RESEARCH ETHICS & CITIZEN SCIENCE

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INTRODUCTION

A FRAMEWORK

INTRODUCTION: FRAMEWORK

- "Trust the science!"
  - What does this mean for experts?
  - What does this mean for non-experts?
- Research Ethics: focuses on ethical norms or principles that can help to secure trust in scientific inquiry.

INTRODUCTION: FRAMEWORK

- Research Ethics: focuses on ethical norms or principles that can help to secure trust in scientific inquiry.
  - Human subjects research
  - Non-human animal research
- Broad question: what are the ethical norms or principles that ensure the responsible conduct of research?

INTRODUCTION: GOALS

- Understand key principles governing human subjects research
- Understand unique ethical challenges for research ethics emerging from citizen science
- Understand the need to develop an ethical framework for trust in citizen science research

INTRODUCTION: STRUCTURE

- On Research Ethics
- Human Subjects Research and Trust in Science
- Ethical Challenges in Citizen Science
- Research Ethics and Trust in Citizen Science

ON RESEARCH ETHICS

ESTABLISHING TRUST

RESEARCH ETHICS: ESTABLISHING TRUST

- Ethical research enables trust by safeguarding structures that serve the epistemic aims of scientific inquiry.
- Ethical research enables trust by safeguarding structures that promote the collaborative nature of scientific inquiry.
- Ethical research enables trust by safeguarding structures for socially responsive and accountable inquiry.

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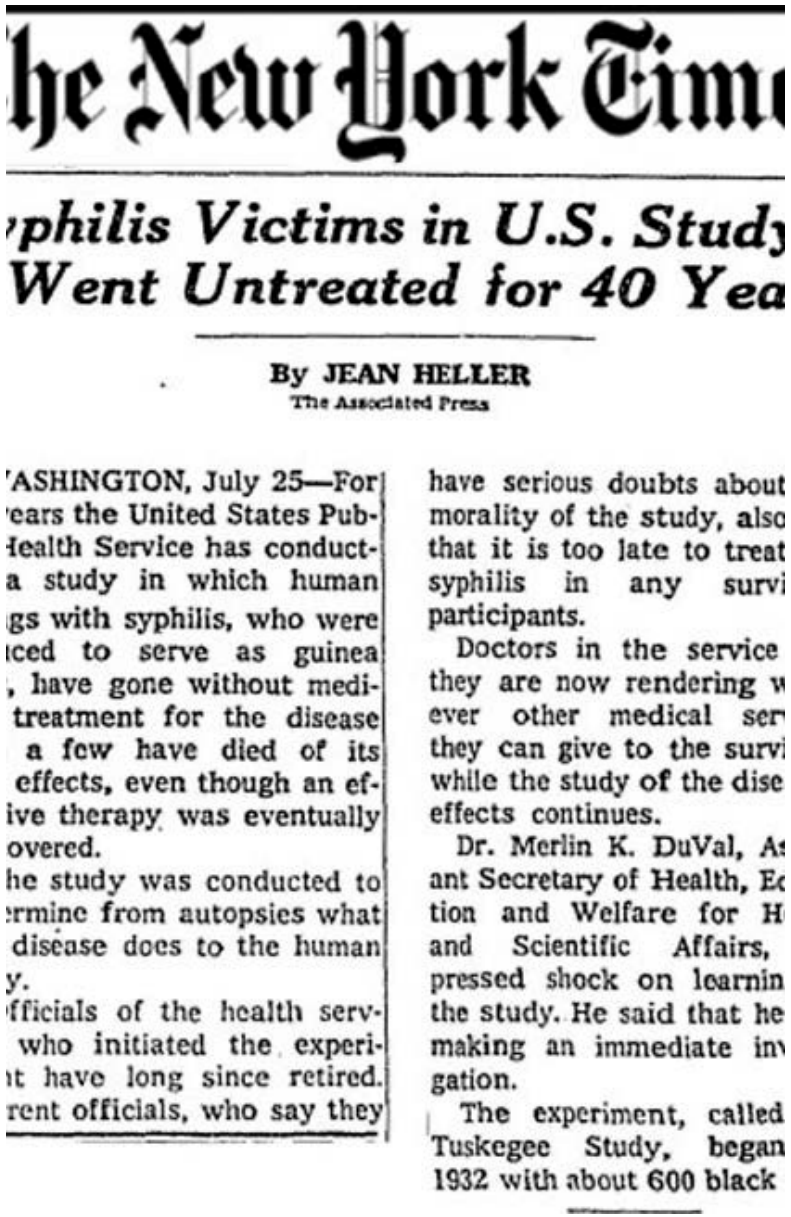
HUMAN SUBJECTS RESEARCH

