*** SEEKING VOLUNTEER PARTICIPANTS ***

Are you aged 60 or older? Do you live in Ferguson or a nearby community? Have you been touched in some way by events since Michael Brown’s death? Would you like to share your perspectives?

*** IF YES, please consider volunteering for the Elder Voices on Ferguson: Life Story Interview Project. Dr. Tom Meuser, Gerontology Program, University of Missouri—St. Louis, is leading this project.

**Why this study?** Older adults have witnessed much in their lives and often have important wisdom to share (e.g., for young persons). Since Michael Brown’s death, the views of older adults have received little attention in the popular media. *A primary goal of this project is to give older residents of Ferguson and surrounding communities a public voice on issues of race relations and larger life lessons.*

**What will I be asked to do?** Participation involves sitting for a 2 hour, video recorded interview about your life story (childhood to present) and answering a list of questions about racial injustice and race relations. The consent form provides all the details, including potential risks and benefits. Participation is fully voluntary and you may withdraw without penalty at any time.

**What happens to the video from my interview?** What you say in the video concerning the race-related questions will be transcribed and reviewed for important themes and ideas. A quotation from your video could be used in a published article, but your name will not be shared. Portions of your interview may also be used for public education through an *Elder Voices on Ferguson* website or DVD. You may request that your face be blurred and voice altered for privacy. Finally, you will receive four copies of your full life story interview in the form of an edited “Keepsake DVD” to share with family.

**What are the risks and benefits?** The primary risks are emotional discomfort associated with answering questions about racial issues and public presentation of portions of your interview. While your name will never be used, you could be identified by some viewers. Portions of your interview may appear on a website hosted by UMSL called *Elder Voices on Ferguson*. Some might view this exposure as a negative. There’s a positive side, too, in that your comments may help educate and motivate others.

**How do I learn more and sign up for this study?** Call Dr. Meuser (314-516-5421) or send him an email (meusert@umsl.edu) to learn more and start the sign-up process. If you choose to proceed, Dr. Meuser will arrange for his student assistant to meet with you in person to discuss the project, review the consent form, and schedule your interview. Most interviews will take place in Spring-Summer, 2016.
Dear Volunteer:

You are invited to participate in an interview-based research study about your life story (childhood to present) and personal experiences and beliefs concerning racial injustice and inequality in advancing age. Up to 40 volunteers will take part in this study.

Dr. Tom Meuser, Director of the Gerontology Program at UMSL, is leading this study, with assistance from co-investigator, Dr. Sheila Clarke-Ekong, from UMSL’s Anthropology Department, and consultant, Dr. Nancy Morrow-Howell from Washington University’s Friedman Center for Aging.

The death of Michael Brown in 2014 and other challenging events involving police and minority youth are motivators for this study. The perspectives of older citizens have received little attention in popular media. Age often brings wisdom, and our hope is to expand public and professional conversations about race through our interviews. Dr. Meuser and his team invite you to share your perspectives.

Participation in this study is voluntary and involves a video recorded interview with a trained graduate student. Interviews may take place in your home or in our on-campus studio. You will be asked questions about your general life story and about personal and beliefs experiences concerning racial injustice and inequality. While recent events motivate this study, any events or perspectives from your full life story would be relevant.

Here is an example question from our list for this study:

“You represent one generation in the struggle for racial equality and justice. How are other generations (e.g., younger) similar or different from yours?”

an equal opportunity institution
You are under no obligation to answer any questions or discuss any topics from your life that make you uncomfortable. You can simply ask to move on. You may also withdraw from the interview at any time and without penalty. Your participation is fully voluntary.

**Use of the Interview Video.** If you choose to participate, the video of your interview will be used by Dr. Meuser and his team in three ways:

1. **Examination of Themes & Ideas.** What you say in response to the study questions will be transcribed to paper and reviewed – along with the other interviews – for common and unique themes. Your name and all other personal identifiers (including the names of others, specific locations) will be deleted from transcripts and kept separate to protect your confidentiality. Brief quotations may be taken from your interview to highlight important themes in a written report or academic paper, but your name will not be listed with such quotations.

