <input type="checkbox"/> Email Addresses   | <input type="checkbox"/> Religion  |
| <input type="checkbox"/> Social Media Usernames or Handles                       | <input checked="" type="checkbox"/> Age  |
| <input type="checkbox"/> URL/IP Addresses  | <input type="checkbox"/> Marital Status  |
| <input type="checkbox"/> Social Security #s                                      | <input type="checkbox"/> Household Composition                                       |
| <input type="checkbox"/> Dates of Birth  | <input type="checkbox"/> # of Children   |
| <input type="checkbox"/> Dates (of graduation, arrest, marriage)                 | <input type="checkbox"/> Place of Birth  |
| <input type="checkbox"/> Student #s  | <input type="checkbox"/> Education   |
| <input type="checkbox"/> License/Certificate #s                                  | <input type="checkbox"/> Major   |
| <input type="checkbox"/> Account #s  | <input type="checkbox"/> Income  |
| <input type="checkbox"/> Vehicle/Serial/Device #s                                | <input type="checkbox"/> Job Title   |
| <input type="checkbox"/> Facial Photographs or Images                            | <input type="checkbox"/> Place of Work   |
| <input type="checkbox"/> Biometric Identifiers, including Voice and Fingerprints | <input checked="" type="checkbox"/> Other: <u>Physical and mental health history</u> |

#### 10. Recruitment Methods

Describe the recruitment methods you plan to employ. (Attach recruitment materials and site-specific permissions to recruit, if applicable.)

One week prior to the date of data collection, guests of the Community Day Center of Waltham (CDCW) will be notified of the research study. Joshua Lepson and Sankirth Madabhushi will hand-deliver flyers (attached to this proposal) detailing the basic components of the study, particularly highlighting the \$10 gift card to Hannaford's. Additionally, Joshua Lepson, Sankirth Madabhushi, and Executive Director of the CDCW Carolyn Montalto will explain the general goals of the study, what the study entails, and mention that participation is entirely optional. After explaining this, one of the three aforementioned individuals will highlight that completion of the survey questions guarantees a \$10 gift card to Hannaford's supermarket.

#### 11. Study Design

Describe the scientific design of your research. Be sure to include a discussion of the appropriateness of your chosen research methods.

The cross-sectional study will be conducted using an online survey through Brandeis Qualtrics. Online surveys are an appropriate method of delivering the study because guests of the Community Day Center of Waltham (CDCW) are proficient in computer skills and have daily access to computers each time they

attend the CDW. Should a guest of the CDCW encounter difficulties with the computer format of the survey, Joshua Lepson or Sankirth Madabhushi will serve as proxies. Joshua Lepson and Sankirth Madabhushi are both proficient in computer skills. The survey has been translated into Spanish for any CDCW guests unable to read the survey due to language barrier issues. From experience working with CDCW guests, Executive Director of the CDCW Carolyn Montalto and Joshua Lepson can attest that the only language barrier that exists among this population is between Spanish and English. Furthermore, because Joshua Lepson is proficient in Spanish, he can answer any questions Spanish speaking guests may have while reading the informed consent form and taking the survey.

Inclusion and exclusion criteria mentioned in question 8 will be used to determine which participants will serve as research subjects. There will be no control group, as there no experimental manipulation of variables will ensue. We will take a cross-sectional approach because our data will be collected to assess the prevalence of health disparities experienced by homeless individuals and will not investigate the causes of a particular intervention.

## 12. Procedures

What data recording methods will you employ?

- Handwritten Notes  Computer  Video Recording  Audio Recording  Photograph  
 Other:

What Data Collection Tools/Study Instruments will you use? (Attach all study instruments.)

- Online Survey  Paper Survey  Interview Guide  Standardized Test  Behavioral Measure(s)  
 Other:

How will you interact with your subjects/conduct your research?

- In person (1 on 1)  In person (group)  Email  Telephone/Skype  Online  Standard Mail  
 Other:

Describe all procedures, steps, and actions you will be performing in chronological order – be as detailed as possible.

- Include a discussion of the specific data you will be collecting and what you plan to do with it.
- Describe in detail your plans for protecting the subjects' privacy and data confidentiality/anonymity, if applicable.
- *Note: If helpful, you may use bullet points and/or attach flow charts, graphs, timelines, etc.*

One week prior to the date of data collection, guests of the Community Day Center of Waltham (CDCW) will be notified of the research study. Joshua Lepson and Sankirth Madabhushi will hand-deliver flyers (attached to this proposal) detailing the basic components of the study, particularly highlighting

the \$10 gift card to Hannaford's. Additionally, Joshua Lepson, Sankirth Madabhushi, and Executive Director of the CDCW Carolyn Montalto will explain the general goals of the study, what the study entails, and mention that participation is entirely optional. After explaining this, one of the three aforementioned individuals will highlight that completion of the survey questions guarantees a \$10 gift card to Hannaford's supermarket. One of the three aforementioned individuals will state the research study consists of anonymously answering a series of 24 questions via a confidential online survey. Questions will probe physical and mental health history, with a particular focus on the quality of medical care received and continue to receive at local hospitals. The goal of the study is to improve the care physicians provide to individuals experiencing homelessness in the Waltham area, and to educate the Greater Boston area on inequities individuals experiencing homelessness face in receiving adequate healthcare.