KEY PRINCIPLES AND TRUST



he New York Time

yphilis Victims in U.S. Study Went Untreated for 40 Yea

By JEAN HELLER
The Associated Press

'ASHINGTON, July 25—For ears the United States Pub- Health Service has conduct- a study in which human gs with syphilis, who were ced to serve as guinea , have gone without medi- treatment for the disease a few have died of its effects, even though an ef- ive therapy was eventually overed.

he study was conducted to ermine from autopsies what disease does to the human y.

fficials of the health serv- who initiated the experi- t have long since retired. rent officials, who say they have serious doubts about morality of the study, also that it is too late to treat syphilis in any survi participants.

Doctors in the service they are now rendering w ever other medical ser they can give to the survi while the study of the dise effects continues.

Dr. Merlin K. DuVal, As ant Secretary of Health, Ed tion and Welfare for H and Scientific Affairs, pressed shock on learnin the study. He said that he making an immediate inv gation.

The experiment, called Tuskegee Study, began 1932 with about 600 black

Public Health Reviews, Vol. 34,

Ethical Failures and History Lessons: The U.S. Public Health Service Research Studies in Tuskegee and Guatemala

Susan M. Reverby, PhD[1]

STRACT

ethics is often thought of as having been "born in scandal and raise tectionism." Less often acknowledged is that bioethics has been so nourishe lodramatic frames that the effort to provide a different form of analysis has blematic. Using examples of the author's scholarship on the history and cove he United States Public Health Service's untreated syphilis study in Tusk 32-72) and its sexually transmitted diseases inoculation research studi atemala (1946-48), these histories of medical malfeasance, governmental ch, and the use of racist and imperial power are examined for the limitatio otional understandings of "bad scientists" and failures to obtain consent. ued that these two tragedies, which have provided an explanation for susp medical and public health research, need to be understood in the conte earch hubris and institutional power. They remind us of the necessity tection of human rights against dangerous excesses of zeal in human rese the need for researchers to imagine themselves in similar situations.

y Words: Bioethics, Tuskegee, Guatemala, United States Public Health Ser hilis, sexually transmitted disease, media

ggested Citation: Reverby SM. Ethical failures and history lessons: the blic Health Service research studies in Tuskegee and Guatemala. *Public H iews.* 2012;34: epub ahead of print.

HUMAN SUBJECTS RESEARCH AND TRUST

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- **The Belmont Report**: respect for persons, beneficence, and justice.
- **Shamoo and Resnick (2015)**: scientific validity, social value, informed consent, respect for persons, beneficence, equitable subject selection, protection for vulnerable subjects, independent review

