

CONSENT TO PARTICIPATE IN RESEARCH

***Community and Patient Partnered Research Network (CPPRN)***  
***SCREENING AND ENROLLMENT CONSENT***

The Community and Patient Partnered Research Network, or CPPRN for short, is part of a national network **working to improve the information and treatments available to all patients, families, providers, and communities about health and healthcare decisions that may affect them.** Participants in this project (CPPRN) and other projects in our research network voluntarily contribute certain information to a research information database (registry). CPPRN is focused on under-resourced community members who may be at risk for behavioral health and social challenges such as stress, sadness, and/or housing or job insecurity.

The CPPRN is a joint effort across Los Angeles and New Orleans. This network is funded by PCORI, the Patient Centered Outcomes Research Institute and its network, PCORNet. The CPPRN researchers from UCLA include Kenneth Wells, MD, MPH; Sheryl Kataoka, MD, MSHS; Bowen Chung MD, MSHS; Armen Arevian, MD, PhD, and Sarah Starks, PhD. The CPPRN researchers from New Orleans include Benjamin Springgate, MD, MPH and Ryan Pasternak, MD, MPH located at Louisiana State University Health Sciences Center-New Orleans (LSUHSC-NO) and Ashley Wennerstrom, PhD, MPH, located at Tulane University.

**WHAT IS THE SCREENING PROCESS ABOUT?**

- This screening is a brief, voluntary set of questions that you can answer to see if you are eligible to enroll in the CPPRN research network.
- During the screening, you will be asked about mental health, substance use, and possible social stressors that you may have experienced.

**WHAT WILL WE ASK YOU TO DO IN THE SCREENING?**

- If you agree, you can answer the screening questions on your own right here or I can read the questions to you in a private place. The screening will take about 10-15 minutes.
- There are no right or wrong answers. Based on your answers, we will know right away if you qualify to be part of the network.

**WILL YOU GET PAID TO PARTICIPATE?**

Yes, I will give you a \$10 ClinCard (like a gift card) for completing this screening. If you choose to enroll in the CPPRN, we will give you another \$10 for joining the network, for a possible total of \$20.

**WHAT HAPPENS IF YOU JOIN THE CPPRN NETWORK?**

We hope that you will find it meaningful to be part of a new national set of programs working to provide better information for patients, caregivers, providers, and communities. Any information we obtain will only be used for research purposes and will be presented anonymously; that is, without naming you.

The goal of our project is to use this information to improve the information and treatments available to all patients, families, providers, and communities about health and healthcare decisions that affect them.

If you choose to enroll in the CPPRN, the information you provide will be part of a research information database (registry).

## **WHAT WILL WE ASK YOU TO DO IF YOU CONSENT TO PARTICIPATE IN CPPRN?**

1. *Provide us with your contact information*, such as your telephone number and other ways to contact you.
2. *Agree for us to use the information you give us today for research to learn about who is in the CPPRN network and who may benefit from needed services.*
3. *Agree to be contacted about other research studies.* We may contact you to give you information about opportunities to participate in future research studies and ask if you would like more information. You can choose whether or not to participate at that time.

### **OPTIONAL OPPORTUNITIES:**

4. *Agree to be contacted about opportunities to contribute to CPPRN research planning efforts.* Because CPPRN is a community-partnered program, decisions about research studies are made in partnership with community members. We may invite you to participate in these planning efforts. You can let us know whether you are willing to be contacted about these opportunities, and if you do agree to be contacted, you can decide whether to participate in any of the activities at that time.
5. *Provide authorization for us to obtain data about the services you receive from health, social, and/or justice agencies.* We may contact you in the future to ask you to complete forms allowing us to obtain information about the services you receive. You can decide at that time whether to give us that authorization, and you will be able to specify which information we may access.
6. *Provide authorization for us to connect your network profile with other, available PCORNet network profiles, if any.* You may have a profile in another PCORNet network, such as limited information from healthcare providers that does not identify you individually. We can match this to your profile to better understand your health and healthcare experiences.

