# HIV Research in the Age of Big Data: Developing a Framework for Community-Led Big Data Research through the Eng/aging Project

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## ISSUE

- *Citizen science*—active participation in collecting, analyzing, and sharing data by lay people with lived and living experience—has been pivotal to the history of HIV research[1] and has promoted community-based participatory research (CBPR) in health research more broadly[2]
- HIV researchers are now turning to *big data*, which has largely circumscribed citizen scientists. Long-established values and principles of citizen science/CBPR have not yet reached into big data science research
- Data science necessitates a renegotiation of the role of citizen science given two shifts:
  1. Data are typically not originally collected for research purposes
  2. Opportunity for collaboration comes after data collection
- As a result, big data reduces an ability to shape the conceptualization of research as well as data collection, including who gets asked, what gets asked, and how.
- As data science research becomes more popular, there is a need to develop new ways to engage people with lived and living experience in this form of research

## RESEARCH QUESTIONS

- How do we authentically engage people with lived/living experience in big data HIV research?
- What is the potential of citizen science in big data HIV research and what are the challenges?

## GOAL

Build a framework to transform extractive big data research into a collaborative dynamic of richly textured analysis of the lives of people with lived/living experience "in" the big data. We aim to ensure the historical contributions of HIV citizen scientists are not diminished via the realm of big data.

## Literature cited

1.Epstein, S. (1996). *Impure Science: AIDS, Activism, and the Politics of Knowledge.* Berkeley: University of California Press.

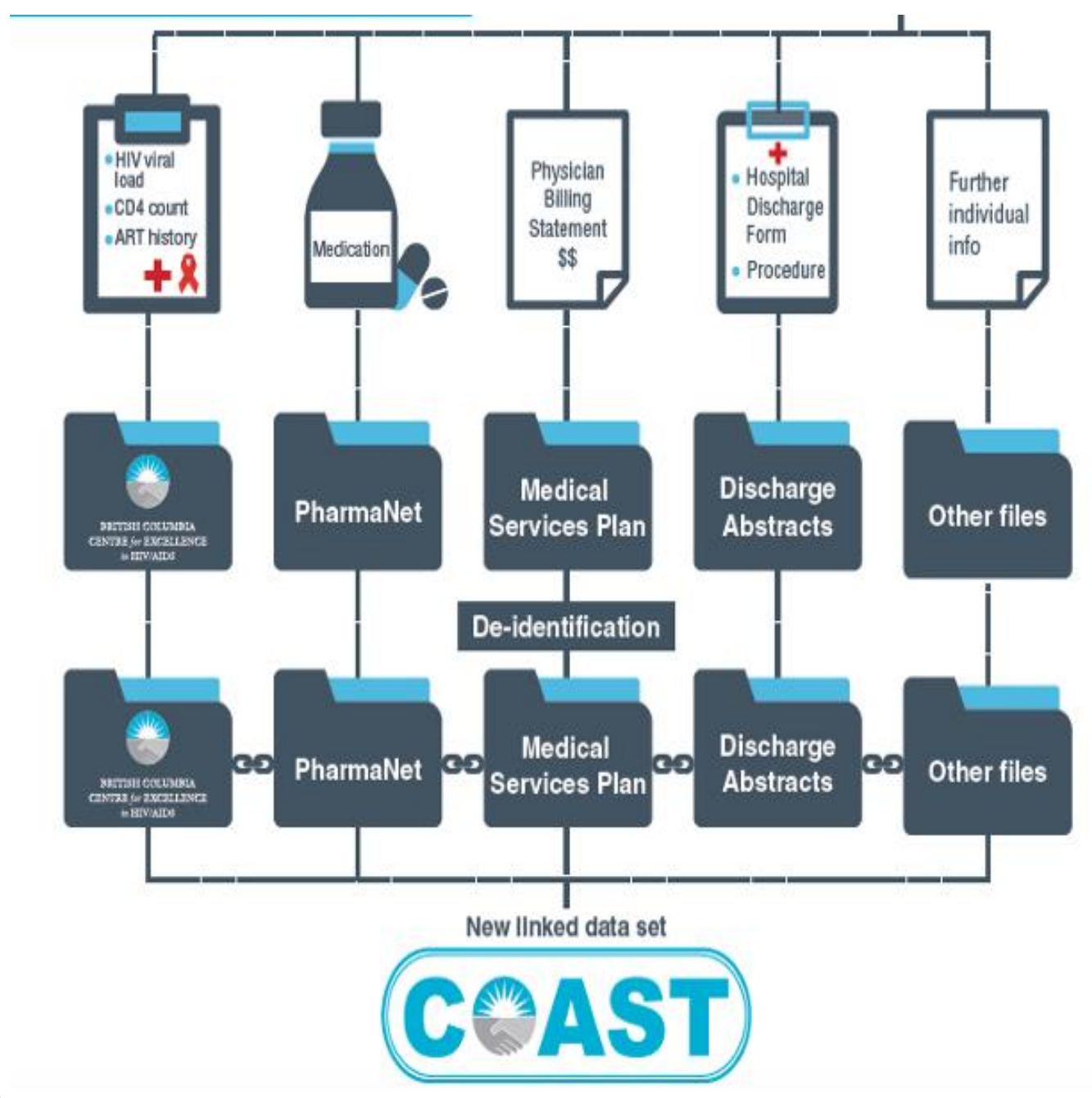
2. Guta, A., Strike, C., Flicker, S., Murray, S.J., & Upshur, R. (2014). Governing through community-based research: Lessons from the Canadian HIV research sector. *Social Science and Medicine, 123*: 250-261. https://doi.org/10.1016/j.socscimed.2014.07.028