2. **Elder Voices on Ferguson Project Website or DVD.** Segments (clips) from your video recorded interview may appear in a special website or DVD (or other media) to educate the general public about the project and lessons learned. This website will be associated with UMSL and may remain available online for years in the future. *This use of your interview may be worrisome to you; options are provided below for you to protect your privacy (e.g., blurring your face, altering your voice).*

3. **Keepsake DVD.** The full interview will be edited and titled to create a “Keepsake DVD” for you to have and use as you wish. You will receive four copies to share with family and friends. Dr. Meuser coordinates the *UMSL Life Review Project* which produces these videos for persons who volunteer to tell their life stories to his students. He will extend this same service to you at no charge as a “thank you” for participating in the Elder Voices on Ferguson Project.

**Risks of Participation.** There are two primary risks for participation: (1) emotional discomfort; (2) that you may be recognized in a video product from this effort.

Talking about how issues of racial inequality and injustice have impacted your life and that of others may be upsetting. As noted above, you are under no obligation to answer questions that make you uncomfortable. You may ask the interviewer to take a break or move on to a new question. It may also be possible to reschedule your interview for a future date if present discomfort is a problem for you. It is important to recognize that some emotional discomfort could occur. A sheet listing counseling resources is attached to this consent form and is yours to keep should you need such support in the future.
The video component of this project is not confidential – it is very public. The reality of being seen and heard by others through the Elder Voices on Ferguson Project website or DVD might be worrisome to you. You can make choices below (e.g., blurring of your face) to increase your privacy, but it may still be possible for people who know you to recognize you. Such recognition could cause embarrassment or discomfort now or in the future. You could also feel pride in being part of this effort and having others view and listen to your perspectives.

**Benefits of Participation.** There are two primary benefits of participation: (1) learning about yourself and your beliefs; and (2) the satisfaction that comes from giving to others. Our goal in this project is to highlight the views and beliefs of older adults who have witnessed and/or been subject to racial inequality and injustice. The team believes that adding these voices – your voice if you choose to participate – will enhance present knowledge and dialogue at an important time in our history. You may learn something about yourself by participating in the interview. Your video could also educate and help others grappling with these issues, now and in the future. You may also appreciate sharing the “Keepsake DVD” you will receive following your participation. These are all potential benefits.

**Choices for Showing Your Video to the Public.** You choose how you want segments of your video recorded interview shown for public education. Three options are presented below. Review each option and choose the best one for you by writing your initials and today’s date on the applicable line.

_________________________  **Option 1 – Full Public Presentation.** I understand that my face, voice and statements will be viewed by others without restriction. My name and other identifiers (e.g., specifically where I live) will not be shown, but it is likely that some viewers will recognize me.

_________________________  **Option 2 – Face Blurred.** I understand that my face will be blurred digitally to enhance my privacy. The general outline of my face and hair color will still be visible, but fine facial details will appear blurry and pixilated to viewers. Your image will be blurred to the point where specific features of your face mesh together and are no longer distinct. A professional video program (Adobe Premiere) will be used for this purpose and Dr. Meuser will supervise this work. I understand that my voice and statements will be heard by others without restrictions. My name and other identifiers (e.g., specifically where I live) will not be shown, but it is possible that some viewers will recognize me. (Please Note: Making this choice will not impact on how you appear in your Keepsake DVD which will be yours to use as you wish.)
Option 3 – Face Blurred & Voice Altered. I understand that my face will be blurred digitally to enhance my privacy. The general outline of my face and hair color will still be visible, but fine facial details will appear blurry and pixilated to viewers. Your image will be blurred to the point where specific features of your face mesh together and are no longer distinct. I understand, also, that the pitch of my voice will be altered: a low pitched voice will sound high; a high pitched voice will sound low and deep. A professional video program (Adobe Premiere) will be used for each process and Dr. Meuser will supervise this work. I understand that my altered voice and statements will be heard by others without restrictions. My name and other identifiers (e.g., specifically where I live) will not be shown, but it is possible that some viewers will recognize me. (Please Note: Making this choice will not impact on how you appear in your Keepsake DVD which will be yours to use as you wish.)

