



**ENGAGE FOR EQUITY (E2) PROJECT VALUES,
DATA SHARING, OWNERSHIP
AND PUBLISHING AGREEMENT**

FINALIZED AT ENGAGE FOR EQUITY NATIONAL RESEARCH TEAM MEETING
SEATTLE, JANUARY, 2017



ACKNOWLEDGMENTS

This document was adapted, in part, from the Research for Improved Health: Publication Guidelines (March 2011).

SECTION 1. INTRODUCTION

Members of the *Engage for Equity* (1R01NR015241-01A1) project have a unique relationship, which comes with the opportunity and responsibility to work collaboratively to protect and share our data, store that data, and share our experiences and results with others. This Shared Values, Data Sharing, Ownership and Publishing Agreement serves as a foundation for decision making and partnership among the national research team, as co-investigators in the Engage for Equity project (UNM, UW, RAND, NICWA, University of Waikato, CCPH), and Think Tank members. As our partnership has and will continue to grow, this Agreement serves as a foundation, guiding decisions around adding new investigators or students, data sharing, dissemination and publishing collaboratively.

For the purposes of this Agreement, data means primary source information gathered in the course of the *Engage for Equity* project. Moreover, the process of sharing information can take many forms – oral presentations in informal (community) and professional (tribal, government, conferences, classroom) settings; communications with the media; preparation of reports, grants, and manuscripts; and information on websites. Dissemination, or knowledge dissemination, is the process of presenting the research results back to the participating communities or partnerships as well as within the public domain. We equally value the opportunities to publish and disseminate academic as well as non-academic publications as equal forms of knowledge production and use. For this Agreement, the term “publication” refers to all forms of publication and dissemination of information, including presentations.

SECTION 2. AGREEMENT INTRODUCTION

Section 2.1. Mission and Goals

This Agreement emphasizes our core goals of promoting health equity and contributing to the knowledge and science of partnering practices in Community-Based Participatory Research (CBPR) and Community Engaged Research (CEnR).

Section 2.2. Project Values And Principles

We restate our values to be aligned with principles of social justice, diversity and inclusion. This Agreement is an expression of the principles of CBPR in the conduct of our research project and dissemination of the results. The data sharing, data storage, publication and dissemination of the research results will follow generally accepted principles, which include:

- Anonymity of Individuals and Partnerships: The research results will be presented in an aggregate



or grouped manner. That is, individual participants or partnerships will not be identified. For the report of aggregated data of each community-academic partnership who takes the Key Informant (KI) and Community Engagement Surveys (CES), the partnership has the right to decide if they want to be identified or not identified in the research results. In order to be named in the results, both community and academic partners must consent to be identified.

- Privacy and Confidentiality: All information collected from individual participants and partnerships will remain private and confidential.
- Respect: The cultural and intellectual integrity of any participating partnerships or projects must be respected in all publication and dissemination. Concerns can be brought to the publications committee, which serves as an oversight committee, as needed.

SECTION 3. RESPECTIVE RESPONSIBILITIES

Section 3.1. National Research Team (UNM with subcontracted partners)

Opportunities exist for everyone involved in the national research team to be involved with publication. At regular intervals, the team will brainstorm a list of potential articles and other dissemination venues, and team members can elect to join to different publications teams. National team members volunteering on specific sub-committees (e.g., quantitative data, intervention, and so on) can also express an interest in leading a manuscript or be part of the writing team. Research team members can be involved in different ways, from active writing and editing, to consultation and review of conceptual matters. Authorship order, as much as possible, will be negotiated at the onset of the publishing process.

Section 3.2. Think Tank

Similarly, opportunities exist for Think Tank members (see appendix A) to be involved in writing and publishing efforts. These can occur in several different ways. First, a newsletter will circulate biannually describing project updates, manuscript development ideas and/or other dissemination efforts such as a conference abstracts. If interested, Think Tank members can contact Principal Investigator (PI) Nina Wallerstein, who will connect the Think Tank member with other authors if needed. Second, Think Tank members participating in subcommittees can also express interest in publication efforts emanating from such committees' work. Think Tank members can be involved in different ways, from active writing and editing, to consultation and review of conceptual matters. Authorship order will be reflected accordingly.

