

## Appendix A



### **FREQUENTLY ASKED QUESTIONS**

<b>Why do we need a Bronx Community Research Review Board (BxCRRB)?</b>	<p>While academic research is an important tool to reduce health disparities, many researchers historically have engaged in a wide range of abuses. These include the Tuskegee syphilis experiments, sterilizing low-income women without their consent, and more recently researchers at Johns Hopkins University who placed low-income families in subsidized housing without telling them that their apartments had lead paint in its walls.</p> <p>The BxCRRB is made up entirely of Bronx residents who review proposals by academic researchers to make sure the interests of the community are being considered. The BxCRRB is different from an Institutional Review Board (IRB). IRBs also review research proposals to ensure ethical practices, but they are mostly accountable to universities and research institutions. In contrast the BxCRRB exists to hold researchers accountable to the Bronx community.</p>
<b>What is the Bronx Community Research Review Board?</b>	The BxCRRB (known as the “CRAB”) represents many of the diverse communities of the Bronx, engaging researchers in conversations with residents on research projects in the borough.
<b>What are the goals of the BxCRRB?</b>	<p>The goals of the BxCRRB are:</p> <ol style="list-style-type: none"><li>a. Educate Bronx residents about research being done in the community.</li><li>b. Increase the community’s understanding of and participation in research.</li><li>c. Empower the community to express their needs and concerns about health research done in the community.</li><li>d. Get the results of research that is done in the Bronx back to the community for its benefit.</li><li>e. Educate researchers about the community and the residents of the Bronx.</li></ol>

	<ul style="list-style-type: none"> <li>f. Increase researcher understanding of and respect for the community.</li> <li>g. Listen to and use input from the community to ensure that their needs and concerns about health research are reflected in research.</li> </ul>
<b>Is the BxCRRB an Institutional Review Board?</b>	No. The traditional IRB is located in an institution that works directly with the researcher. The BxCRRB is community-based, not institutional.
<b>Who can participate in the BxCRRB?</b>	<p>To participate in the BxCRRB, you must:</p> <ul style="list-style-type: none"> <li>a. Must be a Bronx resident.</li> <li>b. At least 18 years old.</li> <li>c. Speak and read English.</li> <li>d. Available to attend meetings and trainings.</li> </ul>
<b>Will BxCRRB members be paid?</b>	No. BxCRRB members are volunteers who receive a stipend and reimbursements for travel costs.
<b>Where are BxCRRB meetings held?</b>	<p>Meetings are held in the conference room on the ninth floor of the Bronx Supreme Court building at the following address:</p> <p style="text-align: center;"> The Bronx Health Link  Suite 916 (at 161<sup>st</sup> St.)  851 Grand Concourse  Bronx, New York  10451 </p>
<b>When are BxCRRB meetings held?</b>	Meetings are held on Tuesdays approximately every six weeks (tentative). Trainings for new members will be held in sessions approximately every two weeks.
<b>How does the BxCRRB work?</b>	There are up to twelve members of the BxCRRB. There are rotating co-facilitators for each meeting.
<b>Who sponsors and supports the BxCRRB?</b>	Two organizations sponsor and support the BxCRRB: The Bronx Health Link and Albert Einstein College of Medicine. The Bronx Health Link promotes greater health equity and social justice in the borough through research, advocacy, and programs. Albert Einstein College of Medicine is the medical school of Yeshiva University.
<b>How do I apply to be a member of the BxCRRB?</b>	If you are interested in becoming a member of the BxCRRB, you must submit a completed application form. For any further questions, contact Paco Martin del Campo. Mr. Martin del Campo's phone number is 718-590-2646, and his email address is <a href="mailto:fmartindelcampo@bronxhealthlink.org">fmartindelcampo@bronxhealthlink.org</a> .

## EMPOWERING COMMUNITY

### About Research...

Conducting research can be described as collecting information about an idea or topic. Research is like planning a trip to a new place. You will need a map to find routes to take you to your destination. Along the way, you will also discover new sights, much like researchers uncover new information that can benefit the community.



### Did You Know?

Although you may not realize it, everyday you hear and learn about research that is being done. This research may give you information about new medicines, changes in the environment and how people's practices affect their health!