*** Following your participation in the study, you will have the option to review your video use choice with Dr. Meuser and choose a less or more restrictive option. For example, if you choose Option 2 now, you could decide later that you want your face seen by others after all and switch to Option 1.

Confidentiality. As noted above, your recorded interview will be transcribed and your name and other personal identifiers (e.g., exactly where you live) will be kept separate from what you shared verbally with the interviewer.

As part of this effort, your identity will not be revealed in any publication that may result from this study. Your confidentiality will be protected when quotations are used from your interview in written reports and academic papers which may come from this study. You will never be named as a participant in this study in any publication or other media.

In rare instances, a researcher's study must undergo an audit or program evaluation by an oversight agency (such as the Office for Human Research Protection) that would lead to disclosure of your data as well as any other information collected by the researcher.

Limitations for Video. This study is not confidential with respect to the video of your interview. Segments from your interview will be posted for others to view on a special Elder Voices of Ferguson website and possibly through other media (e.g., DVD). If you choose Option 2 or 3 above, alterations to your video may enhance your privacy somewhat, but not completely. Others may still recognize you.

Be aware, also, that your interview on the website and other media could be available to the public for many years to come. No specific end date is planned. Your interview could inform public discussions about race for many years to come.
CONSENT TO PARTICIPATE

If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator, Dr. Tom Meuser, at 314-516-5421. You may also ask questions or state concerns regarding your rights as a research participant to the Office of Research, at 314-516-5899.

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy of this consent form for my records. I hereby consent to my participation in the research described above.

____________________________________  _____________________
Participant's Signature                                          Date

____________________________________  _____________________
Signature of Investigator or Designee            Date
LIFE REVIEW ORIENTATION LETTER

Dear volunteer interviewee:

Thank you for your interest in being interviewed through the UMSL Life Review Project. This letter and the attached documents describe the Project and what your participation will involve. Be sure to read through each document carefully. Feel free to contact me by telephone or e-mail if you have any questions or concerns.

Interviews are conducted year-round by faculty and/or graduate student interviewers. Most are scheduled on weekday mornings (typically 9:30 - Noon), and video recorded in a studio space in Bellerive Hall on the South Campus. Interviews may also be conducted in the volunteer’s home (or other private location) upon request. There is no cost to participate. Interviewees receive an edited “Keepsake DVD” of 4-8 weeks after participation. Three copies of the DVD are provided at no charge; additional copies are $15 each.

Interviews recorded through the Project serve three purposes: (1) education of graduate students (i.e., through the experience of conducting the interview, by viewing de-identified interview segments in class); (2) community service through the Keepsake DVD given to the participant; and (3) qualitative research on common life issues and concerns associated with advancing age (e.g., life lessons and wisdom, experiences with forgiveness, retirement from driving and personal mobility, end of life preparation).

You are under no obligation to answer questions that make you feel uncomfortable in any way; you can say no to any question and still participate fully in the Project and receive your Keepsake DVD.

Three documents are enclosed for your review: video consent form (2 copies, you keep one), the life review interview guide, and qualitative research summary.

VIDEO CONSENT FORM: The consent form is a modified version of the standard University consent for video recording. By signing the consent, you agree participate in a video recorded interview concerning your life story, personal values and beliefs.

