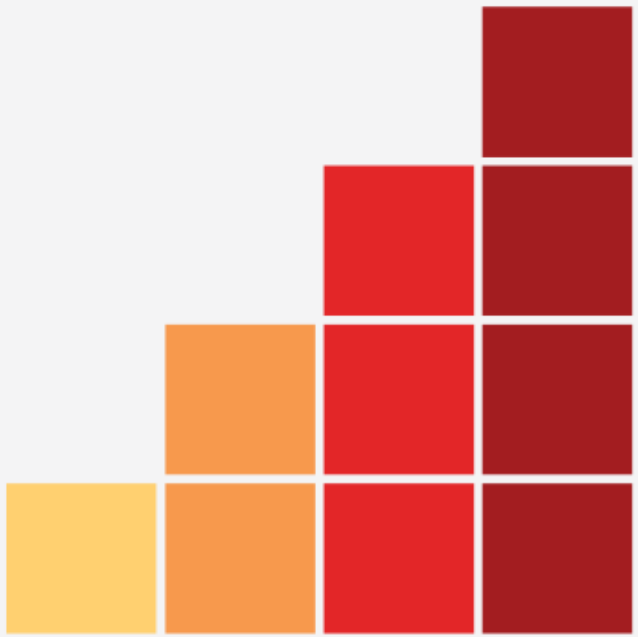


DATA ETHICS TOOLKIT

A Toolkit for Data Ethics in the Participatory Sciences

Editors
Caren Cooper
Lisa M. Rasmussen
Elizabeth Jones

citizenscience.org/data-ethics

2022

Students from many disciplines

from many countries

Generated a long list of ethical questions

- participant privacy and confidentiality
- location privacy
- commercial exploitation
- academic exploitation
- safety and liability
- open-access data
- intellectual property
- data ownership and stewardship
- data quality
- fraud
- gamification and persuasion

Caren Cooper

Created the Ethics Working Group

Association for Advancing Participatory Sciences

Citizen Science discipline	Ethical framework
Medicine	Traditional Human Subjects
Public health	Community-engaged Scholarship
Biodiversity conservation	Contributory design / traditional volunteering
Geography & Astronomy	Data-intensive principles
Biochemistry	Game design principles

Caren Cooper

Ornithologist and Social Scientist

Lisa Rasmussen

Philosopher

‘Ethics gap’ due to (1) no regulatory oversight and (2) lack of unity across multiple disciplines.

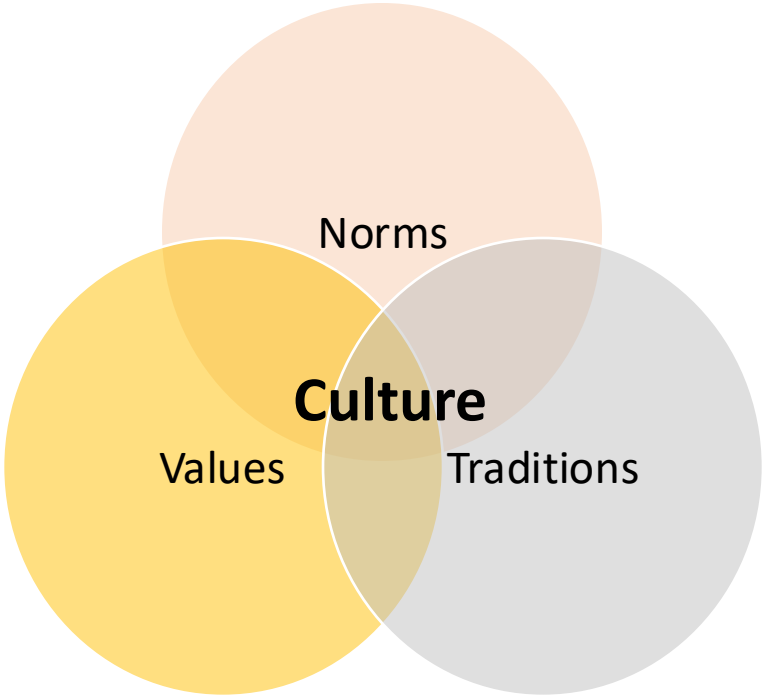
Aim: fill the gap with ethical norms and culture supported by a professional association.