## ADVANCING SCIENCE

### What This All Means...

The Bronx Health Link and Albert Einstein College of Medicine have partnered to educate the Bronx community about what research is and how it can benefit the community. This will be done through a project called The Bronx Community Research Review Board (BxCRRB).



### A BxCRRB Member Is One Who...

- Is a Bronx resident
- Is at least 18 years old
- Speaks and reads English
- Will be available to attend monthly meetings and trainings
- Will receive payment and a MetroCard for participation



## TRANSFORMING HUMANITY

### Building Trust, Building Community...

As a result of past abuses, rules have been developed to protect the rights of people and communities that participate in research. The BxCRRB is asking community residents to get involved in a process known as "community informed consent".

### The BxCRRB will ensure community informed consent by:

- Reviewing new research studies being done in the Bronx.
- Educating researchers about community concerns, needs and values.
- Educating the community to break down mistrust about research.
- Building links between researchers and the Bronx community.
- Encouraging researchers to become reliable and accountable to the Bronx community.

# **Appendix B**

## **BxCRRB Member Recruitment Interview**

**Hi Mr. /Mrs/Ms. \_\_\_\_\_**

**My name is \_\_\_\_\_, and I am a staff person with the Bronx Health Link.**

**This is \_\_\_\_\_ and \_\_\_\_\_ and they both work with the agency. We are interviewing you for membership on the Bronx CRAB and we appreciate your being here and taking time from your busy schedule to meet with us today.**

**We will be meeting for about a half hour and we have a series of questions to ask you –there is no right or wrong answer, this is more for all of us to get to know each other as we start the CRAB. If you are unclear about any question, please stop us and ask us to clarify the question.**

### **Facilitator Note to Prospective Candidate ( read aloud)**

**We will start with a few questions on your background – this is to help you feel comfortable since interviews are sometimes hard – talking about yourself to strangers is not always easy.**

**Once these are done, we will start on some specific questions that relate to membership on the BxCRRB.**

**How would you like for us to address you – by your first name or your full name?**

**Facilitator Instructions: If they want us to call them by their first name then we should ask them to call us by our respective first names, etc**

**Facilitator (read aloud) We will be begin with some background and personal questions to help you at ease since you may not have experience with interviews and this process may cause some nervousness.**

**To start – let me remind you what the BxCRRB is, the mission of the BxCRRB and what is expected of the members**

**The Bronx Community Research Review Board is a project that is being put together by The Bronx Health Link and Albert Einstein College of Medicine.**

**Its main purpose is to bring a community voice to health research projects being done in the Bronx and educate Bronx residents about health research, why it is important and how the community can become involved and benefit. If you become a part of this project, you will be required to commit yourself for one year to this project and attend all trainings and meetings.**

1. Tell us more about yourself (how long you have lived in the Bronx - where you have worked, where you went to school, what you do in your spare time, what you read and what television programs you watch, and your favorite newspaper and the last book your read... )

Response:

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2. Tell me about the one thing in your life you're proudest of.

Response:

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3. Tell me about how you have been involved in your community ( the definition of community is wide- can include work (unions, party committees), community service, volunteering, sports, community boards, PTA, classroom mommy/grandmother, churches)

**Note to facilitator – they can go back into the past as far they want – e.g. high school**

**Probe: Tell me a little about what you did ?**

**How long were you involved?**

**Would you do it again?**

**Why did you leave or stop participating in this group**

Response:

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4. What does teamwork mean to you?

Probe: Tell me about a time when you worked in a team with a group of people.

**Tell me a little about what you did ?**

**How long were you involved?**

**Would you do it again?**

**Why did you leave or stop participating in this group**

Was there any conflict and how did you resolve it?

Response:

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**Bronx CRBB questions**

1. Why are you interested in being a part of the BxCRRB project?

Response:

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2. Tell me what you feel you can bring to this board?

Response:

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3. Why should people care about and get involved in research?

Response:

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4. One of our goals is to have BXCRRB members going into the community to educate fellow borough residents about its work - how and who do you think you will be able to reach in the community ?

Response:

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Thank you so much for your responses.

**We will be in touch with you in approximately next two weeks with the first training scheduled for May 8, 2012. If chosen, will they be available.**

Do you have any questions for us?