There are three issues with respect to consent and confidentiality that are important for you to understand and consider:

ELDER VOICES ON FERGUSON

If you are an Elder Voices participant, ~30 minutes of your 2-hour life review interview will focus on a set of questions on racial prejudice and perceptions of life in our area since the death of Michael Brown. The rest will be the standard life review interview detailed below. Contact Dr. Meuser (314-516-5421) if you have any questions.
A. An objective of the UMSL Life Review Project is to provide an opportunity for students to learn about life story interviewing and the aging process through firsthand experience. One way this is accomplished is by having students play the role of interviewer. Another way is by showing short segments (clips) from past interviews to educate students about specific aspects of aging (e.g., retirement, illness, caregiving). The Project maintains a Gerontology Video Library (GLV) of de-identified clips for teaching purposes. “De-identified” means that the interviewee’s last name, address, and other obvious spoken identifiers are edited out and not shown. The video library is maintained in a password-protected system and only available for use by University of Missouri faculty for teaching purposes. By signing the Video Consent Form, you agree that clips from your interview may be used for teaching purposes as part of the GLV.

B. Your name and address will be kept confidential in the Project office (i.e., via a password-protected spreadsheet). Others will not know that you participated unless you choose to tell them. The video recording of your interview is not fully confidential, however. The video recording will show your face and voice. It is possible that a student viewing a clip from your interview might recognize you. The likelihood that this would occur and be problematic may be low, but it is something you need to be aware of. By signing the Video Consent Form, you acknowledge and understand these limits to confidentiality.

C. Research Component: Another objective of the Project is to support the qualitative research of Dr. Meuser, the Project Coordinator. “Qualitative research” is the study of what people say in response to specific questions and follow-up questions on a topic. The questions that interest Dr. Meuser are listed in the attached Qualitative Research & Consent Script. At an appropriate time during your interview, the interviewer will go over this document with you and ask if you are open to responding to these questions. If interested, you will choose which questions are appropriate for you in cooperation with your interviewer. You can choose to say “no” to the research questions altogether, or you may choose to answer just some or all of them. These are common life review questions, and your responses may become part of your Keepsake DVD. Your answers to research questions will be transcribed in text form and a code number will be assigned for analysis. Your name will be kept separate and confidential from your specific answers.

If you are comfortable telling your life story on camera with these limitations concerning confidentiality, then please sign this form, and return it in the enclosed stamped/addressed envelope. Your name will be added to the wait list for the Project, and you will be contacted by telephone to schedule your interview in the coming few months. If we call you to schedule and you are away or cannot participate for another reason, you will have the option to remain on the wait list for another time.

INTERVIEW GUIDE: The enclosed life review interview guide provides an overview of the interview process, as well possible topics and questions to discuss during your life review. This will be helpful for you to start thinking about your life story before the actual day of the interview.
A Life Review interview can be both an enjoyable and challenging process. A full life story cannot be covered in a single 2-hour interview, so our goal is to tell the basics of your life story from birth to present, including important relationships, events and achievements. Despite the time limitations, you may be surprised and pleased by how much can be covered.

As the interviewee, your comfort is of utmost importance. You don’t have to share anything that makes you uncomfortable, and you can ask to stop the interview at any time. Recalling difficult or painful memories is, however, an important part of the life review process, and you may shed a few tears. This is normal. There are sure to be some laughs, too, as you recall joyful times. Be open to what happens, but also know that you are in control of how you respond. If you find yourself getting into something that is too deep for a brief interview, just say so and you can move on to something else.

Much of the life review interview is open and flexible in structure. The interviewer and the volunteer interviewee decide, together, where to focus and what stories are important. As noted above, there is a 10-15 minute research component to the Project. The interviewer will orient you to this when it seems appropriate during the flow of your interview. Responding to the research questions is optional; you may decline and still complete a full life review interview and receive our Keepsake DVD. If you do agree to answer some or all of the research questions, your verbal consent will be recorded by the interviewer. There is not a separate consent form for you to sign.

Persons suffering from depression or other serious mental health issue may find the life review process to be very challenging. Some may choose to delay their life review until a later time when feeling better. If you are having emotional difficulty and participate in the life review interview, what you say could indicate a need for professional assistance (e.g., if risk for suicide is suggested; threat to harm another is indicated). Dr. Meuser supervises the interview process and he may contact you afterwards to discuss serious concerns about your well-being.

