

Data Sharing Plan: Cameron County Hispanic Cohort (CCHC)
Hispanic Health Research Center,
University of Texas School of Public Health, Brownsville campus (UTSPH-B)

Updated February 25, 2019

The Hispanic Health Research Center of UTSPH-B has an interest in sharing specimens and data with other qualified research groups of individual researchers and teams who may wish to contribute analyses for the benefit of the scientific and health care communities, in the best interests of the participants and their families from whom these data are derived. In principle the data will first be shared by conventional mechanisms of presentation at scientific meetings and publication in peer-reviewed journals. On request, access to data may be given to new investigators under the conditions and using the processes listed below.

There are a few caveats where transfer of data is under consideration. In general, data that are still in the process of analysis and not yet published may be considered to be not ready for sharing, specifically data that have not yet been fully reviewed, cleaned and subjected to sufficient analysis to ensure that they are reliable and appropriate. Sharing of complex datasets may also necessitate collaborative agreements with the group who generated all or some of the data. The HHRC cannot provide a warranty, given or implied, as to the sufficiency, accuracy or fitness of transferred data for the purposes of the recipient researchers.

Principles and Procedures for Data sharing

1. A small group of investigators has been central to the development of this cohort which has been recruited using several funding sources since 2003. Consultation with and inclusion of one or more of these investigators depending on the project is needed for approval, but this is in no way intended to inhibit wide participation of collaborators. Two core PIs have played essential roles in generating the cohort data; Dr. Joseph McCormick and Dr. S. Fisher-Hoch. **At least one of these, usually both, should be on each paper or acknowledged** in recognition of their role in the concept of the cohort, its design, recruitment, organization, oversight and the collection of data. Other Brownsville faculty may also appropriately be added as authors where they have made specific contributions. The roles of these co-authors will be active and supportive in the preparation of manuscripts.
2. Consistent use of acronyms should be applied. For example, The Cameron County Hispanic Cohort is abbreviated to CCHC. Core statistics, such as rates of diabetes and obesity should be cross checked for consistency. If these are calculated in a different way for different purposes this needs to be clearly explained. **The Core PIs of the CCHC must review all manuscripts using CCHC data** before they go out so that major inconsistencies in data and messages can be detected and adjusted as necessary.
3. All persons handling the CCHC data must be added to the Committee for the Protection of Human Subjects (CPHS) approval for these data.
4. An application with required preliminary information must be submitted to one of the core PIs for approval. At this point authorship should be agreed, and if appropriate collaborative agreements drawn up. Access to data will be provided only when this process is complete.
5. Acknowledgements of the core team should be made in all presentations using these data. The field team's contribution is enormous, very time consuming and very difficult, and that we should all understand and communicate the difficulty and the efforts needed to gather data. Updated photographs and names should be requested from the core PIs.
6. All manuscripts must acknowledge the support of MD000170 P20 funded from the National Center on Minority Health and Health disparities (NCMHD), the University of Texas Houston Health Sciences Center, Center for Clinical and Translational Science CCTS-CTSA award UL1 TR000371 from NCATS. These awards need to be checked for updating.

Procedures;

1. The form reviewed and agreed on by the core PIs must be completed and submitted for approval.
2. The application will be reviewed, discussed as necessary and approved if it is appropriate. It will then be circulated to all central CCHC investigators for their information and comments.
3. CPHS approval will be verified for investigators planning to handle data.
4. On approval access will be made available by Gloria de Luna and Hugo Soriano who are the CCHC Data Managers.
5. Once access has been activated the team preparing the manuscript has 6 months to submit to a journal, unless good arguments can be made for additional time.
6. A similar process is in place for new ancillary studies (additional questionnaires, use of specimens, additional specimens, new examinations etc.)

Joseph B. McCormick
Susan P Fisher-Hoch