

Butler Center for Research RESEARCHER COLLABORATION AGREEMENT

Prior to beginning data collection, the RAT/PB Chairperson will review these guidelines with the researcher. The researcher will then be asked to sign a copy of these guidelines indicating that s/he understands and agrees to comply with these guidelines at all times. If the principal researcher is a student, his/her academic advisor will be asked to sign a copy of the guidelines as well. Research conducted in a manner which is inconsistent with these guidelines may result in suspension or termination of project approval.

- 1) The research protocol must include defined roles for each member of the study team. A Study Team Roster Form must be included with the research proposal (investigators may substitute a list of study team members and their roles from the protocol in lieu of the Study Team Roster Form). For a list of defined roles and a sample list of their responsibilities, please see the BCR Research Policy Manual, section 5.2, "Defined roles".
- 2) All members of the study team must maintain confidentiality of patients and patient information encountered during the course of conducting research (including all verbal and written communication with patients). A signed Research Confidentiality Agreement for all members of the study team must be included with the research proposal.
- 3) In order to ensure the utility of the research results and enhance the relationship between HBFF and the research community, the research must be conducted with scientific integrity and in accordance with professional standards for research. Throughout the process of data collection, data analysis, and presentation of study results, the researcher must maintain an objective view of the research questions and should seek to establish positive relationships with program staff.
- 4) Researchers must provide each subject with the following information to ensure that subjects are able to provide informed consent for participation: 1) a statement that the study involves research, 2) a full explanation of the procedures to be followed, 3) the expected duration of the subject's involvement, 4) a description of the potential discomforts and risks, 5) a statement describing how confidentiality will be maintained, 6) a statement that participation is voluntary and participants have the right to withdraw their consent and discontinue participation at any time without jeopardizing their relationship with HBFF, and 7) the name of a person the subject may contact if they have questions about the research or their rights as a human subject. Each participant must sign a consent form that indicates his or her willingness to participate in the project. Participation by children under the age of 18 also requires that the child's parent or legal guardian provide written consent for the child to participate in the study. Upon completion of the research procedures, the principal investigator must attempt to remove any confusion, misinformation, stress, physical discomfort, or other harmful consequences that may have arisen with respect to the participants as a result of the procedure.
- 5) Researchers must agree to HBFF policies regarding authorship (please see the BCR Research Policy Manual, section 5.2, "Authorship").
- 6) Upon completion of the research study, the researcher is responsible for communicating the purpose, nature, outcome and possible practical or theoretical implications of the research to program staff in a manner they can understand. Researchers must provide HBFF with at least one written copy of a summary of research findings before the stated deadline for project completion. For more information on dissemination of study results, please see the BCR Research Policy Manual, section 5.2, "Dissemination of results".
- 7) HBFF owns data collected by HBFF staff members about HBFF patients. The Foundation also owns research done in collaboration with other organizations, but collected by HBFF employees. This does

not mean that HBFF employees have exclusive rights to publish the data. Rather, after data collection is completed, data will be stored at HBFF, either electronically or as paper files. For projects conducted primarily by outside researchers, HBFF prefers that paper and electronic records be stored at HBFF after data analysis is completed at a HBFF site.

- 8) Students completing research as a part of an undergraduate or graduate course or degree requirement are required to agree to the same conditions as non-student researchers. HBFF will provide data entry if the project is completed under the auspices of an existing HBFF research project. Students are required to complete data entry if the project is beyond the scope of current HBFF research. The student's faculty advisor is responsible for advising the student in data analysis and the resulting paper or presentation. If the student and/or faculty member desire to publish the study results, they are held to the same requirements as non-student researchers.
- 9) Researchers must conduct research according to stated purpose and procedures as described in the approved proposal. Any major variance from approved research protocol or issues to be studied must have prior approval of HBFF.
- 10) Researchers should maintain regular communication with the RAT/PB regarding progress on the project and should notify the Chairperson of any major anticipated delays in completing the project by the proposed deadline.
- 11) HBFF retains the right to determine how the Foundation's name will be used in any published papers. Prior to submission for publication researcher must provide HBFF with a copy of the submitted manuscript and indicate the journal(s) to which it will be submitted. Submission to any publication other than professional, refereed journals must receive prior approval from HBFF. HBFF retains the rights to distribute copies of research findings for educational purposes.

The signature of the research (and advisor where applicable) indicates that the researcher understands these guidelines and agrees to follow these guidelines at all times. Research conducted in a manner inconsistent with these guidelines may result in suspension and/or termination of project approval.

Signature of Researcher

Date

Signature of Academic Advisor (when applicable)

Date

Signature of RAT/PB Chairperson

Date