

Healthy African American Families Community Participatory Research Collaboration Agreement DRAFT 1/26/04

Healthy African American Families (HAAF) promotes community participatory research in service of improving the health of communities of color. This Collaboration Agreement establishes the principles of community participatory research that are generally applied in HAAF projects with academic partners. Under this agreement, HAAF serves as a guardian for these research principles on behalf of community, and facilitates the equal participation in community research of collaborating communities and academic partners. Each project may involve different partners and a different scope of work. An agreement for a particular project consists of the following:

- 1) A research collaboration agreement concerning the principles and broad terms of research;
- 2) a specific project description, including any special features that affect the scope of the agreement or modify its participatory nature;
- 3) a signature list for the main academic partners and HAAF on behalf of its community partners (with other signatures possible depending on project scope); and
- 4) a list, updated as the partnership expands, of participatory community partners on the Support Council who assert by signing the partnership list, that they have read and agree to the terms of partnership under this agreement.

PART I: Partnership Principles and Procedures

Community Participatory Research Principles: This project will follow principles of community participatory research (Minkler and Wallerstein, 2002). The underlying principles are:

- 1) The project seeks to enhance the community's welfare through empowering the community to address its own health issues.
- 2) The project will be designed to increase community knowledge of the issue.
- 3) Community and academic participants will be involved in all project phases, including planning, implementation, research and evaluation, analysis, interpretation, and dissemination.
 - a. Community participants and academic researchers contribute to the shaping of the project issues and scope.
 - b. Interested members of the community and community agencies will be provided opportunities to participate in the research process.
 - c. Project membership is considered to be open or inclusive of those who wish to join and are willing to participate actively, rather than closed or exclusive in membership.
 - d. Each project will have a Support Council, consisting of HAAF, its academic partners for the project, and major participating community organizations who agree to commit to regular meetings and an oversight role. The Council will be co-lead by HAAF and an academic partner; a community organization co-lead may also be designated if appropriate to the particular project. This is most likely when that partner has initiated the request for a particular project. The Council will be convened by the co-chairs or their designees from within the same organization. The Council which will attend to barriers to participation, and uphold the principles of this agreement. Depending on scope of the project, the project may also have an Executive Council as a subset of the Support Council that sets the frame for key stages of the project.
 - e. All participating members (academic and community participants) are acknowledged as having expertise and commitment that is relevant to the scope of the project.
 - f. Community participants will be partnered with academic participants in analytic issues, including interpretation, synthesis, and verification of conclusions, and supported as needed in the research and scientific methodology.

- g. Community participants will be partnered with academic participants in identifying the relevant project outcomes.
 - h. The project will periodically assess the experience of participating for community and academic participants and attend to their concerns.
- 4) The project may consider the political, social, and economic determinants of the main health issue addressed by the project.

Mechanisms to voice and resolve differences of opinion or concerns about fairness of the process will be implemented through the Support Council, and each participating agency will have one vote.

- 5)
- 6) Dissemination of the research results will be the responsibility of all project participants, and academic and community partners will have opportunities for presentations and publications, under the governing conditions of the Council (see below).

Rights, Conflicts, and Responsibilities: Acknowledging that conflicts in partnership most commonly arise over financial matters, credit for work, and responsibility and opportunities for publication and dissemination, the following sections present principles and models for handling those issues within the project.

Financial Arrangements: Each partnership agency contributes to the project at least in part through in-kind contributions, particularly in development phases. Academic and community partners will work together to consider their specific needs for funding activities related to the project and their overall needs for financial stability. Participation in high-quality research evaluations of community projects may help achieve funding or other needs of participating partners. Most projects will require development of a funding plan. Plans for developing financial support for the project, including services and research, will be submitted to the Support Council for review for fairness and equity in relation to partner need given the project, prior to submission.

Authorship for Product and Publications Development and Presentations: This is a community-based participatory research project, in which academic centers and community agencies participate as full partners in all phases of the research and community project. This means that the project design, data collection, analysis and interpretation of data, publications, presentations, and other products will be generated with community participation. Participation of individuals in particular products will be based on participation in the work supporting the product, with oversight of the relationships and resolution of any disputes through the Council. We will follow usual journal guidelines regarding authorship on papers. Authors will be expected to contribute to papers and be responsive to reviewer concerns in a timely manner (i.e., within two weeks or as designated by the Council). Some papers may have a group of participants acknowledged with a shorter list of authors, spanning the major categories of participants. Research Works developed jointly by academic centers and community partners shall be jointly owned by all contributing partners, and decisions regarding marketing and distribution shall be jointly made by all contributing partners. In general, research works shall be disseminated for public benefit, either freely or at nominal charge to cover distribution/processing fees.

Ordinary journal policy is for the paper's first (or senior, sometimes last) author to decide on authorship list and order, but the Support Council will resolve disputes and has the right to review overall fairness of the process. At the Council level, the full Council will discuss and act as advisory, but the final resolution will be by majority vote among the main partners who have executed the Collaboration Agreement.

The Council may designate a committee to provide oversight for product and dissemination issues, and that committee will report to the Support Council. The Council will set a policy for authorship of

products from that project, after the formal project phase is concluded. The usual expected policy will be circulating the product/press release/presentation abstract to the co-signatories of the agreement for comments. A broader circulation list may be designated by majority vote of the Support Council.

