

Title: Implementing CAPABLE in Permanent Supportive Housing

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## Informed Consent to take part in a Human Research Study

### KEY INFORMATION

#### Implementing CAPABLE in Permanent Supportive Housing

You are invited to participate in a research study conducted by Benjamin Henwood, Ph.D., at the University of Southern California, because you are living in supportive housing. You must be 44 years of age or older. This study is funded by the Southern California Clinical and Translational Science Institute at USC. Your participation is voluntary. You should read the information below, and ask questions about anything you do not understand, before deciding whether to participate. Please take as much time as you need to read the consent form. You may also decide to discuss participation with your family and friends. If you decide to participate, you will be asked to sign this form. You will be given a copy of this form.

A person who takes part in a research study is called a “research subject.” The use of “you” in this consent form refers to you as the research subject.

The following is a short summary of this study to help you decide whether or not you should participate. More detailed information is listed later on in this form.

#### **Purpose of the Study**

##### **Why am I being invited to take part in a research study?**

We have invited you to take part in a research study because you are living in supportive housing at the Skid Row Housing Trust (SRHT). To be eligible for this study, you must be: (a) older than 44 years old; (b) cognitively intact; and (c) have some or a lot of difficulty performing activities of daily living (ADLs).

##### **What should I know about being in a research study?**

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You may discuss whether to participate with family, friends and/or your doctor.
- You can ask any questions before making a decision.

##### **Why is this research being done?**

We are inviting you to take part in a research study because we are trying to evaluate the effectiveness of a program being implemented at SRHT called CAPABLE, which stands for Community Aging in Place – Advancing Better Living for Elders. CAPABLE is a client-directed, home-based intervention that consists of time-limited services from an occupational

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therapist, a nurse, and a handyman working collaboratively with you to address many geriatric conditions.

#### **How long will I take part in this research?**

We expect that you will be in this research study for a 12-month period. During this time, we will collect information on demographic characteristics, physical health, mental health, health services, residential stability, abuse or neglect, substance abuse, and history of homelessness. We will also assess your ability to complete activities of daily living, whether you have recently fallen, and whether you are experiencing depression or pain at the start of the study and again at 6-, and 12-month follow-ups. All information will be collected remotely via phone or internet video-conferencing due to the COVID-19 pandemic

More detailed information about the study procedures can be found under the “*What can I expect if I take part in this research?*” section.

#### **Is there any way being in this study could be bad for me?**

You may feel uncomfortable because you may be asked about sensitive topics. You do not have to answer any questions that make you feel uncomfortable. There is a small risk that people who are connected with this study will learn your identity or your personal information; however, steps will be taken to minimize this. If people not connected with the study learn about some of the sensitive information you provide, there is a chance that you could have problems getting a new job, keeping a current job, finding housing, or getting insurance (health, disability, or life insurance). In highly unlikely situations, information you provide about illegal activity could result in you being charged with a crime. The research team may not be able to keep confidential any disclosure or endorsement of thoughts to harm yourself. In the event that you tell the research staff that you are thinking about killing yourself or you answer yes to a question about having thoughts about suicide, the research staff will ask you more questions about the thoughts. Depending on how intense your thoughts are or how much you feel like hurting yourself, the research staff may provide you with referrals for treatment, work with you to contact your personal physician, trusted family member, or therapist to discuss your thoughts of harming yourself; or work with you on a plan that may include getting you to a hospital for safety.

More detailed information about the risks of this study can be found under the “*What are the risks and possible discomforts?*” section.

#### **Will being in this study help me in any way?**

We cannot promise any benefits to you or others from your participation in this research.

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#### What happens if I do not want to be in this research?

Participation in research is completely voluntary. You can decide to participate or not to participate. Your relationship with USC or your housing provider will not be affected whether or not you participate in this study.

Your alternative to participating in this research study is to not participate.

### DETAILED INFORMATION

To follow, please find more detailed information about this study than already provided above.

#### About this consent form

Please read this form carefully. It provides important information about participating in research. You have the right to take time in making decisions about participating in this research. If you have any questions about the research or any portion of this form, you can ask us at any time. If you agree to participate in this research you will be asked to sign this form online. A copy of the signed form will be mailed to you for your records.

#### Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, please feel free to contact Benjamin Henwood, Ph.D.: USC School of Social Work, (213) 821-6449 or [bhenwood@usc.edu](mailto:bhenwood@usc.edu)

This research has been reviewed by the USC Institutional Review Board (IRB). If you wish to speak with someone from the IRB, you may contact the IRB at (323) 442-0114, by email at [irb@usc.edu](mailto:irb@usc.edu), or by mail at the following address:

USC Institutional Review Board (IRB)  
1640 Marengo St., Suite 700  
Los Angeles, CA 90033

The IRB is available between the hours of 8:00 AM and 4:00 PM, Monday to Friday. Contact the IRB for any of the following:

- If your questions, concerns, or complaints are not being answered by the research team,
- If you cannot reach the research team,
- If you want to talk to someone besides the research team,
- If you have questions about your rights as a research participant, or
- If you want to get information or provide input about this research.