Here is some material for you to read and if you have any questions, please do not hesitate to call us for an answer.



**Member Selection Process**  
The Bronx Health Link, Inc.  
May 1, 2012

**Interviewer #1**

Name of Candidate: \_\_\_\_\_

**Membership Criteria**

1. Is candidate Bronx resident or employee?     Yes     No
  
2. Does this person have community networks?     Yes     No  
    a. If yes, please explain \_\_\_\_\_
  
3. Was this person able to answer questions completely?     Yes     No  
    a. Please explain \_\_\_\_\_
  
4. Was this person easy to talk to - consider, whether they were engaged in the discussion, did they ask question, did they seem interested in the project for their individual growth as well for its potential for the community?     Yes     No  
    a. Please explain \_\_\_\_\_
  
5. Where there any time commitment issues for this person?     Yes     No  
    a. If yes, please explain \_\_\_\_\_

Other Comments:

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**Final Rating**

Not Selected     Alternate     Selected

## Appendix C

### Training Program - Evaluation Form

Workshop Title: Institutional Review Boards Date: June 5, 2012

For each of the following areas, please indicate your reaction:

Content	Excellent	Good	Needs Improvement	Not Applicable
Covered Useful Material				
Practical to My Need and Interest				
Well Organized				
Presented at the Right Level				
Effective Activities				
Useful Visual Aids and Handouts				
<b>Presentation</b>				
Instructor's Knowledge				
Instructor's Presentation Style				
Instructor Covered Material Clearly				
Instructor Responded Well to Questions				

How could this workshop be improved?

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Do you have any other comments or suggestions?

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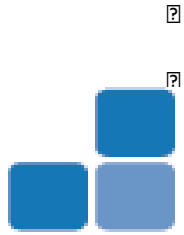
Overall, how would you evaluate this workshop training session?

Excellent

Good

Fair

Poor



# THE BRONX HEALTH LINK

851 Grand Concourse Room 914  
Bronx, NY 10451  
Tel. (718) 590-8506

I, \_\_\_\_\_ (print name), received from The Bronx Health Link Inc, \_\_\_\_\_ in cash and a \$4.50 metro card for my participation in the Bronx Community Research Review Board.

Date: September 18, 2012

Signature \_\_\_\_\_

# Appendix D

## Review Proposal Application for Researchers

### I. Principal Investigator Contact Information

Name: \_\_\_\_\_

Office Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_ Cell: \_\_\_\_\_

\_\_\_\_\_

E-mail Address: \_\_\_\_\_

In addition, please attach:

- Resumes of key research staff
- Copies of or list of relevant previous publications by researchers
- Letter of support

II. Funding Information: Please list all funding sources. Attach additional pages as needed.

- This study is not funded
- Funding Source:

\_\_\_\_\_ Funding  
Source: \_\_\_\_\_

Will any of this funding be allocated to involvement of the community in the project?

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### **III. Protocol Information**

**Please use the following literacy guidelines when responding.**

- **The answers should be written at an eighth grade reading level.**  
**Suggestions for meeting an eighth grade reading level include:**
  - **Use one or two syllable words whenever possible**
  - **Write short sentences and paragraphs.**
  - **Define all medical or technical terms in lay language.**
  - **Avoid contractions such as don't**

**Title of the Study:**

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**Duration of Study:**

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**Please attach a copy of the informed consent for, if applicable.**

### **IV. Study Aims**

- 1. What questions do you want your research to answer?**

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**2. Why are you interested in answering these questions?**

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**3. How will the research address the questions posed?**

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**V. Participant Information**

**1. How will participants be recruited?**

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**2. What is the age group of participants?**

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**3. Will any vulnerable communities be involved in the study? If yes, please describe.**

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**4. What are the risks to individual participants of this study?**



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**5. What are the benefits to individual participants of this study?**

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**VI. Community Partners**

**Please list the community partners you have identified to assist with your research efforts? Attach additional partners on a separate sheet.**

**A. Name and brief description of agency:**

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**B. Name of Contact Person:**

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**C. Address:**

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**1. Will the community partners recruit participants for you? Please describe.**