NSF - Cultivating Cultures of Ethical STEM (CCE-STEM)

Training -----> Education

→

THINK LIKE
AN
ETHICISTS



→

\+ = Ethical conduct → Trustworthy Field

Elizabeth Jones

Science Historian

Acknowledgments

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BUILDING TRUSTWORTHY DATA PRACTICES FOR CITIZEN SCIENCE

ETHICAL RIGOR + TECHNICAL RIGOR = TRUSTWORTHY DATA

There are multiple ways to engage with the Toolkit:

Download the Toolkit

Download a printable PDF of the toolkit and accompanying worksheets and work through the worksheets by hand.

Download the Toolkit >

Earn an Ethics Badge

Work through the interactive tutorial version of the Toolkit and earn an ethics badge for completion. The tutorial, available through SciStarter, is divided into short lessons, which you can navigate sequentially or in the order of your choice.

Access the Tutorial >

Build an Ethical Community of Practice

By taking part in discussions, whether to get feedback and/or offer suggestions, you will become a valuable part of building an ethical community of practice together.

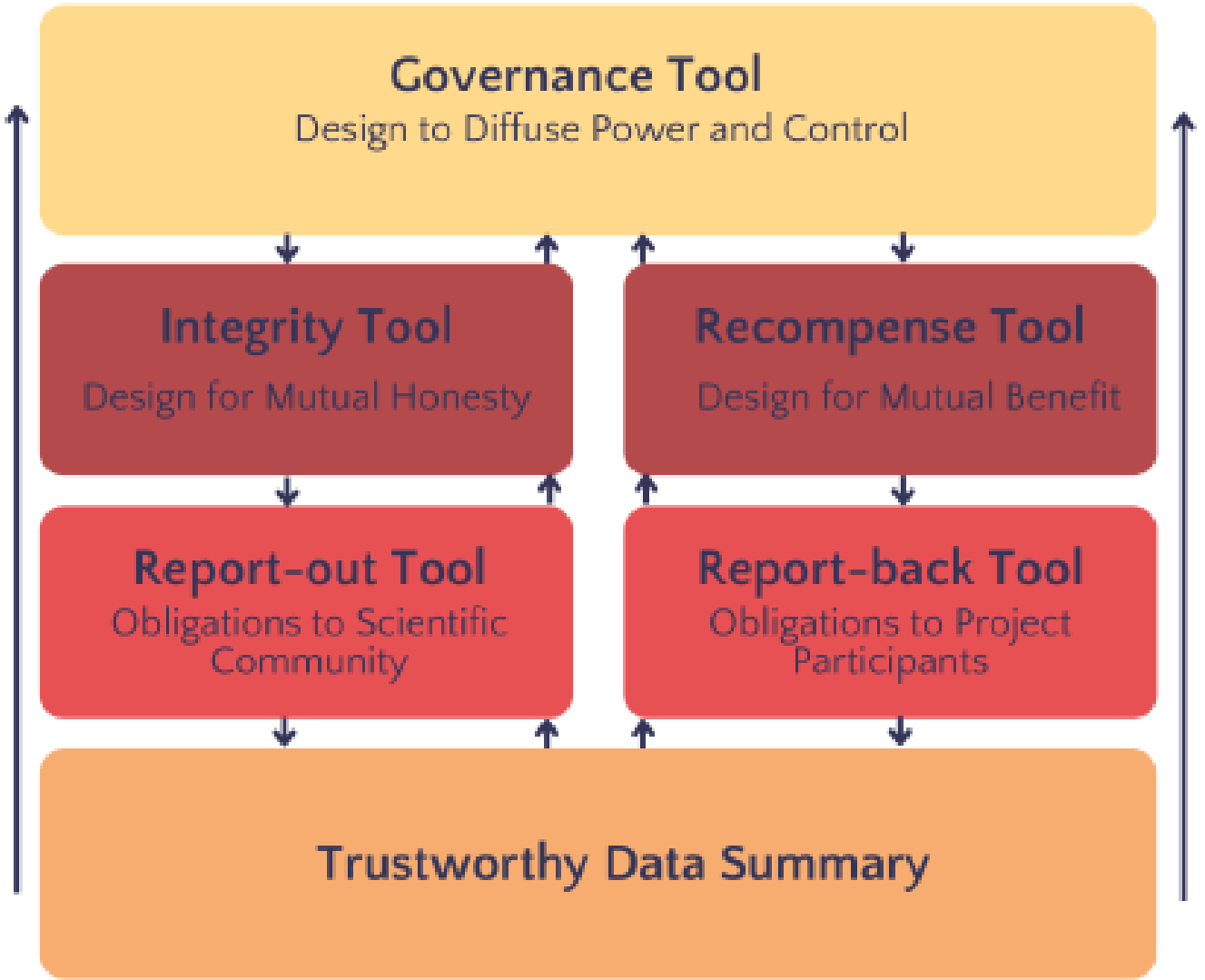
Join the Community of Practice >

scistarter
Science we can do together.

Download the Toolkit

Toolkit organization and interrelationships

Commitments to science



Commitments to participants

PERSPECTIVE article

Front. Clim., 06 July 2021
Sec. Climate Risk Management
https://doi.org/10.3389/fclim.2021.637037

This article is part of the Research Topic
Open Citizen Science Data and Methods
View all 28 Articles >

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Perspective: The Power (Dynamics) of Open Data in Citizen Science

Caren B. Cooper[1]*, Lisa M. Rasmussen[2] and Elizabeth D. Jones[1]

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COMMENTARY
10.1029/2022CSJ000025

Equitable Data Governance Models for the Participatory Sciences

Caren Cooper[1,2], Vincent Martin[3], Omega Wilson[4], and Lisa Rasmussen[5]

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Key Points:

- Common structure for data governance in participatory science is to centralize data and centralize decisions about data use/re-use
- Equitable structures for data governance in participatory science can centralize data while decentralizing decision-making

CITIZEN SCIENCE:
