

## **Access, Exchange, and Use of Social Determinants of Health Data in Clinical Notes (SDOH)**

### **Synchronous Patients and Care Partners Focus Group: Prospective Agreement (English)**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0955-XXXX. The time required to complete this information collection is estimated to average 90 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, to review and complete the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer.

## MEDPANEL SYNCHRONOUS OR “LIVE” ONLINE FOCUS GROUP (Patients/Care Partners) PARTICIPANT AGREEMENT AND CONSENT

MedPanel, Inc. wishes to invite you to participate in a live online focus group on <Topic X>, scheduled <Date X>, 2021 from <time in participant’s time zone>. MedPanel is conducting these focus groups on behalf of the Office of the National Coordinator for Health Information Technology and researchers at Harvard Medical School. All information about you will be kept strictly confidential.

The following is an overview of the focus group activities, should you choose to participate in the focus group:

**Online Focus Group Participation:** This “live” virtual focus group is scheduled for <Date X> from <Time X> to <Time Y>. This meeting will be conducted live in real-time with the use of Focus Vision, an online focus group platform. You will see other focus group participants at the same time, though everyone will be anonymous. A MedPanel representative will facilitate a guided discussion to capture:

- Your experience as a patient/care partner
- Your feedback on social determinants of health and their documentation in the medical record
- Your feedback on your experience with answering questions online

You may stop participating in the focus group at any time.

**Researcher Engagement with the Focus Group:** During the live focus group, the Harvard research team will be silently observing the focus group interactions and will hear participant feedback. However, researchers will not be able to see your face. During the discussion, the researchers from Harvard may send questions via “chat” to the MedPanel facilitator if they would like additional information or clarity. The only personal identifier the research team may learn about you is your *first name*, which will be used during the discussion. To maintain your confidentiality, it is advised that you limit use of additional personal identifiers during the meeting such as your last name or where you live.

**Transcription of Focus Group Content:** The Focus Group and its participants’ contributions will be audio recorded and transcribed for the research team’s internal use, such as clinical research, training, reports and presentations (“Transcript”). Only the transcription will be shared with the research team. The audio recording will be kept on a secure server at MedPanel and destroyed once the project is over. By agreeing to participate in the focus group, you understand and consent that:

- The Transcript may now or in the future be used for appropriate internal presentation and you waive any right to inspect or approve.
- MedPanel or the research team may distribute the Transcript solely for the internal uses described above.
- The Transcript may be retained by MedPanel and the research team, for a period of 3 years on a secure server, and thus may be subject to continuing use and disclosure for the purposes described in this Consent.

At all times and in all uses, including in the Transcript, your identity will remain confidential to MedPanel and will not be made known to the research team.

Should you participate, MedPanel will collect the following personal information and hold it confidentially:

- Full Name (not sent or shared with our Client; it is collected by MedPanel Inc. to record your participation)
- Email Address – Also not sent or shared with our Client.
- Year of birth
- Race/Ethnicity (optional)

Your participation in this focus group is voluntary. If you have questions about your rights as a research participant or would like to speak with someone independent from the research team, please contact the Human Subject Protection Office (617) 975-8500.

**Please indicate which applies to you:**

I agree to the terms of this SYNCHRONOUS OR “LIVE” ONLINE FOCUS GROUP PARTICIPANT AGREEMENT AND CONSENT.

I do not agree to the terms of this SYNCHRONOUS OR “LIVE” ONLINE FOCUS GROUP PARTICIPANT AGREEMENT AND CONSENT. (Note: this will disqualify you from participating.)

Thank you for your cooperation.

**PARTICIPANT:**

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Signature

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Print Name and Date