HUMAN SUBJECTS RESEARCH AND TRUST

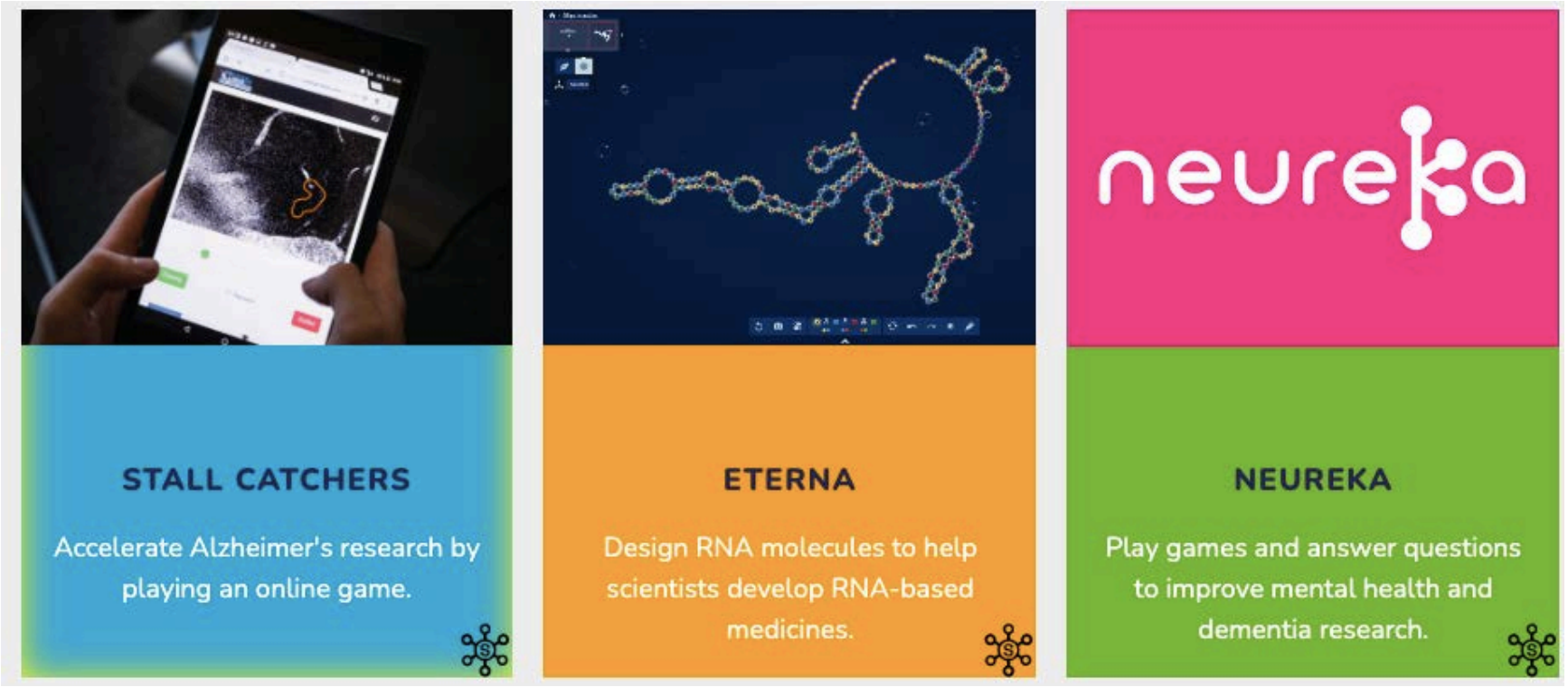
Rasmussen (2019 and forthcoming):

- Federal funding for research
- Connected to academic and medical research institutions
- Regulations to ensure compliance with ethical safeguards

CITIZEN SCIENCE

ETHICAL CHALLENGES

WHAT IS CITIZEN SCIENCE?