## **PARTICIPATION IS VOLUNTARY**

You do not have to participate if you do not want to. When giving us contact information or completing questionnaires, you can skip any question or stop the interview at any time. Your choice about participating in this screening will not affect the care or services you are receiving in any way.

## **WILL CPPRN GIVE YOU TREATMENT AS PART OF THIS PROJECT?**

No, the project does not provide treatment.

## **POTENTIAL BENEFITS**

### **SCREENING**

- It is likely you will not directly benefit from choosing to participate in the research
- We will give you a CPPRN Resource Guide (via a link to a website) with information on mental health and other services available in the community.
- Your participation in taking the screener may help improve understanding of how to help people in the community who need mental health, substance use, or social support services.

*ENROLLMENT – in addition to the benefits of screening*

- You can receive information about mental health or substance use that might help you or someone you know.
- You will be given the opportunity to participate in future research studies.
- You will be given the opportunity to help make decisions about what research projects are developed in your community and how those projects are designed.
- The results of the CPPRN research may help improve understanding of how to help people in the community who need mental health, substance use, or social support services.
- You might be given the opportunity to receive future payments by participating in future research studies.

## **RISKS**

### *SCREENING*

- Answering some questions might upset or embarrass you; however, all questions are voluntary and you can skip any questions you do not want to answer.
- If the results suggest you may have a mental health or substance use problem or other social stressors that may need treatment, you might become concerned or worried; but this is only a standard screening. To determine if you might have a problem that needs treatment, you would need to visit a provider for further assessment.

### *ENROLLMENT-in addition to risks of screening*

- If you choose to enroll and participate in this project, you might seek mental health and social services that you did not consider before.

## **CONFIDENTIALITY**

All the information you give us for this study will be kept confidential and will not be shared with anyone outside of the research team, without your express written permission. Information you provide will be kept in locked file cabinets and in secure computer files. Only research staff working on this study will have access to these files. All identifying information (such as your name and contact information) will be destroyed five years after the end of this study, unless you sign another consent form for us to keep that information.

We have obtained a Certificate of Confidentiality from the National Institutes of Health for this Study. The Certificate of Confidentiality helps us to keep others from learning that you participated in this study. We will rely on the Certificate of Confidentiality to refuse to give out study information that identifies you even if we get a court subpoena. For example, if we received a subpoena for study records, we would not give out information that identifies you.

The Certificate does not stop us from making the following disclosures about you to local authorities if you tell us that a child or elderly person is being abused, or if you tell us you have the intent of harming yourself or others. If that is the case, we may not be able to keep information that may identify you or what you tell us private. If we need to provide that information to someone who can protect you from that harm:

- Giving state public health officials information about certain infectious diseases,
- Giving law officials information about abuse of a child, elderly person or disabled person.
- Giving out information to prevent harm to you or others.

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

- You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.
- You may refuse to answer any questions that you do not want to answer and still remain in the study.

### **LOS ANGELES COUNTY DEPARTMENT OF MENTAL HEALTH CLIENTS OR LEGAL-ENTITY CONTRACTORS**

Clients served by the Los Angeles County Department of Mental Health directly operated clinics or legal-entity contractors with questions or concerns regarding the impact of their research activities on access to or quality of their usual care may contact the Los Angeles County Department of Mental Health Human Subjects Research Committee at (213) 639-6348

### **WHO CAN YOU CONTACT?**

- Dr. Kenneth Wells is the Principal Investigator of CPPRN in Los Angeles and can be reached through the CPPRN program coordinator, Krystal Griffith, at (310) 794-2967.
- Dr. Benjamin Springgate is the Principal Investigator of CPPRN in New Orleans and can be reached at (504) 568-5723 or through the NOLA CPPRN project manager, Olivia Kacsits, at (504) 568-6097.
- If you have any questions about your rights while taking part in this study, or you have concerns or suggestions and you want to talk to someone other than the researchers about the study, please call OHRPP at (310) 206-2040 or write to: UCLA Office of the Human Research Protection Program Box 951406, Los Angeles, CA 90095-140
- Email: [participants@research.ucla.edu](mailto:participants@research.ucla.edu)
- If you are in New Orleans and have questions about your rights while taking part in this study, or have concerns or suggestions and want to talk to someone other than the researchers about the study, please call the Tulane University Human Research Protection Office at (504) 988-2665 or write to Tulane University Human Research Protection office at 1440 Canal Street, Suite 1705, TW-8436, New Orleans, LA 70112. You may also call the LSUHSC-NO Chancellor at (504) 568-4801.
- You can have a copy of this information sheet to keep for your records.
- You can visit the CPPRN website, [www.cpprn.org](http://www.cpprn.org).