SECTION 4. DATA RELATED ISSUES

Section 4.1 Involvement in data collection

The UNM team, including Nina Wallerstein (PI), Shannon Sanchez-Youngman (co-I), Blake Boursaw (co-I, statistician) and Monique Jaquez (program coordinator) and Elizabeth Dixon and others, under the supervision of Blake Boursaw, have overseen data collection (see Appendix for names). Data collection procedures are in accordance with Institutional Review Board (IRB) regulations and approvals from the University of New Mexico Health Sciences Centers (UNM Study # 16-098). Approval for new team members' involvement in data collection is based on IRB requirements.



Section 4.2. Data ownership and data sharing

A UNM data use agreement that involves data transfer and sharing of complete data sets was signed in 2016 by Dr. Wallerstein as PI and by two members of the national research team, Drs. Leo Morales and John Oetzel. Any other national research team members who want access to the full data set will need to contact the PI and complete UNM data sharing agreements. The individuals who have access to the analyzed aggregated data are the full national research team members and others, such as students or new members of partner research teams, who will have to be added to the IRB. Identifying information will be removed before entry into any database.

Section 4.3. Data storage

Personally-identifiable information associated with the web-based KI or CES surveys will be maintained to enable participant follow-up, but no personal identifiable information will be downloaded or shared out of REDCap. The online KI and CES survey data will be stored using a password-protected, encrypted University of New Mexico, College of Nursing laptop computer. Dr. Oetzel will receive access to REDCap but will not be able to see identifiers. Dr. Morales and all others will be sent encrypted versions of data sets by email, with encryption keys sent in a separate email.

Section 4.4. New data collection, analysis or proposals

Team members interested in new data collection efforts, data analysis or modifications to the existing protocol, or use of data in other proposals should contact the PI. Interested parties should submit a brief proposal detailing the aims of the project, timelines, team members, significance, and any other important information relevant for review. Proposals must be in line with the existing project aims and values. Those proposing new data collection efforts or modifications to the existing protocol will be responsible for needed IRB materials and for additional financial costs related to the project.

Section 4.5: Obligation to NIH

Data sharing policies of this Agreement are in compliance with National Institutes of Health (NIH) standards where “in general, recipients own the rights in data resulting from a grant-supported project” unless the award specifies alternative rights. Materials developed with the award can also be copyrighted without NIH approval. Moreover, NIH stresses the importance of data sharing as an essential component of advancing knowledge and improving health. For a complete NIH data sharing policy and resources please refer to: <https://grants.nih.gov/policy/sharing.htm>

SECTION 5. PUBLICATION AND WRITING

In connection with the Project, the parties agree to establish a Publications Committee whose function shall be to review and decide matters pertaining to the distribution and use of research data and to the scholarly and other publication of the results of the research. All Committee decisions will be consistent with the terms of any approvals of the relevant IRB and tribal government as well as NIH and University publication policies, the terms of the grant supporting the project, and usual and customary academic standards pertaining to scholarly publications.

The Committee's membership will include the six PIs from the main grant (UNM) and subcontracts (University of Washington, University of Waikato, National Indian Child Welfare Association, Community



Campus Partnerships for Health, RAND). Approval of manuscripts by this Committee will provide the PI with a sense of which team members are interested in the potential topics and will help to avoid drafting similar or overlapping papers, submitting papers to the same journal, and publishing articles in an illogical sequence. In order for manuscripts to be reviewed for approval, an abstract including potential authors and a timeline for completion should be submitted (see below for full guidelines).

Section 5.1. Dissemination and Publication Responsibilities

Role of Principal Investigator

The Principal Investigator (PI) will facilitate the review of proposed publications with the Publications Committee. All research results and knowledge generated by this project will be presented, discussed, and approved by the Publications Committee before the results are disseminated externally to the general public, including scientific publications and conferences. If *Engage for Equity* publications also involve *Research for Improved Health* (RIH) data, the RIH publication review and approval processes will also be followed.