One week after the above announcement, Joshua Lepson and Sankirth Madabhushi will return to the CDCW to set up the online survey. As mentioned in previous questions, a private room within the CDCW will be devoted for conducting the survey. An informal announcement will be made by Executive Director Carolyn Montalto that the research survey will commence. Potential research participants, guests of the CDCW, will enter the designated study room one at a time. Inside the room, potential research participants will initially be accompanied by Joshua Lepson and or Sankirth Madabhushi who will have already pulled up the online survey via an anonymous link and entered the confidential survey password. **The terms *anonymous link and confidential survey password* indicates that only Joshua Lepson, Sankirth Madabhushi, and Dr. Saadoun will have access to the link where the online survey is located and the password required to enter the survey once the link is obtained.** Joshua Lepson or Sankirth Madabhushi will encourage potential participants to ask questions regarding the study and will remain in the designated study room until the potential participant either consents or does not consent to the study according to the online informed consent page. If a participant does not consent, they will be brought to a page reading "Thank you! We recognize that this survey may be challenging to complete, and we wholeheartedly respect your decision to opt out. Please exit this room and instruct a staff member you have completed the survey." If a participant does

consent, Joshua Lepson and or Sankirth Madabhushi will leave the designated study room and encourage the research participant to come find either one of them should they have any questions. Subjects that click on “I consent, begin the study” will be taken to the demographics section of the online survey. Subjects will input their name, age, race, and gender. Names will be coded using a random combination of characters (j3l14) and the list that links name with name code will be entirely separated from data. Names will be collected solely to ensure that two sets of responses from the same individual are not recorded. If duplicates are observed, the first set of responses will be maintained and the second set will be discarded. Race, age, and gender data will be compared to identify any correlations between a perceived lower quality of medical care by the research subjects across any of the three demographics.

After demographic information has been entered, subjects will be brought to a page concerning homelessness information. One question will be concerning inclusion/exclusion criteria: “Have you experienced homelessness at least once during the past year?” If subjects enter “No,” they will be brought to the end of the survey. If a subject selects “Yes,” they will be asked for how long have they been experiencing homelessness. The next section of the survey consists of questions regarding physical illness. Subjects will be asked if they have ever or currently experience any of the following physical illnesses: history of head injury, high blood pressure, heart disease, diabetes, cancer, chronic pain, arthritis, asthma, lung problems, chronic liver disease, hepatitis A, B, or C, human immunodeficiency virus (HIV), and scabies/body lice. Subjects will also be provided with an “Other (please specify):” option that allows them to enter text, and a “I don't recall the name of the illness” option. Following this question, subjects will be asked the number of times they have attended an emergency room, have been hospitalized, or have seen an outpatient physician in the past year. After, a question regarding the quality of medical care received in each of the three previous circumstances will read, “When visiting an emergency room for a **physical illness**, I felt I was given the medical care I deserved and needed.” Responses will range from strongly agree to strongly disagree. Specific physical illness will be collected to establish the greatest areas of physical medical need among homeless guests of the Community Day Center of Waltham (CDCW). This information will be shared with local hospitals to identify key areas of focus for providing care to individuals experiencing homelessness

in the Waltham area. Questions containing “I felt I was given the medical care I deserved and needed” will be asked to assess the degree with which research subjects feel they have been appropriately cared for in local hospitals and with local physicians. This data will be analyzed to assess the quality of medical care provided to individuals experiencing homelessness in the Waltham area from the perspective of individuals experiencing homelessness. Analysis will be compared to demographic data to investigate potential correlations. After the physical illness survey section, the same process will be repeated for mental illness in the following section. Subjects will be asked if they have ever or currently experience any of the following mental illnesses: depression, anxiety, excessive alcohol consumption requiring medical intervention, Substance use (other than alcohol and tobacco), schizophrenia, bipolar disorder, post traumatic stress disorder (PTSD), and Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD). Following this question, the identical set of questions asked for physical illnesses will be asked for mental illnesses. Questions will commence with subjects being asked the number of times they have attended an emergency room, have been hospitalized, or have seen an outpatient physician in the past year. The identical question regarding the quality of medical care received in each of the three previous circumstances will read, “When visiting an emergency room for a **mental illness**, I felt I was given the medical care I deserved and needed.” Specific mental illness will be collected to establish the greatest areas of mental health medical need among the homeless population in Waltham. This information will be shared with local hospitals to identify key areas of focus for providing care to individuals experiencing homelessness in the Waltham area.

The last section of the online survey consists of a series of questions regarding trust of local hospitals consisting of Newton-Wellesley Hospital, Mt. Auburn Hospital, and St. Elizabeth’s Hospital. Subjects will be asked to rate whether they strongly agree, agree, somewhat agree, neither agree nor disagree, somewhat disagree, disagree, strongly disagree, or whether they have never been here before for the following statements regarding the aforementioned hospitals: (1) “Physicians from the following hospitals treat me with respect.” and (2) “I trust physicians from the following hospitals.” These questions will provide a quantitative assessment of the degree of trust among local hospitals, allowing for identification of which hospitals provide the best care to individuals

experiencing homelessness from their perspective. Once this information has been ascertained, we intend to identify key aspects of care inherent to the hospitals where individuals experiencing homelessness feel they are treated with respect and feel they can trust their doctors. Additionally, this data will be shared with each respective hospital in attempt to improve healthcare for individuals experiencing homelessness at the respective hospital. When data from this research project is prepared for publication, specific names of hospitals will be omitted, and rather, an average of data across all three hospitals will be presented.

After subjects have completed the above online survey, Joshua Lepson or Sankirth Madabhushi will ask the subject to input their name in a secure online Excel spreadsheet in Brandeis Box. Once they have recorded their name, Joshua Lepson or Sankirth Madabhushi will provide the research subject with a \$10 gift card to Hannaford's. Joshua Lepson, Sankirth Madabhushi, the PI Dr. Mayada Saadoun, and anyone else the IRB requires that access be given to will have access to this Brandeis Box spreadsheet.

