HERN Principles of Practice

The Health Experiences Research Network (HERN), launched in 2014, is a partnership between faculty affiliated with University of Wisconsin-Madison, Johns Hopkins University, Oregon Health & Science University, and Yale University. HERN is committed to implementing the Database of Individual Patient Experience (DIPEx) methodology in the United States so that each qualitative research study is conducted with rigor and its corresponding public-facing web-based "module" is interpretive, deeply descriptive, and holistic. Because dialogue, diverse viewpoints and collaborative inquiry are essential to these dimensions of quality in qualitative research, we are committed to using team-based approaches, and multidisciplinary collaborations in our DIPEx studies. To support the development of high-quality modules in the USA, we are committed to abiding by DIPEx International Guidelines (see summary below) and to the following "Principles of Practice", appropriately adapted to the U.S. context. These principles of practice have been drafted by identified qualitative researchers at each of the Network institutions, who come together as the 'Qualitative Research Subgroup.' It was then approved by the HERN Steering Committee in July, 2017. Beginning in September 2018, we will welcome the energy, dedication and talent of additional researchers who wish to produce additional US-based DIPEx modules, and who are prepared to commit to the guidelines, practices and expectations for interactions with HERN specified later in this document.

DIPEx International Guidelines

The DIPEx International guidelines, shown below, provide important scaffolding to ensure quality work for our international network.

1. Is the research funded through a competitive, peer-reviewed research stream?
2. Does each website include AT LEAST 30 interviews, 20 topic summaries and 250 extracts from the interviews?
3. Are articles based on the research published in peer reviewed social science and clinical journals?
4. Has the site been evaluated and demonstrated that the material covers the issues that are important to the patient group?
5. Has the data been shared with experienced researchers for secondary analysis (and if so has this led to peer reviewed publications?)
6. Are there independent assessments of the quality of the processes involved, or examples of the impact of the research and websites?
7. Are the sites endorsed by voluntary organizations that represent patients' experiences?

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Each of the DIPEx International Guidelines are intended to ensure that each country's website and accompanying research projects adhere to the norms of high-quality qualitative research. But we recognize that each topic (and accompanying website module) may not meet all of these criteria. For example, some projects may be funded by individual donors, and secondary analyses are likely to emerge only after HERN has been in operation for some time, as was the case with the Oxford-based initiative in the U.K.

In addition, HERN works in a somewhat different context than the health experiences research team at Oxford and elsewhere. Our country is larger, and our teams are therefore more dispersed and diversified and generally do not share a single institutional infrastructure. While our team-based model is a strength of HERN, we have created the following "principles of practice" to ensure that the quality of our work is consistently outstanding.

1. Each module will have a qualitative lead or co-leads responsible for the science of the study and trained in the DIPEx methodology prior to implementation. In most cases, with the possible exception of large mixed-methods projects which include a DIPEx module, a qualitative lead will function at minimum as module co-PI.
    a. Qualitative leads must be experienced qualitative researchers.
    b. Qualitative leads must have in depth knowledge of and exposure to the DIPEx methodology. Initial training may occur through a formal, group DIPEx training course, and/or via training, mentorship and on-going supervision mechanisms created by DIPEx-experienced researchers within HERN. On-going training as module implementation proceeds will occur through engagement with HERN's Learning Network (see below).

2. Interviews will be conducted by or under the supervision of the qualitative lead(s). The qualitative lead will train other researchers involved in data collection and oversee the quality of the interviews. Researchers who collect qualitative data will be integral members of the project team, intimately involved in all phases of module development. Module development is an iterative process that includes: establishing goals of the study, creating and repeatedly consulting a project-specific advisory board, defining and ensuring a maximum variation sample is achieved, developing and refining the interview guide, monitoring saturation, analyzing and data, preparing material for publication on HERN's website, and disseminating findings.

3. Researchers who collect data will all be familiar with the DIPEx methodology. This includes the use of a coding buddy defined as an additional qualitative or mixed-methods researcher who did not participate in the data collection, thereby bringing a fresh perspective to data analysis and interpretation.

4. To assure continuous learning within HERN and quality of modules produced across the USA, teams working on new modules will:
    a. Include a team member within the HERN network with experience working on a previous module
    b. Share their work, while in process, with HERN's Qualitative Research Subgroup, via our Learning Network
    c. Have benefit of learning about team practices (e.g., team-based approaches to data analysis) established or emerging within HERN
    d. Present material for the module proposed to appear on the www.healthexperiencesusa.org web site for review and approval by HERN's full Steering Committee prior to publication on the site

5. The Qualitative Research Subgroup functions as a Learning Network where cross-module learning can regularly occur, guidance can be offered, ideas can be workshopped, and emerging practices and insights can be shared and documented. The Learning Network is committed both to excellence in US-based implementation of the DIPEx methodology, and to innovation and flexibility as we continue to gain experience and expertise. Qualitative research leads working on new modules will join this Learning Network for the duration of their project, participating regularly in teleconferences/meetings during the course of module development and presenting their progress, insights, and issues to the group for discussion and guidance at a minimum of three meetings. Leads will also present a draft of their module content to the entire HERN steering committee in advance of moving forward to publish it on the HERN website so that the committee can review and approve.

6. Because HERN is committed to deeply engaging patients and participants in each module, each new module will have an advisory board with multiple patient/participant representatives in addition to clinician and other experts in the module's content area.

7. Researchers who serve on the HERN Steering Committee have already committed to including all Steering Committee members as funded consultants on each module. We also encourage new projects to include at least one team member from an institution in the Network besides the home institution of the primary applicant. This team member might function as a co-PI, co-investigator, coding buddy, or project-specific advisory board member. Researchers wishing to first join the HERN network must include an experienced HERN steering committee member in their first module as co-PI, co-investigator, or coding buddy.

8. To assure our Network continues to adapt as we learn, these Principles should be re-visited and revised annually.

Procedural Requirements for Researchers Seeking to Join HERN to Produce a New Module

Organizations or teams that aspire to membership in the HERN are encouraged to seek consultation from the Steering Committee regarding selection of topics and from the Learning Network regarding research methods prior to applying for funding.

Researchers seeking to join the Health Experiences Research Network must:

1. Adhere to Sections 3 and 6 of HERN's adopted by-laws document (see attached).
2. Have an established track record in health experiences research.
3. Review and be prepared to commit to the DIPEx International Guidelines and HERN Practice Guidelines 1-7 (see above).
4. Include funding for HERN-related expenses related to website development, the Learning Network, and the on-going costs of running the Steering Committee.
5. Once approved to proceed, the proposed module's qualitative research lead will join a meeting of the Qualitative Research Subgroup to discuss a plan for training in the DIPEx methodology; for including an experienced HERN researcher on the study team; for on-going participation in HERN's Learning Network throughout implementation of the project; and for seeking Steering Committee approval prior to publishing study findings as a module on HERN's website.

On-going Tasks for the Qualitative Research Subgroup

- This committee is tasked with the goal of ensuring the rigor of methods used by all HERN members, Specifically, the Committee is responsible for
    - (a) Assuring that all research teams affiliated with HERN have been suitably trained in DIPEx methods (along with adaptations developed for modules based in the U.S.)
    - (b) Working with each research team as they field their initial modules, in accord with Section 6 of the by-laws and
    - (c) Reviewing and advising on drafts of the modules as they are being completed.