THEORY AND PRACTICE

A Positionality Tool to Support Ethical Research and Inclusion in the Participatory Sciences

ESSAY

CAREN COOPER
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JAN-MICHAEL ARCHER
HASIBE CABALLERO-GOMEZ
CHRIS HAWN
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GRAISE LEE JENNI
NA'TAKI OSBORNE JELKS
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ubiquity press

Equitable payments for research participation: A successful case of exceptionalism

Research Ethics
1–5

DOI: 10.1177/17470161251335426
journals.sagepub.com/home/rea
Sage

Lisa M. Rasmussen[1], Elizabeth D. Jones[2], Vincent Martin[3], Omega R. Wilson[4], and Caren B. Cooper[5]

> *Making decisions for the data within one's control requires acknowledging the ethical commitments and interests guiding your project.*

Addressing Privacy

There are several techniques that can help decrease or remove privacy risks that could harm people and/or the environment. These techniques vary, but include minimization (collecting only the data absolutely necessary for the conduct of the research), obfuscation (blurring of collected data to prevent privacy risks), and security (ensuring that access to information is controlled)

Findable
Accessible
Interoperable
Reusable

FAIR Principles

The FAIR Principles refer to data that are "Findable, Accessible, Interoperable, and Reusable." These are intended to promote open science and wide sharing of data through standardization of data sets. They may also be useful for purposes other than open science.

Collective Benefit
Authority to Control
Responsibility
Ethics

CARE Principles for Indigenous Data Governance

The CARE Principles are "Collective Benefit, Authority to Control, Responsibility, and Ethics." These principles arose in response to the FAIR principles, to acknowledge that open science practices as codified in the FAIR principles "does not fully engage with Indigenous Peoples rights and interests" (https://www.gida-global.org/care). For example, in some cases, the need for increased control, especially to enable community benefit or limit how the data are used, is balanced with open science.

Pause and Think

Can you think of ways in which a project leader's positionality might differ from the positionality of participants and partners?