**13. Deception/Incomplete Disclosure**

If using deception or incomplete disclosure, justify the need for its use in this research and describe how/when you will debrief your subjects. (Attach debriefing form, if applicable.)

Not Applicable

**14. Risk and Benefits**

What risks do you foresee for subjects in this research? Remember, all research involves some risk, even if only minimal.

Social     Psychological/Emotional     Physical     Legal     Economic     Loss of privacy/confidentiality  
 Other:

Describe in more detail the risks to subjects checked above.

We will be interviewing individuals experiencing homelessness about their experiences with homelessness, their experiences with receiving healthcare, and their substance use. Therefore, the main concern would be a potential loss of privacy. However, we are using a secure means of storing this information (Brandeis Box/Qualtrics).

Describe your provisions for managing the risks discussed above.

We are using a secure means of storing this information (Brandeis Box/Qualtrics). The survey is protected by an anonymous link and a confidential

password. Since Joshua Lepson and Sankirth Madabhushi will be pulling up the survey and entering the password in a private room in the Community Day Center of Waltham (CDCW), **they, along with Dr. Saadoun**, will be the only individuals with access to the anonymous link and a confidential password. **The terms *anonymous* link and *confidential* survey password indicates that only Joshua Lepson, Sankirth Madabhushi, and Dr. Saadoun will have access to the link where the online survey is located and the password required to enter the survey once the link is obtained. This helps ensure privacy of research information.**

Describe the anticipated benefits to subjects, society, and/or other specific groups from this research. (Note: Compensation is not a benefit.)

We will better understand the struggles of individuals experiencing homelessness as they seek healthcare. In particular, we will learn about the existing attitudes of individuals experiencing homelessness on receiving healthcare, how comfortable they are towards physicians, and if they are receiving quality care in their opinion. This will help use better understand the relationship between individuals experiencing homelessness and healthcare providers, and what aspects of this relationship need to be improved.

#### 15. Costs and Compensation

Describe any costs to subjects for their involvement in this research (time, transportation, economic – loss of work, need for child care – etc.).

The individuals experiencing homelessness will be answering a survey that **takes about 30 minutes.**

Describe any form of compensation subjects will receive (cash, gift card, course credit, medical care) as well as the terms and conditions of receiving the compensation (e.g., partial compensation for partial participation, etc.).

Not Applicable

The homelessness individuals who we will interview will receive a \$10 Hannaford's gift card as an incentive and reward. This gift card will give individuals the opportunity to purchase healthy food and need-based supplies for their well-being.

#### 16. Informed Consent

Select all that apply:

- The proposed research will follow standard procedures for obtaining *documented* informed consent.
- Approval for a waiver of *documented* informed consent is being requested.

*Note: One of the two following conditions must be met:*

- The consent document would provide the only link to the subject and the principal risk of the research would be a breach of confidentiality.

Saadoun  
Lepson

- The risk to the subjects is minimal and consent would not be required outside the research context.
- Approval for an alteration to or waiver of informed consent is being requested.
- The proposed research involves children.

Describe the circumstances surrounding your informed consent procedures – remember that obtaining informed consent is a continuous process.

- Describe the setting in which you will be obtaining informed consent, along with any special considerations you will make for vulnerable or non-English speaking subjects (e.g. witnesses or translators).
- If your subjects include children (<18), describe both the parental consent and child assent processes.
- Attach all consent documents and scripts.

Not Applicable: A waiver of informed consent is being requested.

As mentioned in previous questions, a private room within the CDCW will be devoted for conducting the online survey. An informal announcement will be made by Executive Director Carolyn Montalto that the research survey will commence. Potential research participants, guests of the Community Day Center of Waltham (CDCW), will enter the designated study room one at a time. Inside the room, potential research participants will initially be accompanied by Joshua Lepson and or Sankirth Madabhushi who will have already pulled up the online survey via an anonymous link and entered the confidential survey password. Joshua Lepson or Sankirth Madabhushi will explain that the first page of the online survey represents an informed consent form that explains the details of the survey and allows you to either voluntarily consent or not consent to the providing your information for this survey. Joshua Lepson or Sankirth Madabhushi will encourage potential participants to ask questions regarding the study and will remain in the designated study room until the potential participant either consents or does not consent to the study according to the online informed consent page. If a participant does not consent, they will be brought to a page reading “**Thank you!** We recognize that this survey may be challenging to complete, and we wholeheartedly respect your decision to opt out. Please exit this room and instruct a staff member you have completed the survey.” If a participant does consent, Joshua Lepson and or Sankirth Madabhushi will leave the designated study room and encourage the research participant to come find either one of them should they have any questions. The survey will be translated into Spanish for any CDCW guests unable to read the survey due to language barrier issues. From experience working with CDCW guests, Executive Director of the CDCW Carolyn Montalto and Joshua Lepson can attest that the only language barrier that exists among this population is between Spanish and English. Furthermore, because Joshua Lepson is proficient in Spanish, he can answer any questions Spanish speaking guests may have while reading the informed consent form and taking the survey.

- If requesting a waiver of standard *documented* informed consent procedures, detail the reasons why and the conditions that necessitate the request.
- If requesting an alteration to or waiver of informed consent, detail the reasons why and the conditions that necessitate the request.

Not Applicable: Standard procedures for obtaining documented informed consent will be followed.