☐ **I consent** to taking the **screening survey** for the CPPRN.

This means I will take the 10-minute survey to see if I am eligible to enroll in the study. I also consent to give my email and/or phone number in case I don't finish the survey in time.

**SIGNATURE OF RESEARCH PARTICIPANT**

YOUR NAME: \_\_\_\_\_

YOUR SIGNATURE: \_\_\_\_\_

DATE: \_\_\_\_\_

☐ If **eligible**, **I consent to enroll** in the CPPRN.

This means I will provide my contact information. I agree for the study to use the information I gave today for research to learn about who is in the network and who may benefit from needed services. I agree to be contacted about other research studies that I might be interested in.

☐ If **not eligible**, **I consent to enroll as an associate** of the CPPRN.

This means I may be contacted to participate in research study planning efforts.

☐ If **not eligible**, **I do not consent to enroll as an associate** of the CPPRN.

This means we will not contact you or keep your contact information.

**I am also interested in the following optional activities as part of enrollment in the CPPRN:**

☐ I agree to be contacted about opportunities to contribute to research planning efforts as part of the CPPRN.

☐ I agree to be contacted to discuss providing authorization to the CPPRN to obtain data about the services I receive from health, social, and/or justice agencies.

☐ I agree to link information from other PCORnet networks to my CPPRN profile.

**SIGNATURE OF RESEARCH PARTICIPANT**

YOUR NAME: \_\_\_\_\_

YOUR SIGNATURE: \_\_\_\_\_

DATE: \_\_\_\_\_

**CPPRN STAFF USE ONLY**

NAME: \_\_\_\_\_ SIGNATURE: \_\_\_\_\_

DATE: \_\_\_\_\_

# Community and Patient Partnered Research Network (CPPRN)



- Please check off each statement after you read it.
- **YOU CAN KEEP THIS FORM**

## Things you should know about joining the CPPRN:

- ☐ 1. We are asking you to participate in CPPRN because you reported experiencing such things as trauma, financial or housing stress, or mental health or substance use problems, or being a family member or caregiver for someone with those experiences.
- ☐ 2. We are asking you to provide us with contact information so that we may contact you about future research. If we do contact you, you can decide whether or not to participate at that time.
- ☐ 3. You don't have to be in the CPPRN. You can leave the CPPRN at any time.
- ☐ 4. Whether you want to be in the CPPRN or not, the care or services you are currently receiving will not change.
- ☐ 5. You will be given a CPPRN Resource Guide for places to go for services. It is up to you to decide whether to go and where to go.
- ☐ 6. CPPRN cannot guarantee that you will get an appointment for an assessment or what services you will receive.
- ☐ 7. **Optional: You will be given the option to agree to be contacted about research planning efforts**
- ☐ 8. **Optional: You will be given the option to allow us to obtain data about your services.**
- ☐ 9. **Optional: You will be given the option to allow us to connect your CPPRN data with other PCORnet data.**
- ☐ 10. **Do you have any questions?**

# Community and Patient Partnered Research Network (CPPRN)



- Please check off each statement after you read it.
- **YOU CAN KEEP THIS FORM**

## Things you should know about being an associate of the CPPRN:

- ☐ 1. We are asking you to provide us with contact information so that we may contact you about helping with planning efforts of future research projects. If we do contact you, you can decide whether or not to participate at that time.
- ☐ 2. You don't have to be associated with the CPPRN. You can stop being associated with the CPPRN at any time.
- ☐ 3. Whether you want to be associated with the CPPRN or not, the care or services you are currently receiving will not change.
- ☐ 4. You will be given a CPPRN Resource Guide that outlines places people can go for services.
- ☐ 5. Do you have any questions?