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Visual Voices: An Arts-Based Assessment of the Perceived Identity of Aging Maine Residents

Student-led Mini-Grants

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# Visual Voices Approved Consent Form

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<b>Creator</b> Collyn Baeder, Zoe Hull, Rebecca Masterjohn, Virginia Sedarski, Adrian Jung, Michaela A. Hoffman, and Nicole O'Brien

# UNIVERSTIY OF NEW ENGLAND (UNE) CONSENT FOR PARTICIPATION IN RESEARCH

# **Project Title:**

Visual Voices: An Arts-Based Assessment of the Perceived Identity of Aging Maine Residents

#### Research Team:

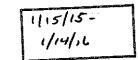
The principal investigators for this project are listed below. If you ever have any questions about this project please do not hesitate to call or email them. The appropriate contact information is provided on the last page of this form.

- Collyn Baeder, Master of Public Health Student
- Zoe Hull, Master of Public Health Student

The UNE faculty advisors are listed below:

- Rebecca Boulos, MPH, PhD; Public Health Faculty
- Regi Robnett, PhD, PTR/L; Occupational Therapy Faculty

Approved for Use Between



University of New England Institutional Review Board

Nicole O'Brien, UNE Master of Social Work Student, and Rebecca Masterjohn, Virginia Sedarski, and Adrian Jung, UNE Occupational Therapy students, are also investigators for this project. Donna Wolf, Park Danforth resident is the community liaison for this project, providing advice and guidance to the students.

#### Introduction:

The purpose of this form is to provide you with information about this research project. If you choose to participate, this form will document your decision. Please read through this entire form. You may also request that the form be read aloud to you.

You are encouraged to ask any questions that you may have about this project now, during, or after the project is complete. You can take as much time as you need to decide whether or not you want to participate. Your participation is voluntary, which means that choosing to participate is entirely your decision. You will not be forced to take part in any aspect of the project.

## What is this project about and why is it being done?

You are being invited to participate in a research project called "Visual Voices: An Arts-Based Assessment of the Perceived Identity of Aging Maine Residents." The purpose of this project is to learn from Park Danforth residents about their perceptions and experiences, specifically how they see

themselves and how they feel seen by other people, such as family, friends, and health care providers. This project will use art and group discussion to explore the research topic, a process known as Visual Voices. Through the project activities, the research team intends to give Park Danforth residents an opportunity to reflect and share their experiences and views, and by doing so, create greater awareness in the community.

#### Who will be participating in this project?

In order to learn about the experiences of aging Maine residents, ten independent living residents from Park Danforth are invited to participate in this research project.

#### What will I be asked to do?

Between January and April 2015 you will be asked to participate with nine other Park Danforth residents in 10 weekly sessions, and will be invited to participate in 3 art exhibits for a total of 13 events. This is an arts-based participatory research project that uses painting, drawing, writing, and group discussions to learn about the experiences and views of Park Danforth residents. The project is also designed to help develop a sense of community, provide an opportunity to explore your creativity, and expand upon self expression skills.

## This project will consist of:

- 1 introductory session,
- 6 art-making and discussion sessions,
- 1 session to compare the art and have photographic portraits taken,
- 1 session to prepare for the art exhibits.
- 3 art exhibits,
- 1 final closing session to talk about how the project went.

#### During this project you will be asked to:

- Fill out two short surveys.
- Create an individual artwork and written statement focused on how you see yourself and your identity.
- Participate in the creation of two group artworks focused on how you feel seen by other people.
- Participate in discussions with other Park Danforth residents about how you see yourself and how you feel seen by others.
- Participate in 3 art exhibits.
- Have your portrait taken by a professional photographer.

Group photographs will also be taken during the sessions and art exhibits.

#### What are the possible risks of taking part in this project?

None of the things that the research team asks or talks about during the project sessions are designed to make you feel uneasy or uncomfortable; however, it is possible that group discussions could raise distressing emotions. You do not have to discuss anything, or answer any questions, that might make you feel uncomfortable, and you can stop taking part at any time if you feel uncomfortable. Your participation is voluntary, which means that you can decide what you would like to discuss.

The research team will ask the group not to repeat anything discussed during the sessions with anyone outside of the group. However, please be aware of the possibility that any information shared during the group discussions could be repeated by other group members to people outside of the group. Therefore, if there are things that you do not want people outside of the group to know about, then it is recommended that you do not share that information.

Please note that each of the sessions' discussions will be tape-recorded. A member of the research team will also be taking notes on things like how active the group is when talking, and reactions to the artwork and writings. The audio recordings will be typed word-for-word and used to document the major discussion points. The recordings and transcripts will be maintained as password protected encrypted electronic files.