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**2. Will community partners have any additional roles in the research effort? If yes, please describe.**

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**3. Will the community partners be paid for their assistance? How?**

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**4. If there are no community partners, explain why.**

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**VII. Community Involvement during Study**

**1. What will you do to make your study materials and questions clear and understandable to the affected community?**

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**2. What risks to the community are involved in the study?**

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**3. What benefit will the community gain from this study?**

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**VIII. Community Involvement after Study**

**1. What is your plan to inform the community of research results?**

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**2. How will you publish the results and what plans do you have to credit or include community partners in this process?**

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**3. Do you intend to collaborate with CBOs and/or community members in the future and, if so, how?**

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**4. How will you apply any lessons learned through the current study to strengthen community involvement in future studies?**

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**BxCRRB CHECK LIST**

Based on the researcher's responses to the *Review Proposal Application*, please answer yes or no to the following statements

<p><b><u>I. Principal Investigator Contact Information:</u></b></p> <p>1. The information on the Principal Investigator (PI) is complete</p> <p>2. All additional attachments are included.</p> <p>Comments:</p> <hr/> <hr/> <hr/> <hr/>	<p>1. <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p>2. <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p><input type="checkbox"/> Resume</p> <p><input type="checkbox"/> Prior Publication List</p> <p><input type="checkbox"/> Letters of support</p> <p>?</p>
<p><b><u>II. Funding Information</u></b></p> <p>1. The information on the funding sources is provided</p> <p>2. Indicates if any of the funding will be allocated to community based organizations.</p> <p>3. Describes how the funding will be allocated to community based organizations.</p> <p>4. Explains why funding will not be allocated to community based organization.</p> <p>5. Indicates if any of the funding be used to hire community residents.</p> <p>6. Describes the positions community members will fill.</p> <p>Comments:</p> <hr/> <hr/> <hr/>	<p>1. <input type="checkbox"/> Yes    <input type="checkbox"/> No    <input type="checkbox"/> N/A</p> <p>2. <input type="checkbox"/> Yes    <input type="checkbox"/> No    ?</p> <p>3. <input type="checkbox"/> Yes    <input type="checkbox"/> No    <input type="checkbox"/> N/A</p> <p>4. <input type="checkbox"/> Yes    <input type="checkbox"/> No    <input type="checkbox"/> N/A</p> <p>5. <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p>6. <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p>?</p>

**III. Protocol Information**

- 1. Title of the study is provided.
- 2. The duration of the study provided.
- 3. Informed consent for is included.

Comments:

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**IV. Study Aims**

- 1. Clearly describes what questions the research will answer.
- 2. Clearly describes the researcher's interest in these questions.
- 3. Clearly describes how the questions will be addressed.

Comments:

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**V. Participant Information**

- 1. Clearly describes how participants will be recruited.
- 2. Indicates the age group of the participants

- 1.  Yes  No
- 2.  Yes  No
- 3.  Yes  No  N/A

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- 1.  Yes  No
- 2.  Yes  No
- 3.  Yes  No

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- 1.  Yes  No
- 2.  Yes  No?
- 3.  Yes  No?
- 4.  Yes  No?
- 5.  Yes  No?

**Comments:**

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**VI. Community Partners**

1. Provides all information for community partners.
  - Name
  - Description
  - Contact person
  - Address
2. Indicates if community partners will assist in recruitment.
3. Indicates if community partners will serve any additional roles in the research effort.
4. Describes the additional roles community partners will play.
5. Indicates if community partners will be paid for their assistance.
6. Explains why there are no community partners.

**Comments:**

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1.  Yes  No

2.  Yes  No

3.  Yes  No

4.  Yes  No  N/A

5.  Yes  No

6.  Yes  No  N/A

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**VII. Community Involvement during Study**

- 1. Clearly states what researcher will do to make the study materials and questions clear and understandable to the affected community
- 2. Describes the risk to the community.
- 3. Describes the benefit to the community.

Comments:

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**VIII. Community involvement after Study**

- 1. Indicates plan to inform community of research results.
- 2. Indicates how the results will be published.
- 3. Indicates how community partners will be credited and/or involved in publication.
- 4. Indicates whether the researcher intends to collaborate with CBOs and/or community members in the future and how.
- 5. Indicates how researcher will apply lessons learned through the current study to strengthen community involvement in the future.