**An approval for a waiver of documented informed consent is being requested because the risk to research subjects is minimal and consent would not be required outside of the research context. A non-traditional consent form excluding a section where research subjects explicitly sign the consent form is included as the first question in the online survey (see attached survey form). This non-traditional consent form contains all components of a traditional informed consent form except for a physical signature from research subjects. Thus, research subjects will still be extensively informed as the the content of the study, the potential risks involved, potential benefits, and will consent to survey participation by clicking either "I consent, begin the study" or "I do not consent, I do not wish to participate" in question 1 of the survey.**

**Furthermore, because the risks involved in this research study solely consist of accidental disclosure of survey information and since online surveys typically do not require consent forms outside of a research setting, we are requesting permission for a waiver of documented informed consent. Additionally, because names collected will be coded using a random combination of characters (j3l14) and the list that links names with the name code will be entirely separated from survey data, accidental disclosure of survey data cannot be tied to the name of the individual who gave the responses. This further substantiates that accidental disclosure of data poses a minimal risk.**

#### 17. Data Storage

Describe what you will do with the data you collect (including consent forms, surveys, notes, recordings, etc.). Discuss:

- Where and how they will be stored (note that it is Brandeis University policy that whenever possible, data should be kept on a secure server such as box.com).
- When and how they will be destroyed (note that it is Brandeis University policy that all research data be retained for a minimum of three years after the study has been closed by the IRB and the final report has been submitted to the funder, if applicable).
- Who will have access to them (note that all key personnel must always have access to all data).

The data will be recorded on Brandeis Qualtrics and the data/statistics and the excel sheet will be stored on Brandeis Box. They will be stored for 3 years (until June 2021) and will be deleted off of Brandeis Box afterwards. The individuals with access will be Joshua Lepson, Sankirth Madabhushi, and Mayada Saadoun.

#### 18. Additional Committee Approvals

- Yes  No This research involves human blood, fluids, tissues, or cell lines; infectious agents; select agents; or rDNA.

Saadoun  
Lepson

Yes  No This research involves animals.

#### 19. Bibliography/Citations

List the works you cited in this application (particularly in your discussion of previous related research).

Fine, A. G., Zhang, T., & Hwang, S. W. (2013). Attitudes towards homeless people among emergency department teachers and learners: a cross-sectional study of medical students and emergency physicians. *BMC Medical Education*, 13, 112. <https://doi.org/10.1186/1472-6920-13-112>

Henriquez, S.B. (2013). Guidance on housing individuals and families experiencing homelessness through the Public Housing and Housing Choice Voucher programs. *U.S. Department of Housing and Urban Development Office of Public and Indian Housing: NOTICE PIH 2013-15 (HA)*. <https://www.hud.gov/sites/documents/PIH2013-15.PDF>

Institute of Medicine (U.S.) (Ed.). (1988). *Homelessness, health, and human needs*. Washington, D.C: National Academy Press.

Martins, D. C. (2008). Experiences of Homeless People in the Health Care Delivery System: A Descriptive Phenomenological Study. *Public Health Nursing*, 25(5), 420–430. <https://doi.org/10.1111/j.1525-1446.2008.00726.x>

#### 20. Supporting Documents

Please attach to this application:

- Assurance:** PI or Faculty-Student
- Consent Documents:** Informed consent/assent forms, information sheets, consent/assent scripts, computer consent screen
- Recruitment Materials:** Fliers, texts of e-mails or letters, scripts for phone calls, etc., as well as site-specific permissions to recruit if working with an outside organization (i.e., letters of permission from each organization that details their understanding of your project, their support and involvement in your project, and the duration of their involvement in your project)
- Study Instruments:** Surveys, questionnaires, interview guides, tests, photographs, equipment diagrams or photographs, etc.
- Translation Certification(s),** if applicable
- Permission Letter(s):** Data Use Agreements (DUAs), Memorandums of Understanding (MOUs), etc.
- Grant Proposal,** if applicable
- International Research Addendum,** if applicable
- Other:**

#### 21. Additional Comments

**RICH/COLLINS COMMUNITY LEADERSHIP AND IMPACT FELLOWSHIP**  
**Mid-Year Grant Report:** Expected Completion of Project: Fall 2018  
*Joshua Lepson*

**Part 1: Narrative Report**

Homelessness is a pervasive issue that innervates every racial, gender, and social class in the United States. Within Massachusetts, 17,565 individuals were classified as experiencing homelessness as of January 2017<sup>1</sup>. Among these 17,565 individuals, many live in Cambridge and Boston, but others reside in Waltham, MA. Within Waltham, many individuals experiencing homelessness utilize the resources of the Community Day Center of Waltham (CDCW), a local Waltham shelter agency dedicated to assisting individuals experiencing homelessness. Conservative estimates taken by the CDCW tallied over 600 individuals utilizing the shelter's resources in 2015. Of these 500 individuals, roughly 87% suffer from at least one persistent health issue or medical condition according to an unofficial health survey conducted at the CDCW (internal, unpublished data). Further, this survey found that among CDCW guests, 48% were hospitalized and 68% used an Emergency Room in the past year. Using the conservative estimate of 600 guests per year, 522 guests suffer from at least one health issue, 240 were hospitalized in the past year, and 408 attended an Emergency Room in the past year. Clearly, the CDCW homeless guest population is plagued by many health issues that require urgent medical attention at local hospitals. Unfortunately, a quick conversation with CDCW guests reveals that when they attend local hospitals, they face gross mistreatment at the hands of emergency medical technicians, physicians, and nurses at some of the world's most prestigious hospitals. For example, one guest suffering from terminal bone cancer in his legs even mentioned being pushed out of a local Emergency Room and forced to walk miles back to Waltham where he had no home. This type of mistreatment is confirmed in literature, where individuals experiencing homelessness cite feeling ignored and treated like animals in the health care system<sup>2</sup>.