# What are the possible benefits of taking part in this project?

Research shows that participation in creative activities can help people feel good and healthy both physically and emotionally. Hopefully, participation in this project will be a positive experience that makes you feel good. This project will also give you the opportunity to share your thoughts and opinions with the community and develop relationships with other residents.

There is no financial compensation for participating in this project. However, you will be able to keep your framed artwork, as well as a copy of your professional portrait. The research team will also create a one-page document showing your portrait, artwork, and written statements and provide you with several copies to keep. You can share these documents with your friends and family or health care providers which may help them learn more about you.

By participating in this project you will be benefiting the community by giving community members and health care providers a better understanding of the experiences of aging adults.

#### What will it cost me?

The only potential cost related to this project is the cost of travel to the art exhibits taking place outside of Park Danforth.

#### How will my privacy be protected?

- The project sessions will be held in the Park Danforth third floor activity room, and only people that are participating in the project will be allowed to attend.
- If you would like, you can use a nick name during the project sessions in order to protect your privacy. If you would like to use your real name, then it will only be used for purposes that you permit. The only time that your real name will be required is on this consent form. You will not be asked to include your name on the surveys that you fill out for this project. Your name will not be included in any art exhibits or publications unless you give your permission.
- Your artwork, written statements, and portraits will only be displayed in art exhibits and publications if you give your permission. If you give your permission, the artwork, written statements, and portraits will be exhibited at Park Danforth, UNE, a venue in Portland, and at a medical facility. Also, if you give your permission, the artwork, written statements, anonymous survey results, group photographs, and quotes from the discussion recordings will be used in publications in scholarly journals, and in UNE news publications.

#### How will my data be kept confidential?

The research team will take special care to maintain the confidentiality of the data collected during this project:

- The hard copies of the project surveys will be kept in a locked office in a locked filing cabinet at UNE. Names will not be associated with survey data.
- The audio recordings and their transcriptions will be saved to password protected encrypted electronic files and will only be available to the research team and professional individuals that are contracted to transcribe and analyze the data.
- The photographs from this project will be saved to password protected encrypted electronic files and the original files will be deleted from the camera. The photographs will only be used for purposes that you

permit.

- Copies of the artwork and written statements will be saved to password protected encrypted electronic files. They will only be used for purposes that you permit. Your original artwork will be kept at Park Danforth between project sessions and you will keep it at the end of the project.
- The one-page documents that show your artwork, written statements, and photographs will be saved to protected electronic files and you will keep the hard copies at the end of the project.

Your original signed consent form will be maintained by the principal investigators for at least 3 years after the project is complete before it is destroyed. The consent forms will be stored in a secure location that only the members of the research team will have access to and will not be attached with any data obtained during the project.

UNE and the Institutional Review Board may review the project records at any time.

#### What are my rights as a research participant?

- Your participation is voluntary. Your decision to participate will have no impact on your current or future relations with the UNE or Park Danforth.
- You may skip or refuse to answer any question for any reason.
- You can choose where and how you would like your artwork, written statements, and photographs shared.
- You are free to stop participating or withdraw from this research project at any time, for any reason. If you choose not to participate or to withdraw from the project there will be no penalty to you and you will not lose any benefits that you are otherwise entitled to receive.

Please note that if, during this project, you behave in a way that is threatening or upsetting to other participants then your participation in this project may be terminated by the research team without regard for your consent.

# Will I receive a copy of this consent form?

Yes, you will be given a copy of this consent form.

#### Who may I contact with questions?

For questions, concerns, or more information regarding this project you can

contact principal investigator Collyn Baeder at (207) 221-4467 or cbaeder@une.edu.

If you choose to participate in this research project and believe that you may have suffered a research-related injury, please contact faculty advisor Rebecca Boulos, MPH, PhD, at (207) 221-4791 or <a href="mailto:reboulos@une.edu">reboulos@une.edu</a>.

If you have any questions or concerns about your rights as a research subject, you may call Olgun Guvench, MD, PhD, Chair of the UNE Institutional Review Board, at (207) 221-4171 or <a href="mailto:irb@une.edu">irb@une.edu</a>.

Participant Statement: I understand the above description of this research project and the risks and benefits associated with my participation as a research subject. I agree to take part in the project and do so voluntarily.		
Participant's Signature	Date	
Participant's Printed Name		
Researcher Statement: The participant named above had s information, had an opportunity to agreed to take part in this project.		
Researcher's Signature	Date	
Researcher's Printed Name	· -	