Comments:

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1.  Yes  No

2.  Yes  No

3.  Yes  No

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1.  Yes  No

2.  Yes  No

3.  Yes  No

4.  Yes  No

5.  Yes  No

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## **Appendix E**

### **History**

The Bronx Community Research Review Board (BxCRRB) began in 2011 as a community-academic partnership between The Bronx Health Link (TBHL) and Albert Einstein College of Medicine. The goal of the BxCRRB is to initiate a process of community consultation to ensure that researchers respect the rights of participants, address community needs, and will use the data to improve health outcomes. With funding from the National Institutes of Health, TBHL recruited members from the Bronx and trained them in bioethics and clinical research methods in order to review research proposals from researchers from Einstein. Having met with researchers for two years, in 2013 the Board will begin a new chapter of community outreach and education to inform borough residents about clinical research and how it relates to health outcomes.

### **Mission**

The Bronx Community Research Review Board (BxCRRB) advocates for Bronx residents by engaging researchers and communities, assuring culturally-appropriate research practices that are fair and ethical, and addressing health equity, well-being, and social and environmental justice. The BxCRRB educates its community about research opportunities and the benefits of participation, empowers its community to express their needs and concerns related to research, in order to increase the potential benefits of study to the community. The BxCRRB is committed to assuring research study results are appropriately disseminated to the community in order to increase trust between community and research partners and policymakers.

### **Vision**

The BxCRRB vision is to bridge the gap between researchers and Bronx residents in order to build trust and improve the quality of life for all residents. We aim to do this by becoming the premier community advocate addressing:

- Health disparities and inequities
- Socio-economic and environmental justice problems

### **Values**

#### ***RESPECT***

For each other and members of the community



And honesty amongst ourselves and those we serve  
For the opinions of the group and community

***COMMITMENT***

To our community  
To better health care, cures for health disparities  
To accountability  
To service and volunteering

***ACCOUNTIBILITY***

To community and goals of work  
Of researchers to conduct ethical study with transparency

***SERVICE***

To the Bronx and larger community (other impacted neighborhoods)  
Quality health services for our communities

***TRANSPARENCY***

In communication  
In behavior and activities as an IRB

***EMPOWERMENT***

Through education and exchange of resources  
Through co-powering, collective work

***HUMILITY/COMPASSION***

Through learning from and with the community

***SECURITY and PROTECTION***

In safe guarding personal information generated through BxCRRB activities

***CULTURAL HONORABILITY***

Honoring, respecting and celebrating diverse cultural perspectives of our group and community

***DIVERSITY***

Respecting different identities within group and community



Institutional Review Board  
APPROVED  
10/26/2012 through 10/25/2013  
Protocol #: 2008-330

**Consent for Participation in Research Study**  
**Men and Women age 18 and older**  
**Consent for In-person Interviews**

This is an agreement to participate in a research study entitled "Bronx Community Research Review Board." You are agreeing to take part in this study of your own free will. This study is being carried out by:

A.H. (Hal) Strelnick, M.D.  
Dept. of Family and Social Medicine  
Albert Einstein College of Medicine  
1300 Morris Park Avenue  
Bronx, NY 10461

**Confidentiality: (Who May See Your Records)**

Records of this study will be kept private. No one will know you are in the study. No reports, either in writing or given out loud will give your name.

The research records will be kept in a locked cabinet in a protected area in the research offices of the Principal Investigator. The Principal Investigator is the person who is in charge of a research grant, training or other project. For this study, the Principal Investigator, also called the PI, is Dr.Hal Strelnick.

The sponsor which can be a person, government agency or other group pays for the research. In this case, The National Center for Minority Health and Health Disparities of the National Institutes of Health is the government sponsor of the study. They may also look over the records to make sure that the study is being implemented correctly.

In the past, there were no protections for people in research studies. Now all research studies must follow legal rules including this paper which is called Informed Consent. The goal of Informed Consent is to ensure that participants in a research study are aware of who are the key staff, how to contact them, what will be required of the participants and other protections.