Considering this pattern of healthcare mistreatment among individuals experiencing homelessness, I deemed it essential to launch a research project detailing the stigmas individuals experiencing homelessness in Waltham face in local hospitals.

This project, officially titled “Healthcare Mistreatment Among Individuals Experiencing Homelessness” under the Brandeis University Institutional Review Board (IRB) proposal, aims to educate the Greater Boston Community on the extreme barriers to healthcare access and treatment individuals experiencing homelessness face. Partnering with the CDCW, my team and I will conduct an IRB sanctioned research project consisting of an online survey aimed at quantifying the quality of healthcare CDCW guests experiencing homelessness feel they are receiving. My team consists of Dr. Mayada Saadoun, Senior Research Associate and Lecturer within the Heller School for Social Policy and Management at Brandeis University, fellow undergraduate investigator Sankirth Madabhushi, Executive Director of the CDCW Carolyn Montalto, and myself.

Because we are conducting a scientific research study involving humans, we submitted an IRB proposal at the Brandeis University Human Research Protection Program. Initially, my plan was to obtain IRB approval by early April 2018 and commence the research study mid-April. However, I ran into several obstacles with the IRB proposal. My team and I submitted the first round of the IRB proposal March 12th, which clocked in at 60 pages. This document consisted of the official IRB documentation, as well as the entire research survey in both English and Spanish. Although this initial proposal required weeks of arduous work, the meticulous structure of an IRB proposal allowed for my project and team to become organized and clear with our research plans. With acknowledgement of this hard work, the Brandeis Human Research Protection Program replied on March 29th with several revisions to include in the IRB

proposal. My team and I assiduously addressed these changes and submitted a second revised proposal on April 9th. This revised proposal spanned 64 pages. The Brandeis Human Research Protection Program replied on April 19th with another round of revisions, which my team and I are still working on addressing.

Currently, my plan is to fastidiously review the current IRB proposal, addressing each revision suggested by the Brandeis Human Research Protection Program with care and detail. I have learned that every word counts with IRB proposals, and terms such as anonymous and confidential have different meanings in the IRB world than in traditional diction. Ideally, this IRB proposal will be accepted by the Brandeis University Human Research Protection Program in mid-June, allowing for my team and myself to commence the online survey towards the end of June (2018). After completing one to two weeks of data collection, I will analyze the data with Dr. Mayada Saadoun in July. Following analysis, I plan to assemble a presentation for local hospitals, the CDCW itself, the Waltham public, and for the Brandeis University community. Additionally, under the guidance of Dr. Mayada Saadoun, my team and I will begin writing results for journal publication following data analysis.

## References

<sup>1</sup> The U.S. Department of Housing and Urban Development: OFFICE OF COMMUNITY PLANNING AND DEVELOPMENT. (Dec. 2017). *State Estimates: Homelessness in the United States*. <https://www.hudexchange.info/resources/documents/2017-AHAR-Part-1.pdf>

<sup>2</sup> Martins, D. C. (2008). Experiences of Homeless People in the Health Care Delivery System: A Descriptive Phenomenological Study. *Public Health Nursing*, 25(5), 420–430. <https://doi.org/10.1111/j.1525-1446.2008.00726.x>

## **Part 2: The Evaluation**

As mentioned in the previous section, this research project is ongoing and thus, evaluations will be completed once IRB-approved data can be collected. Once IRB approval is achieved, I envision several evaluative components. Primarily, the online survey completed by CDCW guests experiencing homelessness will serve as a principal method of assessment. Data obtained from the survey will be quantitative in nature and will be subjected to statistical analyses. This research survey is attached below as a separate pdf document titled, “Survey (English) revised.pdf”. Questions such as “When I stayed overnight at a hospital as a patient (non-emergency room visit) for a **mental illness**, I felt I was given the medical care I deserved and needed.” will be examined to determine the percentage of CDCW guests experiencing homelessness who feel they are given deficient medical care. These results can be further compared to demographic data obtained from earlier questions in effort to establish racial and or gender associated differences in medical care among the Waltham homeless population. This type of data is crucial to understanding the landscape of healthcare from the perspective of individuals experiencing homelessness and for quantifying what has been merely anecdotal reporting of healthcare mistreatment. Following data collection and statistical analysis, results will be summarized as graphs and synthesized into a presentation. A major goal is for local hospitals such as Newton Wellesley Hospital (NWH) to convene a meeting in which the aforementioned presentation is discussed in the context of improving healthcare for individuals experiencing homelessness in the Waltham area. NWH is of particular interest because CDCW guests are required by law to attend the NWH emergency room since it is geographically closest to the shelter. The mere presence of this meeting will serve as a success since the process of mitigating healthcare mistreatment for the homeless population first relies upon local hospitals acknowledging the extent of this mistreatment. Even if local hospitals such as NWH are resistant

to convening a meeting centered around healthcare mistreatment among the Waltham homeless population, local physicians and hospitals can learn about the results of the research survey via publication. After collecting data, I, along with my team, aim to publish a research article in a reputable journal detailing results from the study. I believe the acceptance of a research article in an established journal would be a tremendous success. A publication would educate a broader audience of healthcare providers regarding the extent of healthcare mistreatment among individuals experiencing homelessness, with the ultimate goal of ameliorating this injustice.