Sometimes unexpected memories may materialize during a life review interview. Please understand that this Project is intended to be educational in nature, and your interview is not a counseling session. If something comes up that is better addressed in a professional context, the interviewer will address this and may ask Dr. Meuser to join the session. You may also choose to call Dr. Meuser later to discuss a past trauma and options for assistance and care (support groups, formal counseling, etc.).

You will receive your edited Keepsake DVD 4-8 weeks after your interview. Three copies are provided at no charge; additional cost $15 each. If you have any pictures of your family, yourself, newspaper or magazine clippings, awards, artwork, etc., that you would like to be included in your DVD, that’s fine. You may bring up to 15 items with you to be scanned or photographed at the time of your interview appointment. The items will be returned at the end of your interview. These will be shown in your DVD at an appropriate moment.
This is a long letter, and it may be beneficial for you to read it over 2-3 times before proceeding. Is everything clear and acceptable to you? Feel free to call Dr. Meuser is you have any questions or concerns.

If you are comfortable with what is presented in this letter and packet, please complete the Video Consent Form and mail it back. This will make you official on the wait list for the Project. You always have the option to withdraw without penalty at a later date.

Your next contact with the Project will be to schedule your life review interview. You are welcome to bring notes with you, but do not script out everything you are going to say. Part of the process is to speak and respond in the moment! I look forward to meeting you in the near future.

Respectfully,

[Signature]

Thomas M. Meuser, PhD
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UMSL Life Review Project:
Orientation Guide for Volunteers

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The UMSL Life Review Project provides opportunities for students to learn about aging in a personal way (i.e., by talking to people about their experiences, values, hopes, etc.) and for area seniors to record their life stories for future generations. Volunteer interviewees receive an edited DVD “Keepsake” Video after taking part in an interview. There is no charge to participate. Those wishing more than 3 copies of the DVD are asked to pay a nominal fee to cover the cost of reproduction.

The basic interview protocol (below) serves as a starting point for the process. The student interviewer and the volunteer interviewee discuss the interview ahead of time and develop a general plan of what to cover. Most interviews last 1-2 hours. Much can be covered in this time, and an important goal is to develop an outline of a person’s whole life story.

The Project maintains a Gerontology Video Library (GLV) of brief clips highlighting different aspects aging and life experience (e.g., career and retirement, volunteerism, health and caregiving, personal values and beliefs, children and family life, attitudes about death and afterlife). It is normal for older adults to consider and reflect on such issues; this is the essence of doing a life review interview. Volunteer interviewees are asked to give consent for de-identified video clips (i.e., 2-5 minute segments, first name only) to be included in a password-protected electronic library for instructor use. Only University of Missouri faculty and teaching assistants have access to the GLV. Clips are shown to supplement lecture material and otherwise enrich the learning of undergraduate and graduate students.

The volunteer’s support of the educational mission of the project makes it a win-win for both parties. Volunteer interviewees may ask that certain topics or segments not be included in the video library - that’s absolutely fine and welcome. The student interviewer edits the Keepsake DVD and clips for the GVL, so he or she can be responsive to such requests. An important objective of the Project is that all benefit and feel comfortable in their participation. Dr. Meuser supervises the interview process, and questions about this requirement may be directed to him at the number listed above.

Interview Protocol

A Life Review Interview can be both an enjoyable and a challenging experience. Many questions may be considered, but rarely would all be answered in a single sitting. Your comfort is of utmost importance. You don’t have to answer any question or delve into any area which causes you discomfort. You can expect your interview to last about 1-2 hours.
As you prepare for the interview, consider how you have grown over the course of your life and the many things you have learned. This interview is an opportunity to learn about yourself, share your perspectives and values, and teach others at the same time.

The interview begins with three standard items (in italics below) that appear early in the edited Keepsake DVD:

- Looking at the camera, please say your first name (My name is______), where you were born/year (I was born in____ in 19___), your age (I am ____ years old), and where you live now (and I live in an apartment (house, etc.) in ________).