Tips:

- *The project leader might come from a high-biodiversity area, while participants' environment may lack biodiversity.*
- *The project leader may be able-bodied while participants may have impairments.*
- *The project leader may prioritize insights from quantitative data while participants value insights from stories and other qualitative data.*

Pause and Think

How can projects be structured so that participants retain some control of their data?

Data Governance Decision Making Structures

Concentrated Control
Participants contribute data to a central entity, who also makes and executes decisions about data

Shared Control
Representatives of participants help make decisions about data use/reuse

Individualized Control
Participants share data but retain authority over its use/reuse

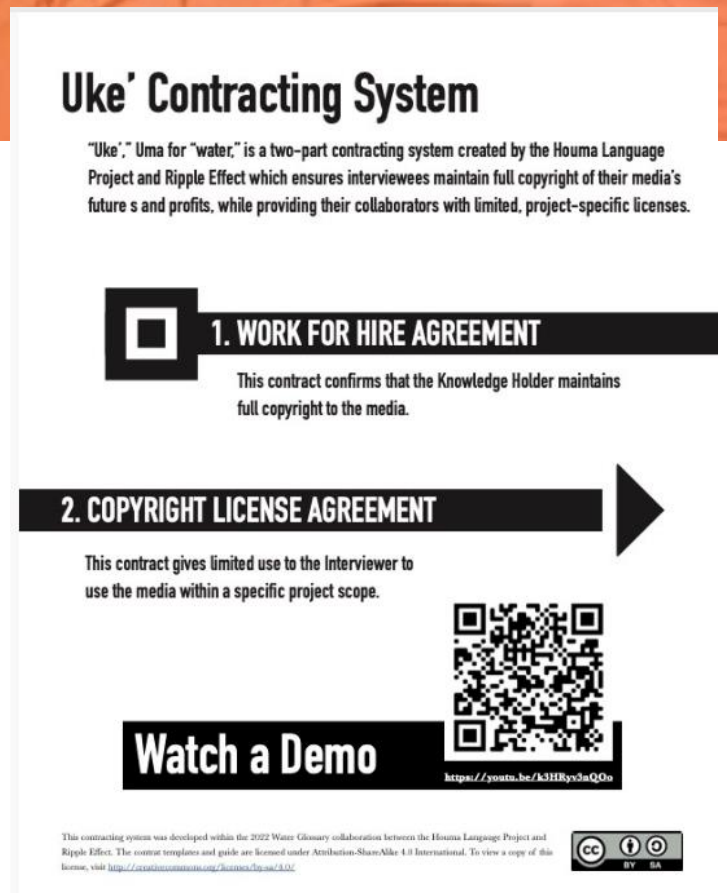
In the worksheet accompanying this tool, project leaders are invited to decide what general data governance structure is appropriate for their project. Projects may require different governance structures at different decision points, so supporting tools in this toolkit will revisit and build on this foundation.

Bottom Line

Project leaders are data stewards accountable for executing data governance decisions. To identify and address ethical issues in data governance, project leaders should establish governance structures to diffuse the concentration of power and control.

Next Steps

Uke' Contracting System



Uke' Contracting System

"Uke'," Uma for "water," is a two-part contracting system created by the Houma Language Project and Ripple Effect which ensures interviewees maintain full copyright of their media's future s and profits, while providing their collaborators with limited, project-specific licenses.

1. WORK FOR HIRE AGREEMENT

This contract confirms that the Knowledge Holder maintains full copyright to the media.

2. COPYRIGHT LICENSE AGREEMENT

This contract gives limited use to the Interviewer to use the media within a specific project scope.

Watch a Demo

https://youtu.be/k3HRyv3nQOo

This contracting system was developed within the 2022 Water Glossary collaboration between the Houma Language Project and Ripple Effect. The contract templates and guide are licensed under Attribution-ShareAlike 4.0 International. To view a copy of this license, visit http://creativecommons.org/licenses/by-sa/4.0/

- Developed in context of Oral Histories
- Adapting it to participatory sciences

Caren Cooper