**Part 3: Final Budget**

*PLEASE SEE ATTACHED EXCEL SHEET TITLED, "Budget (mid grant)."*

#### **Part 4: Personal Growth/Reflection and Final Thoughts**

I feel grateful and lucky to be participating in the Rich/Collins Community Leadership and Impact Fellowship. Because of this fellowship, I have grown as a person and advanced career goals. From a career standpoint, this fellowship has and continues to provide me with essential experience in the field of human research and public health. Coming into this fellowship in January, I was primarily a basic scientist trained in using animal models to uncover molecular mechanisms underlying fundamental biological processes. Through this fellowship, I have and am continuing to learn how to conduct research with human subjects. In the short period of four months, I have delved into the world of human public health research; I have written an entire IRB proposal; I have designed a research survey; I have communicated with major hospitals in the Waltham area; I have learned the difficulties individuals experiencing homelessness face in receiving adequate healthcare. All of these experiences will benefit my future ambitions in medicine, seeing as I plan to be a physician intimately involved in human research. Crucially, none of these learning experiences would be possible without the framework of the Rich/Collins fellowship. I would be unable to conduct a research project investigating healthcare mistreatment among individuals experiencing homelessness without monetary and staff support generously supplied by this fellowship.

Further, the Rich/Collins fellowship has enabled me to pursue a community based project which I am passionate about. In working with the Community Day Center of Waltham (CDCW) and serving on their Board of Directors prior to this fellowship, I received a slight glimpse into the degree of healthcare mistreatment individuals experiencing homelessness in Waltham regularly face. I was shocked and sickened by the notion that an individual could be treated as a second-class citizen by healthcare providers in the most prestigious hospitals simply because they are experiencing homelessness. I also felt powerless in the face of this mistreatment, fearing

that an undergraduate such as myself lacks the experience and resources required to change this deeply entrenched social inequity. The Rich/Collins fellowship drastically changed this misguided perception of helplessness I harbored. The Rich/Collins fellowship has provided me with the monetary and professional resources needed to pursue a research study investigating healthcare mistreatment among individuals experiencing homelessness. Although I have yet to complete the research study, I am confident I can create a lasting impact in the Waltham and Boston community. I believe once healthcare providers are provided with statistics and personal narratives regarding the extent of healthcare mistreatment among individuals experiencing homelessness, they will feel obligated to change their standards of care such that the homelessness population feels they are treated with the care and respect they deserve in hospitals.

Finally, the Rich/Collins fellowship has enabled me to grow personally. Through this fellowship, I have assembled a team to assist me in this project, communicated with key hospital personnel, and discovered my passion for public health research. I learned how to effectively lead a team, communicating with all parties and establishing organized deadlines for each team member. I learned how to use all the resources at my disposal, whether it be public health experts at the Heller School for Social Policy and Management or undergraduates passionate about public health. I feel eternally grateful for this fellowship, for without it, I would be incapable of conducting a research study I am passionate about and would have never received the invaluable experience of conducting a research study with human subjects.

Looking forwards, I hope the finalized IRB proposal will be accepted by the Brandeis University Human Research Protection Program in mid-June (2018), allowing me to commence the research study towards the end of June. I will then devote my resources towards data analysis

and communication with local hospitals both via a private presentation and through publication. I eagerly await the opportunity to collect data, as I feel the results will be instrumental in mediating healthcare changes among individuals experiencing homelessness.

# Homelessness & Healthcare

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## Q1 INFORMED CONSENT

### Quality of healthcare among individuals experiencing homelessness

You are invited to participate in a research study being conducted by Community Day Center of Waltham (CDCW) board member Joshua Lepson, a **Bachelor of Science** candidate in Biology at Brandeis University, and a fellow **Bachelor of Science** candidate in Health: Science, Society, and Policy and Biology, Sankirth Madabhushi. The study is being conducted under the supervision of Dr. Mayada Saadoun, Senior Research Associate and Lecturer within the Heller School for Social Policy and Management at Brandeis University.

Please read this page carefully and do not hesitate to ask **Joshua Lepson, Sankirth Madabhushi, or Carolyn Montalto (Executive Director of the Community Day Center of Waltham) any questions you may have.**

If you choose to participate in this study, **you will be asked to click “I consent, begin the study” at the bottom of this page.** Note that **your decision to consent or not consent to participate in this study is entirely confidential; your decision will only be shared with Joshua Lepson, Sankirth Madabhushi, and Dr. Mayada Saadoun.**

### What is the topic of this study?

We are conducting this research study because we are interested in understanding the quality of healthcare individuals experiencing homelessness receive. By gaining an understanding of the quality of healthcare individuals experiencing homelessness receive, we will be able to recommend significant changes in the ways in which healthcare is delivered to individuals experiencing homelessness in local hospitals.

### Why have you been asked to participate in this study?

You are being asked to participate in this study because you utilize the resources of the Community Day Center of Waltham, a non-profit organization that frequently assists individuals experiencing homelessness.

### If you consent, what will you have to do for this study?

If you consent to participating in this study, you will be given **an** online survey containing questions regarding your basic demographics, past medical history, **and** experiences with

doctors **during visits both inside and outside of hospitals**. The online survey consists of 25 questions and should take roughly 30 minutes to complete.

### **What are the potential risks involved with this study?**

Although your responses to every question will be entirely separated from your name (entirely confidential), some of the questions involve difficult topics. You are free to skip any question and **ask Joshua Lepson or Sankirth Madabhushi to move onto a different section**.

There will always be a risk regarding accidental **sharing** of information with individuals not connected with this study. However, we will take great measures to secure your information and ensure any accidental **sharing does not occur**.

### **Is there any benefit to participating in this study?**

There are no direct benefits to participating in this study, but we hope the study results will lead to improved healthcare at local hospitals for individuals experiencing homelessness.

### **Will you receive anything for participating in this study? Is there any cost?**

You will be given a \$10 gift card to Hannaford supermarket & pharmacy upon completion of the online survey. The only cost will be a small section of your time.