Both the Albert Einstein College of Medicine (AECOM) and Montefiore have a team of people, doctors, nurses, community people and others who review research studies to make sure that the rights of human beings are protected. These teams are called the human research committee, and they can be also review the information from this study.

**The Albert Einstein College of Medicine Committee on Clinical Investigations (CCI) at 718-430-2253, and/or  
The manager of the Montefiore Medical Center Institutional Review Board (IRB) at  
718-798-0406.**

**Whom to Contact for Questions:**

If you have any questions about this research project, you can call Dr. Strelnick at 718-920-4678. You may also call the administrator of the Albert Einstein College of Medicine Committee on Clinical Investigations (CCI) at 718-430-2253, Monday through Friday between 9AM and 5PM.

Before you agree to take part in this interview, I will describe the reason for the study, what you will do, the possible risk, if any, benefits for you and/or the community from the study and other choices you may have to being part of the study.

There are a few reasons for this study:

1. To improve how researchers understand the needs of the community and involve the community in research projects
2. To involve community members to assist researchers on how to include cultural and social sensitivity into their research
3. To improve the overall quality of clinical research that is conducted by researchers in the Bronx by training the community in the research design, proposal review processes and ethics
4. To review proposed research projects
5. To work together with and provide feedback to researchers before they begin their research projects.

There are a few things we will ask of you

- 1) We will ask you to answer questions in an interview
- 2) The interview will last about an hour
- 3) We can interview you in person, on the phone (at a time when it is easy for you to take an hour), or in the offices of Albert Einstein
- 4) We will tape the discussion but your name will never be used in the interview
- 5) We will listen to the tape to help us with our notes and not use it for any other purpose
- 6) Once we are finished with the tape, it will be destroyed
- 7) You will receive a \$20 gift certificate for each interview
- 8) You will receive a stipend and a metro card for each training session and for each Board meeting that you attend

There will be no additional payment for the audio-taping.

Risks – a risk is a possible danger of something happening to you during this study

The risk(s) of being in this study is that some of the subjects we talk about could make you feel uncomfortable. During the study, if a question or topic makes you feel uncomfortable, you have the option to not answer the question tell the interviewer, I do not want to answer that question, and the interviewer will stop. You may also hear someone express an opinion that may make you feel uncomfortable.

1. Benefits: a benefit is something good that can happen to you during this study

There are a few benefits to you that can result from this study

- 1) You will have opportunity to learn about research design, research proposal review and ethics
- 2) You will be able to help researchers learn how to improve how they do research in the Bronx
- 3) Others may benefit from what we learn in this study about how to improve the cultural and social sensitivity of research conducted in the Bronx.

5. Choices to participating:

Participation is voluntary – you can choose not to take part in the interviews. Your health care at AECOM or Montefiore will not be affected in any way if you choose not to be part of the study.

There are two parts to the study, if you volunteer to join the Board, then you will receive the training in research design, research proposal review and ethics.

Because this is voluntary, you will only receive a stipend for the training and for being on the Board. You can choose to stop the interview at any point you want. There will be no harm if you choose not to participate. You will not be treated differently where you receive health care.

\_\_\_\_\_  
Participant (print)

\_\_\_\_\_  
Participant signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Assistant Reading and Obtaining Consent

\_\_\_\_\_  
Date

Informed Consent

I have completed the Informed Consent process; I have read the informed consent form and if necessary, have asked questions relating to my participation in this research study. I understand that this process is a way to make sure that I understand what it means to participate in research; what my rights are, what the study is about and who I can call in case I have more questions or a complaint about the study and how I am being treated as a participant.

In order to ensure that you have a full understanding and that I, as the \_\_\_\_\_, have explained everything accurately, I want to review some of the things that we discussed today as a result of the Informed Consent Process

Is this study confidential? True False

My name will appear in reports about the study True False

I can call Dr. Strelnick at Einstein with questions True False

Name two things you will do to participate in this study

i. \_\_\_\_\_

ii. \_\_\_\_\_

Do you have the right to end an interview during this study if you feel uncomfortable?