- What 3-5 characteristics or adjectives describe you the best? (*Example: I like to think of myself as honest, hard-working, caring, and inquisitive.*)

- Why did you volunteer to participate in this interview today? What do you hope to gain from this experience?

The remainder of the interview is loosely structured around the themes and questions listed below. Over the course of the interview, we do want to capture the general story of your life (birth, early life, school, work, etc.), and the interviewer will help structure this. The rest will depend on you and what’s important to you.

Most interviewees cover many/all of the themes below, but some in more depth than others. It is sometimes helpful to come prepared to your interview with notes (on this page is fine) or a listing of topics. The interviewer will ask you about important topics to cover (or not cover) at the start of the interview process. Since the interview is being video recorded, you can stop at any time and negotiate how to proceed.

- **Your Current Life**
  - Tell me about your current life and activities.
    - Who are the 2-3 most important people in your life now?
    - What is your daily routine like? What brings you joy?
    - What are the most challenging aspects of your life today?

- **About You / Past Life**
  - Tell me about your family of origin – parents, siblings.
  - What stands out in your memory about growing up?
  - Who were the 2-3 most important people in your life when you were young?
  - (If married or widowed) How did you and your spouse meet? What was your early relationship like?
  - What joys and/or challenges occurred during your married life?
(If you had children) Tell me about your child or children. What stands out in your memory about their growing up? What is your relationship(s) like today?

(If applicable) What did it mean for you personally to become a parent? How did parenthood mold you as a person?

We all experience losses in our life. Looking back at the first half of your life, what losses (deaths, other losses) stand out in your memory? What has grief meant in your life?

- **Career & Service**
  - What paying jobs did you hold in the past?
  - Did you consider any as a career or vocation?
  - Was volunteerism a part of your experience, then or now? How so?
  - Did you serve in the military? If so, what branch and position? What was your experience like? How did it mold you as a person?
  - (If applicable) What impact did retirement have on your sense of yourself and personal security?

- **Health**
  - How would you describe your health today? Do you function in handling daily life tasks much as in the past, or are there limitations now?
  - Have health problems been challenges at other times during your life?
  - Have you ever experienced a period of significant anxiety or depression? If so, would you be willing to share a bit about this experience? What helped you through it?

- **Caregiving**
  - Have you served as a caregiver, now or in the past?
  - For whom did you provide care? For what reasons?
  - How does/did serving as a caregiver enrich your life?
  - What challenges do/did you face as a caregiver? What is/was the hardest part for you?

- **Spirituality**
  - What role has faith played in your life?
  - What are the roots of your faith? Has your faith changed over time.
  - What values do you hold especially dear or meaningful?
  - Has your faith helped you to overcome challenges and/or get through some difficult times?
• **Death & End of Life**
  - How does death impact the second half of your life?
  - What losses stand out as particularly meaningful or challenging?
  - What do you believe about death and what may come after?
  - Does death frighten you?

• **Life Review**
  - On balance, are you satisfied with how you have lived your life?
  - Are there any significant regrets?
  - What 2-3 accomplishments are you most proud of? Why?

• **Looking to the Future**
  - What do you expect the next 5-10 years to bring in your life?
  - What are your hopes for yourself and those closest to you?
  - If you could share just one piece of advice to enrich the life of a young person, what would it be?

• **Other Thoughts & Comments**

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**A Note Concerning Interviewees with Dementia:**

Life review can be challenging for persons with dementia, such as Alzheimer’s disease, especially those with more than mild memory loss. It is often helpful to have 1-2 co-interviewees involved in such cases. A spouse and/or adult child may observe the interview and contribute when reasonable to support accurate recall and processing. The focus remains on the primary interviewee’s story, but this process is helped along by the presence and involvement of loved ones.

Participants in the UMSL Life Review Project may be offered this form of joint interviewing. Discuss any questions or concerns with the student interviewer and/or Dr. Meuser (314-516-5421).