Publications and Writing Teams

At regular intervals, the national research team will brainstorm articles for publication, with opportunities for people to express interest in being lead author or members of the writing teams. Once teams are formed, they will need to produce an abstract with an outline and send to the Principal Investigator based on the **Outline of Publication Process** (see section below). Consensus among lead author and co-authors pertaining to roles and responsibilities should be obtained at the earliest planning stages of the manuscript.

The UNM team will maintain a table document of currently in process manuscripts as well as future manuscripts. Both the national research team and Think Tank members will be kept apprised of articles and invited to participate periodically. Manuscripts in progress will also circulate on a biannual newsletter.

Criteria for Authorship

Lead author and co-authors must satisfy at least one of the following criteria to qualify for authorship:

- Individuals who have contributed substantially to the concept and design of the paper/research; synthesis of the literature review; analysis of the data; interpretation of the findings; or discussions and implications for future practice, research, or policy.
- Individuals who can provide essential expertise and offer suggestions to the development and implementation of the manuscript (e.g., academic, Indigenous knowledge, historical clarification, cultural relevancy, etc.);
- Individuals who review and make substantive comments/edits on at least one draft of the presentation/paper; or are part of a detailed discussion of the relevant content.

Authorship on the final publication will be modified, if necessary, to reflect actual work contributed before it is submitted for publication. Moreover, all authors must respect each of the following authorship responsibilities:

- Read and understand the overall manuscript;
- Work within the set timeline; and
- Approve the final draft of the manuscript.



Role of Lead Author

Identification of a lead author is based on the person's interest, willingness to do the work, and time available to complete the activity in the proposed timeline. It should be someone who:

- Coordinates the planning and development of the manuscript in collaboration with research team members;
- Provides a timeline for activities to co-authors;
- Ensures that co-authors outline their contributions and agree on their contribution before the writing process begins;
- Establishes that criteria for authorship and responsibilities are respected;
- Presents brief updates to Publications Committee on approved proposals;
- Forwards final draft to the PI for review;
- For oral publications, presents a post-presentation review to the Publications Committee; and
- Submits the manuscript to the scientific journal, obtaining signatures for disclosure, if necessary, and adheres to all journal submission requirements.

Student Authorship

If a student is writing a thesis or dissertation based on this project the student must follow the Student Involvement Protocol: (still being finalized).

Authorship Order

The lead author will be the first author listed on the publication. The publication writing team can modify authorship order if the responsibility and workload is rearranged. The first author is ultimately accountable for any information presented in a publication, and will propose the author list and order to the publication writing team for discussion and approval based on contributions to the final product.

Format

Knowledge can be disseminated in the following format(s):

- Manuscript in a scientific or peer reviewed journal, book chapter, monograph, etc.
- Oral or poster presentation of a manuscript at a scientific conference or meeting;
- Oral or written presentation to the community or multiple participating communities, including community leaders and program/technical staff;
- Regular *Engage for Equity* newsletter update.

When considering which journal in which to publish products, journals that pose the least difficulty or fewest barriers to community access should be explored first. When a decision is made, for reasons of attempting to influence scholars or funders, to publish an article in a journal that presents significant barriers to community access, the authors should identify ways to make the information accessible to community members, whether it be permission from the journal to share the article more broadly, free of charge, or the development of an article of similar scope and findings for parallel publication in another venue.



Submission Process for Abstracts and Manuscript Outlines

The decision to submit an abstract to a conference or manuscript for publication will be made by the Publications Committee. The Committee must review the abstract of all articles (scientific or for local media), posters and presentations, before the conference. The Publications Committee will return comments and a decision in one week for an abstract and two weeks for a manuscript. If the Committee does not return a decision within the specified timeframe, it is the responsibility of the lead author to follow up with the PI, who will make the final approvals.