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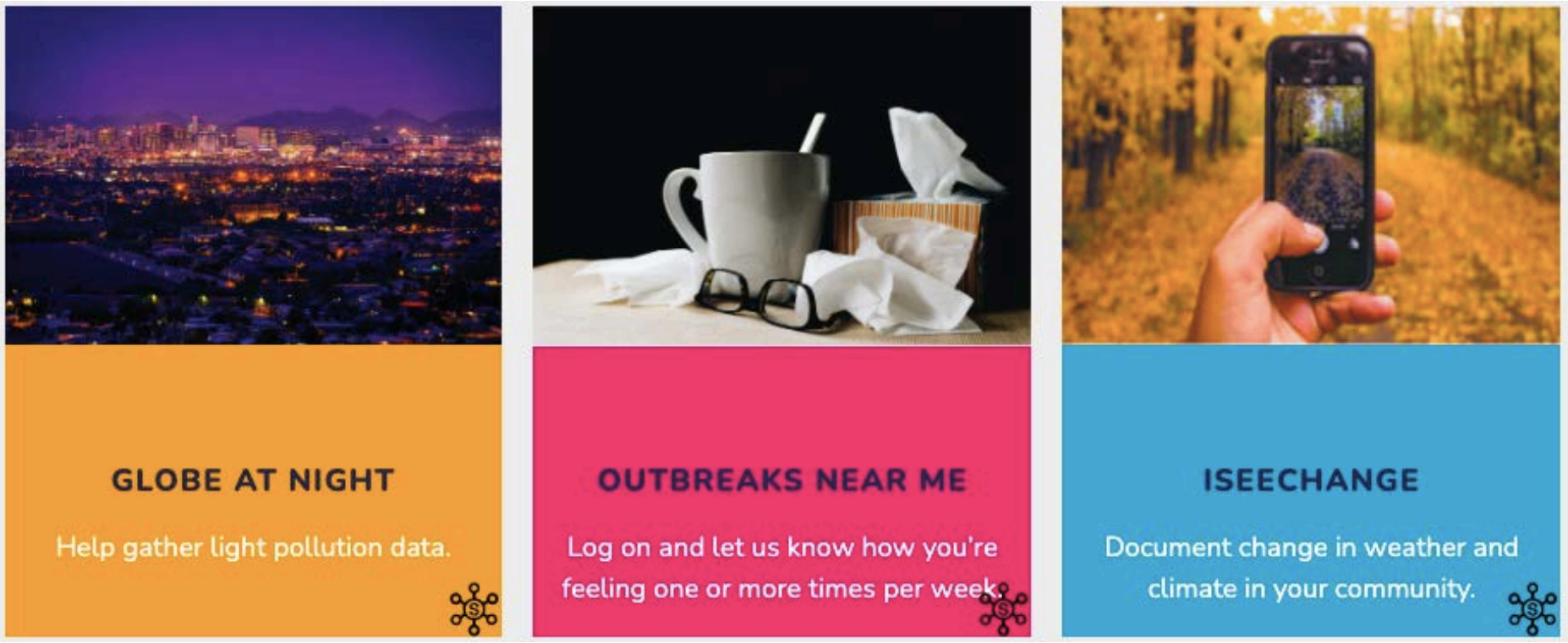

WHAT IS CITIZEN SCIENCE?

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- Collaboration between professional scientists and the public

  "In citizen science, laypeople are actively involved in one or more aspects of the research process, including research design, data collection, subject recruitment, data analysis and interpretation, or publication." (Resnik, Elliot, and Miller 2015)

- "Unregulated" research – outside of institutions and regulatory authorities (Rasmussen 2021 and forthcoming)

WHAT IS THE POTENTIAL OF CITIZEN SCIENCE?

- Potential benefits (Resnik, Elliott, and Miller)
  - Makes large studies possible (time, effort, labor)
  - Studies benefit from knowledge derived from proximity and interest of citizens/public in the outcomes of the study
  - Increases the value of studies *for communities*
  - Engagement and educational outreach
  - Democratize research processes

SOME UNIQUE ETHICAL CHALLENGES

- Can we trust citizen science as science?
  - Data quality, data sharing, accountability structures (peer review, research misconduct), conflicts of interest
- Can citizen scientists trust traditional scientific practices?
  - Accountability to community, labor, compensation, exploitation, credit, resources, power structures, data ownership, intellectual property

TRUSTING CITIZEN SCIENCE

AN ETHICAL NEED

TRUSTING THE SCIENCE

- Can we trust in citizen science as legitimate science worthy of broad trust?
- What if there is broad scale adoption of citizen science prior to the development of sufficient accountability structures?
- Draw back to the earlier work

QUESTIONS?

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