Remote Data Collection Guidelines

During Phase 3 of the [JHU Contingency Plan for Human Subject Research Operations Related to the Coronavirus Outbreak](https://hub.jhu.edu/research-human-subject-research-phase-two-contingency-plan/), research is divided into Tier 1 (High Direct Benefit to Research Participants); Tier 2 (Moderate Direct Benefit to Research Participants); and Tier 3 (Low Direct Benefit to Research Participants). Regardless of which Tier a research study falls into, efforts should be made to [screen research participants for signs and symptoms of the virus](https://intranet.insidehopkinsmedicine.org/heic/_docs/2019-nCoV_phone_triage.pdf) and whenever possible, conduct the research visit remotely, either by phone or email survey. Changes to how data are collected may be documented as a protocol deviation and reported at the time of the next continuing renewal, as along as the University is under Phase 2 of the Contingency Plan.

*Protecting Participant Privacy When Working Remotely*

Research staff who are interacting with patients or remotely accessing PHI will need to have internet access. For employees who do not currently have internet access, free service may be available through [Comcast](https://corporate.comcast.com/covid-19).

Note that protection of PHI continues to be required in a remote environment. Staff should not print out lists of names of research subjects, or work in unprotected files on computers outside the University network. If not already available, remote computer access to study resources should be obtained and tested. Please see JHSPH IT resources for [Working Remotely](https://my.jhsph.edu/Offices/InformationTechnology/AccountsAndNetworkAccess/WorkingRemotely/Pages/default.aspx) including obtaining Zoom, GoToMy PC, and SafeDesktop applications and for establishing shared network drives*.*

Study teams must develop scripts for contacting participants by phone, ensuring that the type of study or medical condition being examined is not revealed to other members of the participant’s household. E.g. “This is X calling from the Johns Hopkins School of Public Health. May I please speak with [Name].” Likewise, messages left for participants must not provide information that would give other people hearing the message information about the participants’ health status.

*Phone Interviews*

Changing in-person study visits to a phone interaction represents not only a change to the way in which the study is conducted, but may also merit modification of the data collection instrument to accommodate the remote format. Research teams should carefully review interview instruments and scripts and consider rationale for reducing the number of items asked to reduce respondent burden. Any changes to the data collected should be documented with the IRB through an amendment.

Calls can be made over the phone or with Zoom, which is HIPAA compliant provides you are using a professional platform. (<https://www.hipaajournal.com/zoom-hipaa-compliant/> )

To preserve anonymity, it is possible to use a dedicated phone or google voice. Resources on how to set up these accounts has been saved in the [OneDrive Research Preparedness Folder](https://livejohnshopkins-my.sharepoint.com/:f:/g/personal/kparris1_jh_edu/EmK_HZ2OyGRLmo7qn7h-4D4BwrlYTpBTd-_DcVLAKUjxzg?e=ZKNhnS).

*Remote Data Collection*

Data can be collected remotely using a variety of tools. Investigators at the School, under the Bloomberg Data for Health Project (BD4H) have identified, tested and deployed methods for interactive voice response surveys, SMS (text-message) surveys and even CATI (call-center based) surveys in multiple countries across Asia, Africa and S. America, and they are available to advise teams on on appropriate modalities, software services and even private-sector partners with expertise or platforms to accomplish these.

Simple "follow-up" (non-HIPAA) surveys can be easily accomplished using Textit.in / Viamo, through interactive SMS (text "death" to 443-393-2228 to try a demo of a SMS-based simple, identifier-free verbal autopsy). Voice-based "robocalls" can also be easily setup, and call-center software is also readily available for free or at really low costs - automating the scheduling of calls, as well as the capture of data.

Surveys can be collected using ONA Collect, KoboToolbox (both enhancements to the very popular ODK) - both of which are very straightforward to use given their programming leverages a simple excel-sheet based "programming language". REDCap and Qualtrics are other options for surveys. Information on how to use REDCap is available in [our resource library](https://livejohnshopkins-my.sharepoint.com/:f:/g/personal/kparris1_jh_edu/EmK_HZ2OyGRLmo7qn7h-4D4BwrlYTpBTd-_DcVLAKUjxzg?e=2SHuZU). Interviews and case report forms can be converted to surveys, which can be administered by email. However, if your study has not used REDCap, we do not recommend starting a data collection project for the sole purpose of remote data collection. Instead, we recommend the use of [Qualtrics](https://ictr.johnshopkins.edu/programs_resources/programs-resources/i2c/qualtrics-survey/), which the University has an institutional license for.