Data Ownership: At the end of the project or at reasonable interim stages, each academic site, HAAF, and other community sites as appropriate, based on Council review and recommendations, will retain a copy of the full data file, de-identified appropriately. Issues of ownership of the data will be regulated by the Council. Any site owning data, or participating in collecting data for the project, must review its participation and role through their internal IRB and/or sign a certificate of compliance with the lead academic IRB for the project. All participating sites/partners will receive a summary of the data even if their involvement is minimal and they are not entitled to the de-identified, full data file.

Internal Review Board Responsibility: It is requested that each participating community partner have at least one participating member (i.e., the Council representative) complete a certification of training for human subjects research through the lead academic partner's Internal Review Board (IRB) website (e.g., UCLA). Each participating partner should determine the status of its own IRB board, and develop plans to coordinate any IRB review through its agency with the review(s) of other participating IRBs.

Review of Papers, Products, and Press Releases: During the life of the project, submitted research papers and abstracts for presentations will be circulated to the Council and to lead participants of partner sites at least one week and preferably two weeks prior to their submission for review and comment. There will be a 5-10 day turn around time for comments to the lead author. Each product will have one or two lead individuals to permit accountability.

While input and full exchange among participating partners is encouraged, consistent with usual scientific policy, partners will not have the right to block submission or enforce changes on scientific papers. Rather, it is expected that the first or senior author of each project will review comments from partners, discuss major differences of opinion with the partners involved, and circulate the final version to partners. If substantial disagreements over interpretation remain, then the lead author (first and/or senior) will include a statement in the discussion section, clarifying the nature of the disagreement in interpretation among Council members for the project. The dissenting Council member(s) also have the right to submit a letter to the journal's editor for publication concerning their disagreement in interpretation.

Similarly, products for community release and presentation will be circulated for comments to community and academic partners, providing a one-to-two week turn around time.

Disputes concerning fairness in authorship or concerning the fairness of internal review, including adherence to the principles of this agreement, will be resolved in discussion by the Council. The deciding vote is by majority vote among the co-signatories of the Collaboration Agreement. The Council also has the right to request a review of disputes over scientific issues by outside scientists and community members. An author/project participant who is not a member of the Council also has the right to request that the Council grant an independent review.

The intent of this agreement is that a balanced consideration will be given to community and academic perspectives in interpretation and presentation. If necessary, the Council has the right to request, in advance of project development, equal academic and community co-leaders.

The Council will develop a plan for handling press releases to ensure coordination with press offices of academic and community partner agencies. For example, press release responsibilities may be handled by the organization of the lead author of a given product; may rotate among participating agencies with

press offices; or be delegated to one agency's press office, with coordinating support from other agency press offices. This issue may also be delegated to a dissemination subcommittee.

PART II Project Description: Witness for Wellness

The project “Witness for Wellness” is a community participatory research partnership project involving Healthy African American Families, UCLA Neuropsychiatric Institute, Charles R. Drew University, RAND, and the community agency partners of Healthy African American Families (HAAF)(see Part IV).

The purpose of the project is to improve the health of the South Los Angeles community, particularly among African Americans and Latinos, through improving community awareness of depression and the ability of community members and organizations to problem-solve to overcome barriers to detection and treatment of depression at the community level. An additional goal is to document the methods, processes, and outcomes of the project, through rigorous science within a community-based participatory research framework.

The project is expected to have several phases.

Phase One was a planning phase establishing a multi-agency Community Mental Wellness Council and framing the issue. This phase was initiated in May, 2003 and is ongoing.

Phase Two was the Witness for Wellness community conference at the Los Angeles Science Museum, July 31, 2003. This conference provided continuing education on depression and its treatment in communities of color and promoted dialogues among community members about the framing of depression, barriers to care, and strategies to improve care at the community level. The conference was evaluated by a pre- and post-survey and by recording the themes discussed in community break-out sessions.

Phase Three is post-conference planning for community work groups, under the direction of the Support Council.

Phase Four involves the tasks of several community-academic partnership work groups. The scope and membership of these groups are the subject of the post-conference planning, and will be shaped by the themes that emerged from the July Conference. Work groups, with facilitation by the Support Council, will have 12-18 months to conduct their community tasks, leading to at least one product for each work group, such as a community toolkit, policy brief, or media release. The work group process and outcomes will be the subject of a qualitative and quantitative evaluation. Some work groups may focus on evaluation issues, such as studying barriers to care at the community level.

During this phase, planning will also occur for a broader research evaluation of the changes expected to occur, and occurring, within the community as the result of the project. This will involve exploring alternative research designs and outcome measures, development of a logic model, and development of a funding plan for the research and program development, through the Support Council and Executive Council.

Phase Five will be a summative community conference to present the work and products of all the work groups, develop overall recommendations that incorporate community feedback, and formulate plans for implementation of recommendations. Prior to or at the time of this report, research funding will be sought for broad-based evaluation of implementation, using the design and outcome indicators developed and piloted in Phase Four. Other communities may be involved in this research, depending on the design.

PART III: Agreement Signatures

The following parties represent the main participating academic partners and HAAF on behalf of the community partners in this agreement. The signatures indicate agreement with the terms of this agreement.

(DATE)
Loretta Jones, Healthy African American Families

(DATE)
Keith Norris, Associate Dean for Research, Charles R. Drew University

(DATE)
Kenneth Wells, Director, UCLA-NPI Health Services Research Center

(DATE)
Paul Koegel, Associate Director, RAND Health Program

PART IV: Participating Community Partners

The following community partners are participating in the project described in this agreement as voting members of the Support Council (or other major role designated in the project). The signatures indicate that the terms of the agreement have been reviewed and will be adhered to while participating in this project.

HAAF STAFF:

LIST SUPPORT COUNCIL AGENCIES AND REPRESENTATIVES