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### **Participation is voluntary**

You are invited to take part in this research because you are a resident of Skid Row Housing Trust, are over the age of 44, are not cognitively impaired, and have some impairments to activities of daily living. It is your choice whether or not to participate. If you choose to participate, you may change your mind and leave the study at any time. Refusal to participate or stopping your participation will involve no penalty or loss of benefits to which you are otherwise entitled.

### **How many people will take part in this research?**

Approximately 60 people will take part in this research.

### **What can I expect if I take part in this research?**

When you enroll in the study, you will complete an interview where we will ask you questions about demographic characteristics, physical and mental health status, health services, residential stability, abuse or neglect, homelessness history, and geriatric conditions. You will complete follow-up interviews during the 6- and 12-month visits about the same topics. All interviews will be conducted over the phone or through on-line video-conferencing.

### **What are the risks and possible discomforts?**

You may feel uncomfortable because you may be asked about sensitive topics. You do not have to answer any questions that make you feel uncomfortable. There is a small risk that people who are connected with this study will learn your identity or your personal information; however, steps will be taken to minimize this. If people not connected with the study learn about some of the sensitive information you provide, there is a chance that you could have problems getting a new job, keeping a current job, finding housing, or getting insurance (health, disability, or life insurance). In highly unlikely situations, information you provide about illegal activity could result in you being charged with a crime. The research team may not be able to keep confidential any disclosure or endorsement of thoughts to harm yourself.

### **Are there any benefits from being in this research study?**

We cannot promise any benefits to you, or other from taking part in this research.

### **What happens if I say yes, but I change my mind later?**

You can leave the research at any time. Your decisions will not be held against you. You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study.

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If you decide to leave the research, contact the investigator so that the investigator can compensate a prorated amount based on your participation.

If you withdraw from the study, you will no longer be able to participate in the study. No new information or samples will be collected about you or from you by the study team. Your withdrawal has no effect on the lawfulness of the data processing that occurred prior to your withdrawal.

It is possible that the investigator may ask you to stop the study before it is finished.

### **Will I be compensated for participating in this research?**

You could receive up to \$75 as compensation for your time. You will be paid \$20 in cash for the initial interview. You will receive an additional \$25 for a 6-month follow-up interview and \$30 for a 12-month follow-up interview. You will receive payment after each interview is completed. Compensation will be prorated if you do not complete all follow-up interviews.

If you receive more than \$600 per year for taking part in one or more research studies, you may be required to pay taxes on that money. This does not include any payments you receive to pay you back for expenses like parking fees [add other expenses if applicable]. You may receive an Internal Revenue Service (IRS) Form 1099 if you receive more than \$600 in one year for taking part in one or more research studies.

### **What happens if I am injured as a result of participating in this research study?**

If you are injured as a direct result of research procedures you will receive medical treatment; however, you or your insurance will be responsible for the cost. The University of Southern California does not provide any monetary compensation for injury.

### **If I take part in this research, how will my privacy be protected? What happens to the information you collect?**

We will keep your records for this study confidential as far as permitted by law. However, if we are required to do so by law, we will disclose confidential information about you. Efforts will be made to limit the use and disclosure of your Personal Information, including research study records, to people who are required to review this information. We cannot promise complete confidentiality. Organizations that may inspect and copy your information include the USC IRB.

Your answers to the survey questions will be identified using a random code or false name. This information will be stored indefinitely in the investigator's office in a locked file cabinet and on a password protected computer. The consent form and any documents containing your name or

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other identifiable information will be maintained separately from your responses and destroyed three years after the study has been completed.

The de-identified data for this study will be maintained indefinitely and may be used in research studies in the future. If you do not want your responses to be used in future research studies, you cannot participate in this study.

When the results of the research are published or discussed in conferences, no identifiable information will be used.

The research team may not be able to keep confidential any disclosure or endorsement of thoughts to harm yourself. In the event that you tell the research staff that you are thinking about killing yourself or you answer yes to a question about having thoughts about suicide, the research staff will ask you more questions about the thoughts. Depending on how intense your thoughts are or how much you feel like hurting yourself, the research staff may provide you with referrals for treatment, work with you to contact your personal physician, trusted family member, or therapist to discuss your thoughts of harming yourself; or work with you on a plan that may include getting you to a hospital for safety.

To help us protect your privacy, this research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The Certificate of Confidentiality will not be used to prevent disclosure to local authorities of child abuse and neglect, or harm to self or others.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This website will not include information that can identify you. At most, the website will include a summary of the results. You can search this website at any time.

**STATEMENT OF CONSENT**

I have read (or someone has read to me) the information provided above. I have been given a chance to ask questions. All my questions have been answered. By signing this form, I am agreeing to take part in this study.

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Name of Research Participant

Signature

Date Signed

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**Person Obtaining Consent**

I have personally explained the research to the participant and/or the participant's legally authorized representative using non-technical language. I have answered all the participant's questions. I believe that he/she understands the information described in this informed consent and freely consents to participate.

Name of Person Obtaining Informed Consent	Signature	Date Signed
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Study ID: UP-19-00361 Valid From: 12/31/2020 To: 8/14/2021