Yes No

Name one benefit that may come as a result of your participation in this study

i. \_\_\_\_\_

Institutional Review Board  
APPROVED  
10/26/2012 through 10/25/2013  
Protocol #: 2008-330

Institutional Review Board  
APPROVED  
10/26/2012 through 10/25/2013  
Protocol #: 2008-330

ALBERT EINSTEIN COLLEGE OF MEDICINE OF YESHIVA UNIVERSITY  
MONTEFIORE MEDICAL CENTER

Consent for Participation in Research Study

Men and Women age 20 and older who present their research to the Bronx Community Research Review Board

Consent for In-person Interviews

This is a voluntarily agreement to take part in a research study entitled "Bronx Community Research Review Board." This study is being carried out by:

A.H. (Hal) Strelnick, M.D.  
Dept. of Family and Social Medicine  
Albert Einstein College of Medicine  
1300 Morris Park Avenue  
Bronx, NY 10461

**WHO MAY SEE MY RECORDS?**

- The research records will be kept private and your name will not be used in any written or verbal reports.
- Your research records may be inspected by members of the research team, the sponsor(s), and other institutions that participate in this study. These are: the sponsor of this research, the National Institutes of Health, the National Center for Minority Health and Health Disparities.
- The research records will be kept in a secured manner and computer records will be password protected.
- The people who reviewed this research study as members of the Albert Einstein College of Medicine Committee on Clinical Investigations (CCI) and the Montefiore Medical Center Institutional Review Board (IRB) may also review your research and medical records.
- The Office of Human Research Protections (OHRP) may also review your research study records.
- All of these groups have been requested to keep your name private.

**Whom to Contact for Questions:**

If any questions arise related to this research project, you can call Dr. Strelnick at 718-920-4678. You may also call the administrator of the Albert Einstein College of Medicine Committee on Clinical Investigations (CCI) at 718-430-2253, Monday through Friday between 9AM and 5PM.

Before you agree to take part in the study, I will describe the purpose, what you will do, risks, benefits and alternatives to being in the study.

**1. The Purpose:**

The purpose of this study is to learn how community members can impact the cultural and social sensitivity and overall quality of clinical research that is conducted by researchers in the Bronx by training in the research design and ethics, reviewing proposed research projects, and interacting with and

providing feedback to those researchers before they begin their research projects.

**2. What you will do: Procedure**

You will answer questions and tell your experiences presenting and receiving feedback from the members of the Bronx Community Research Review Board in an interview that will each last up to 1 hour. The discussion can be over the phone or in our offices. The interview will be completely private. The discussion will be audio-taped. We will not use your name during the interview. The audio-tape will be used only by the research team to answer our research questions. The tape will not be used for commercial or teaching purposes and will be destroyed at the end of the project.

**3. Risks:**

The risk to you are only that some of the subjects we talk about could make you feel uncomfortable. You can choose not to talk about any topic if you feel uncomfortable.

**4. Benefits:**

You will have the opportunity to learn about how Bronx community residents perceive the research design and ethics of your research project. Other researchers may benefit from what we learn in this study about how to improve the cultural and social sensitivity and overall quality of research conducted in the Bronx.

**5. Alternative to participating:**

You may choose not to take part in the study. Your evaluation will not be affected in any way if you choose not to be part of the study.

**CAN I BE ASKED TO STOP PARTICIPATING IN THIS STUDY BEFORE THE STUDY IS FINISHED?**

Yes, you can be asked to stop if you do not attend more than half of the Board training or more than half of its review meetings.

**MAY I STOP THE STUDY AT ANY TIME?**

- Your participation in this study is voluntary and you may withdraw from the study at any time without giving a reason.
- If you agree to participate and withdraw at a later time, some of your information may have already been entered into the study and that will not be removed.
- Your treatment by doctors and staff at the institution(s) involved in this study, now and in the future, will not be affected in any way if you agree to participate and withdraw later.
- Your decision not to be in this research study will not result in any loss of benefits to which you are otherwise entitled.

**WHAT ARE MY RIGHTS IF I TAKE PART IN THIS RESEARCH STUDY?**

- Your participation in this study is voluntary.
- You do not waive any of your legal rights by participating in this research study.
- Your treatment by doctors and staff at the institution(s) involved in this study, now and in the future, will not be affected in any way if you refuse to participate or if you enter the study and withdraw later.