### **What measures will be taken to ensure protection of my responses?**

All information collected through the online survey will remain confidential to the extent permitted by law. Your name will be encrypted with a random sequence of letters and numbers (ex: t9z371). The document that connects your name with the encrypted code will be entirely separate from your responses to the survey questions. In other words, there will be no way to connect your name to your responses. All data, including your responses to survey questions and the document connecting your name to the encrypted code will be stored electronically through a secure, password protected and encrypted Brandeis University service. The researchers **Joshua Lepson, Sankirth Madabhushi, and Dr. Mayada Saadoun** will be the only ones with access to this protected information.

When the data from the online survey is reported in research publications and presentations, it will only be classified according to general trends (**ie: X% of people experiencing homelessness trust physicians**). Your personal information will be completely separated from data that is presented **to** the general public.

### **Can I stop the survey partway through if I change my mind?**

**Yes.** Since participation in this study is entirely **your choice**, you **have** the right to refuse participation in part or all of the study at any point. If you choose to participate now, **you are still free to change your mind** at any point after the survey is complete. Additionally, you may refuse to answer any question in the online survey - simply skip the question(s) and move on.

### **Who can I contact if I still have questions?**

Should you have any questions regarding this research study, please do not hesitate to contact Joshua Lepson at [jlepson36@brandeis.edu](mailto:jlepson36@brandeis.edu), **Sankirth Madabhushi at [sankirth@brandeis.edu](mailto:sankirth@brandeis.edu), or Dr. Mayada Saadoun at [mayada@brandeis.edu](mailto:mayada@brandeis.edu)** . If you have any questions concerning your personal rights as a research subject in this study and are interested in speaking with an individual not directly involved in **organizing** this study, please contact the Brandeis University Institutional Review Board (the University's Committee devoted to the Protection of Human Subjects in research) at 781-736-**8133** or [irb@brandeis.edu](mailto:irb@brandeis.edu) .

### **Subject's Consent**

By clicking "I consent, begin the study" below, I agree that I have carefully read the contents of this consent form, have been encouraged to ask questions throughout the process, and have obtained sufficient answers to my questions. I understand that participating in this survey is entirely voluntary, and that I may terminate my participation in the study at any time for any reason.

- I consent, begin the study (1)
  - I do not consent, I do not wish to participate (2)
-

Display This Question:

*If Q1 = I do not consent, I do not wish to participate*

Opt-out

**Thank you!**

We recognize that this survey may be challenging to complete, and we wholeheartedly respect your decision to opt out. Please exit this room and instruct a staff member you have completed the survey.

Q2 Please enter your name.

*Your name will NOT be tied to your responses in any way. This is solely so we can keep track of any duplicate responses. **Your responses are entirely confidential.***

---

Q3 Please enter your age.

---

Q4 Enter which gender you identify with.

- Male (1)
  - Female (2)
  - Gender fluid (3)
  - Other (4)
- 

Q5 Enter which race you identify with.

- African-American/Black (1)
  - White/Caucasian (2)
  - Latino/Hispanic (3)
  - Asian (4)
  - Native American (5)
  - Other (please specify in this case) (6)
-

---

Q6 Have you experienced homelessness at least once during the past year?

- Yes (1)
- No (2)

---

Q7 For how long have you been experiencing homelessness (your most recent experience if you been have homeless more than once)?

- Less than one month (1)
  - One to six months (2)
  - Six months to one year (3)
  - Longer than one year (4)
-

---

Q8 Have you attended an emergency room, been hospitalized, **or** seen a doctor **at least once** during the past **two years**?

Yes (1)

No (2)

---

Q9 Select any of the following choices that are true regarding your **current and past** physical illness history (note: this does not include mental illness/substance use disorders, which will be asked later).

- History of head injury (1)
- High blood pressure (2)
- Heart Disease (3)
- Diabetes (4)
- Cancer (5)
- Chronic pain (6)
- Arthritis (7)
- Asthma (8)
- Lung problems (9)
- Hepatitis A (10)
- Hepatitis B (11)
- Hepatitis C (12)
- Human Immunodeficiency Virus (HIV) (13)

Scabies/body lice (14)

Chronic Liver Disease (15)

Other (please specify): (16)

---

I don't recall the name of the illness (17)

---

Q10 In the past year, how many times have you attended an emergency room for any of the previously listed **physical illnesses**?

0 (1)

1 (2)

2 (3)

3 (4)

4 (5)

5+ (6)

---

Q11 When visiting an emergency room for a **physical illness**, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
  - Agree (2)
  - Somewhat agree (3)
  - Neither agree nor disagree (4)
  - Somewhat disagree (5)
  - Disagree (6)
  - Strongly disagree (7)
-

Q12 In the past year, how many times have you been hospitalized for a **physical illness**?

- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- 5+ (6)

*Skip To: Q14 If Q12 = 0*

---

Q13 When I was hospitalized for a **physical illness**, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
  - Agree (2)
  - Somewhat agree (3)
  - Neither agree nor disagree (4)
  - Somewhat disagree (5)
  - Disagree (6)
  - Strongly disagree (7)
-

Q14 In the past year, how many times have you seen an outpatient physician (a physician who saw you when you were not admitted to the hospital/Emergency room) for a **physical illness**?

- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- 5+ (6)

*Skip To: End of Block If Q14 = 0*

---

Q15 When visiting my outpatient physician for a **physical illness**, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
  - Agree (2)
  - Somewhat agree (3)
  - Neither agree nor disagree (4)
  - Somewhat disagree (5)
  - Disagree (6)
  - Strongly disagree (7)
-

---

*Display This Question:*

*If Q8 = Yes*

Q16 Select any of the following choices that are true regarding your **current and past** history of **mental illness**.