Outline of Publication Process

The outline for publications to be submitted to the Publication Committee shall include:

- Date
- Publication deadline
- Desired journals (or other forms of publication for editorials)
- Short paragraph outlining the topic, including a research question and specific hypothesis
- Identification of lead author, co-authors, and supportive others, including roles they will play in this process
- (If applicable) Complete list of information/data needed for manuscript
- Publication timeline
- Dissemination activity (e.g., presentation, report, manuscript, web publications)
- Review time by the Publications Committee
- Expected Completion date

Sharing of Manuscripts Prior to Submission for Publication

From time to time manuscripts developed by authors teams may be shared prior to submission for publication. The PI will make the decision to approve/disapprove the distribution of the manuscript.

A draft manuscript must have:

- “Draft” and “confidential” watermarks
- A note that states “do not distribute”

If a draft is shared on a broader scale, then the author team may have to report that the data was reported elsewhere. The author team needs to review any pre-published reports that are widely distributed to ensure that they are not published elsewhere.

Publication Guidelines Acknowledgment

All those who contributed to the research project, but do not meet the authorship criteria, may be offered inclusion in the acknowledgment section of the manuscript. The lead author of the manuscript must acquire written permission from those who are acknowledged. An acknowledgement of the project PIs, Research Partners, administrative and staff members (who worked on keeping the project on task, budget and data management), and Think Tank should be included in all publications. All publications should also acknowledge the funding grant number (National Institute of Nursing Research: 1 R01 NR015241-01A1). If the data also draws from the previous *Research for Improved Health* study, the NARCH number should also be included: U261HS300293; 2009-2013. Finally, the participants (PIs and community partners) who so



generously answered all the questions asked of them should be thanked. Correspondence concerning the specific article should be addressed to the lead author of each product.

An acknowledgements paragraph can include:

The research described in this manuscript was chapter was supported in part by Engaged for Equity (1R01NR015241-01A1), funded by the National Institute of Nursing Research. We thank members of the research team, the Think Tank, and the academic and community partners who have participated in surveys and other data collection. If the manuscript also includes Research for Improved Health data, please add: The research in this manuscript was supported in part by NARCH V: (U261HS300293), with Indian Health Service in partnership with the National Institute of General Medical Sciences, National Institute of Minority Health and Health Disparities, National Institute on Drug Abuse, National Center for Research Resources, Office of Behavioral Social Sciences Research, National Cancer Institute, and Health Resources Services Administration.

SECTION 6. AGREEMENT PERIOD

This Agreement will be in effect from June 1, 2015, for up to five years after the completion of the *Engage for Equity* Study, which would place the end date at May 30, 2025. All parties agree to abide by the terms set forth in this Agreement and will act in accordance with the authorization procedures.

IN WITNESS WHEREOF, the parties have executed this Data Sharing, Ownership and Publishing Agreement. By signing below, I acknowledged I have read and understand this Agreement and abide by stated the guidelines:

Printed Name:

Title:

Name of Institution:

Role in project:

Signature

Date



APPENDIX A LIST OF ENGAGE FOR EQUITY STUDY RESEARCH PARTNERS

University of New Mexico

- (1) Nina Wallerstein
- (2) Shannon Sanchez-Youngman
- (3) Blake Boursaw
- (4) Elizabeth Dickson
- (5) Victoria Sanchez
- (6) Lorenda Belone
- (7) Magdalena Avila
- (8) Lisa Cacari-Stone
- (9) Patricia Rodriguez
- (10) Kasim Ortiz
- (11) Ihsan MI Mahdi
- (12) Abigail Reese

University of Washington:

- (1) Leo Morales
- (2) Bonnie Duran
- (3) Maya Magarati
- (4) Myra Parker
- (5) Nora Coronado

University of Waikato:

- (1) John Oetzel

RAND Corporation:

- (1) Paul Koegel

NICWA

- (1) Sarah Kastelic

CCPH

- (1) Al Richmond
- (2) Paige Reeves-Castro



APPENDIX B PUBLICATION COMMITTEE MEMBERS

All publications and abstracts shall be reviewed by:

Sarah Kastelic, NICWA, skastelic@nicwa.org
Paul Koegel, RAND, koegel@rand.org
John Oetzel, U. Waikato, John Oetzel <john.oetzel@waikato.ac.nz>
Leo Morales, UW, Leo Morales <lsm2010@uw.edu>
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APPENDIX C: THINK TANK MEMBERS