Dear Research Community,

UCSF's Community Engagement program recently held focus groups with study participants and members of research community advisory boards to collect their perspectives on the impact of COVID-19 and UCSF's interim research policies on research participants. Two key messages emerged:

- 1. The need for clear and consistent communication to study participants already enrolled in (or being actively recruited for) studies, explaining UCSF's interim policies adopted during the COVID-19 outbreak and their possible implications for each study and participant.
- 2. Study participants would benefit if they received reassurance about not being forgotten during the COVID-19 outbreak, during which normal research procedures may be changed, postponed or suspended.

We are confident you have already been communicating with your study participants as the <u>Updated Directive to</u> <u>UCSF Clinical and Non-laboratory Researchers</u> has been implemented. If you are not familiar with these directives, information can be found at research.ucsf.edu.

This initiative is to assist and encourage study teams with ongoing communication with participants by offering a standard script and online resources to ensure consistency in messaging and approach and to respond to the focus group feedback.

Suggestions to enhance communication with participants:

- 1. Below are several modular statements that may or may not apply to your study; please assemble those that are appropriate to create a script best suited for your participant population.
- 2. CRCs should review the script with their PI to assure all areas of communication are included.
- 3. Consider developing an action plan for the calls, e.g. prioritizing names on the call list, noting which if any participants should NOT be contacted, etc.
- 4. Once the script is finalized and approved by the PI, CRCs can begin reaching out to participants by phone. (With everyone sheltering in place, a kind voice on the other end of the phone might be even more welcome than usual!)
- 5. Be sure to document all calls and note any questions or issues that may require follow-up.
- 6. If you have participants who might benefit from resources in other languages, please share with them this multilingual, evidence-based, and expert-reviewed COVID-19 resource produced by the COVID-19 Health Literacy Project in collaboration with Harvard Health Publishing

CRCs, if you have specific questions about communicating with your study participants, please discuss with your PI. If you have general questions or suggestions, please stay tuned - details will be forthcoming for an optional Zoom discussion about outreach efforts with your participants, including available resources for responding to their questions.

Best regards,

Kevin Grumbach, MD, Director, Community Engagement & Health Policy Paula Fleisher, MA, Associate Director, Community Engagement & Health Policy Lisa Schoonerman, Associate Director, Training

| Suggested Language and Topics for Study | Participant (| <u>Check-Ins duri</u> | ing the COV | ID-19 Outbreal |
|---|---------------|-----------------------|-------------|----------------|
| mix and match as appropriate for your study | • | | - | |

| 1. | Hello, this is [yo | ur name] from UCSF Depai | tment of I'm | the clinical research |
|----|---------------------------|----------------------------|------------------------|------------------------------|
| | coordinator for Dr | 's study about | and I'm calling to | oday to see how you're |
| | doing and offer a brief t | update on the study and re | search efforts at UCSF | . Is now a good time for you |
| | to talk with me? | | | |

- 2. First, I would like to *thank you* for participating in our study! Your participation is extremely important to us. We could not do this without you people like you and others participating in research are key to UCSF's research mission and we are grateful for your time. Thank you!
- 3. As you know, the clinical research at UCSF and across the country are being impacted by the COVID-19 situation. Scheduled study visits have changed. Visits are now being conducted by phone or video sessions, some postponed and even some suspended during the outbreak. These changes are being made with the goal of protecting study participants such as yourself, our patients, health care workers, and the UCSF community as best possible from risk of COVID-19 infection.
- 4. We do not yet know how long the current situation will last, but I wanted to check in with you and make myself available to answer any questions you might have. And, if there is something that I don't know the answer to myself, I'll check with Dr. _____ and get back to you shortly.
- 5. How are you feeling? Have you experienced any side effects / adverse events since we last talked? [Document any issues reported].
- 6. I understand that concerns about COVID-19, and adjusting to sheltering in place are very difficult for pretty much all of us right now, especially when it comes to navigating health care. It can be really unsettling and I want you to know our study team is here for you if you need assistance.
- 7. By the way, if you have questions about COVID-19, UCSF has a terrific website that is kept current: https://coronavirus.ucsf.edu/
- 8. Even though the study you are participating in has changes because of the COVID-19 outbreak, please know that your participation is still very important to us and we will continue to be in communication with you and support you the best we can!
- 9. During this time of sheltering in place and restricted visits to UCSF Clinics, we have made changes to our usual in-clinic visits to phone calls or video sessions. Would you be okay if we conducted your study visits this way? [answer any questions about remote visits, schedule follow-up session if appropriate]
- 10. For remote visits, we use a video conference tool called Zoom [or insert name of tool that will be used], have you heard of it or used it before? UCSF's Zoom is a secured system and has been approved for use for study visits. Please be assured that every effort will be made to protect your privacy in the same way as when you come in for a visit.
- 11. Thank you again for your time and continued participation in our research study during this challenging time! We hope very much that we will be able to return to normal procedures in the near future, and look forward to seeing you in person soon! In the meantime, please stay home and stay safe, and if you have any issues or questions that are study-related please don't hesitate to contact me. My number is _____.