- Depression (1)
  - Anxiety (2)
  - Alcohol consumption (3)
  - Substance use (other than alcohol and tobacco) (4)
  - Schizophrenia (5)
  - Bipolar Disorder (6)
  - Post Traumatic Stress Disorder (PTSD) (7)
  - Attention Deficit Disorder (ADD)/Attention Deficit Hyperactivity Disorder (ADHD) (8)
  - Other (please specify) (9) \_\_\_\_\_
  - I don't recall the name of the mental illness (10)
-

*Display This Question:*

*If Q8 = Yes*

Q17 In the past year, how many times have you attended an emergency room for any of the previously listed **mental illnesses**?

- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- 5+ (6)

*Skip To: Q19 If Q17 = 0*

---

Q18 When visiting an emergency room for a mental illness, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
  - Agree (2)
  - Somewhat agree (3)
  - Neither agree nor disagree (4)
  - Somewhat disagree (5)
  - Disagree (6)
  - Strongly disagree (7)
-

*Display This Question:*

*If Q8 = Yes*

Q19 In the past year, how many times have you been stayed overnight at a hospital as a patient (non-emergency room visit) for a **mental** illness?

- 0 times (1)
- 1 time (2)
- 2 times (3)
- 3 times (4)
- 4 times (5)
- 5+ times (6)

*Skip To: Q21 If Q19 = 0 times*

---

*Display This Question:*

*If Q8 = Yes*

Q20 When I stayed overnight at a hospital as a patient (non-emergency room visit) for a **mental illness**, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
  - Agree (2)
  - Somewhat agree (3)
  - Neither agree nor disagree (4)
  - Somewhat disagree (5)
  - Disagree (6)
  - Strongly disagree (7)
-

*Display This Question:*

*If Q8 = Yes*

Q21 In the past year, how many times have you seen an outpatient physician (a physician who saw you when you were not admitted to the hospital/emergency room) for any of the previously listed **mental illnesses**?

- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- 5+ (6)

*Skip To: End of Block If Q21 = 0*

*Display This Question:*

*If Q8 = Yes*

Q22 When visiting my outpatient physician (a physician who saw you when you were not admitted to the hospital/emergency room) for a mental illness, I felt I was given the medical care I deserved and needed.

- Strongly agree (1)
- Agree (2)
- Somewhat agree (3)
- Neither agree nor disagree (4)
- Somewhat disagree (5)
- Disagree (6)
- Strongly disagree (7)

End of Block: Mental Illnesses

---

Start of Block: Hospital Trust

Q23 Physicians from the following hospitals treat me with respect.

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)	I have never been here (8)
Newton-Wellesley Hospital (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mt. Auburn Hospital (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
St. Elizabeth's Hospital (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

Q24 I trust physicians from the following hospitals.

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)	I have never been here (8)
Newton-Wellesley Hospital (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mt. Auburn Hospital (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
St. Elizabeth's Hospital (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

**Q25**

**Thank you!**

**We recognize that this survey may have been challenging to complete, and we thank you for your willingness to participate.**

**Should you have any questions regarding this research study, please do not hesitate to contact Joshua Lepson at [jlepson36@brandeis.edu](mailto:jlepson36@brandeis.edu), Sankirth Madabhushi at [sankirth@brandeis.edu](mailto:sankirth@brandeis.edu), or Dr. Mayada Saadoun at [mayada@brandeis.edu](mailto:mayada@brandeis.edu). If you have any questions concerning your personal rights as a research subject in this study and are interested in speaking with an individual not directly involved in conducting this study, please contact the Brandeis University Institutional Review Board (the University's Committee devoted to the Protection of Human Subjects in research) at 781-736-8133 or [irb@brandeis.edu](mailto:irb@brandeis.edu) .**

**Please exit this room and instruct Joshua Lepson and or Sankirth Madabhushi that you have completed the survey. Joshua Lepson and or Sankirth Madabhushi will provide you with your \$10 Hannaford's gift card.**

**Brandeis University**  
**Rich/Collins Community Leadership Impact Fellowship**  
**Department of Community Service**  
**UPDATED BUDGET**



Name of Program:	Exploring Healthcare Mistreatment among Individuals Experiencing Homelessness
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<b>Expenses</b>				
Item	Purpose	Total # Needed	Cost Per Item	Estimated Cost
Hannaford Supermarket Gift Cards	Incentivize Interviews	50	\$10	\$507.50
An additional \$200 was directed towards gift cards with an adjusted estimate of the number of participants in the research study. All gift cards will be given to research participants, and will be exclusively directed towards a healthier option of Hannaford supermarket.				
Total Spent so Far:				\$507.50
Initial Budget Awarded:				\$910
Current Remaining Budget:				\$402.50
<b>Totals</b>		<b>50</b>	<b>\$10.00</b>	<b>\$2,327.50</b>

**Department of Community Service**  
**ORIGINAL PROPOSED BUDGET**



Name of Program:	Exploring Healthcare Inequities for Individuals Experiencing Homelessness
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<b>Expenses</b>				
Item	Purpose	Total # Needed	Cost Per Item	Estimated Cost
Dunkin Donuts Gift Cards	Incentivize Interviews	30	\$10	\$300
McDonalds Gift Cards	Incentivize Interviews	30	\$10.00	\$300.00
Pizza	Presenting Findings	10	\$15.00	\$150.00
Lyft Rides	Transportation to Newton Wellesley Hospital	8	\$20.00	\$160.00

Initial Budget Awarded:

\$910