## METHODOLOGY

**Eng/aging research team:** older adults living with HIV (peer researchers), data scientists, social scientists, and HIV clinicians

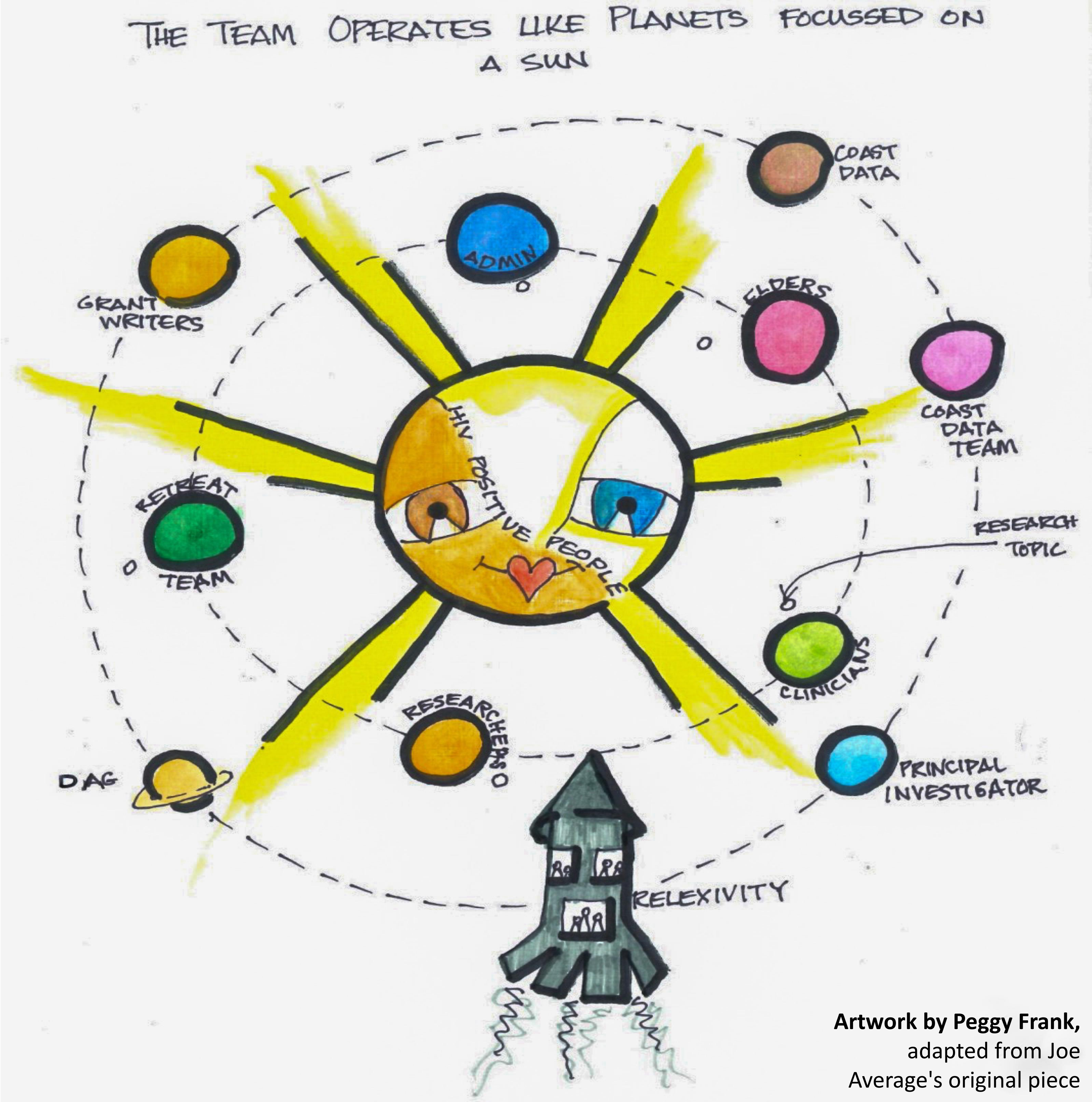
2 integrated, iterative research elements:

**1. Community-led administrative data research on recurrent cardiovascular events and HIV**



**2. Collective critical reflexive analysis of research process**

- Participant observation
- Critical analytical dialogue through *Gathering Wisdom* discussions



**Artwork by Peggy Frank,** adapted from Joe Average's original piece

Further information on the data sets used for this project is at: (https://my.popdata.bc.ca/project_listings/18-223/collectionapprovaldates). All inferences, opinions, and conclusions drawn in this material are those of the author(s), and do not reflect the opinions or policies of the Data Steward(s).

## LESSONS LEARNED

- Co-creating plainer language, graphic knowledge translations tools as the research develops (emergent design) built scientific literacy and critical understanding of administrative data research, which has been key to peer leadership
- Involving peer researchers with varying levels of research experience enabled community capacity to work through the complex, time-intensive analytic approach required of administrative data research
- Full team commitment to community-based research principles is necessary to reimagine conducting big data research (e.g. that is strength-based, and centers community concerns)
- **Community-led big data research is not only ethically sound but strengthens data veracity by being infused with lived/living experiences and reflective of community priorities**

**Figure 1:** Peer researcher, Peggy Frank, drawing "directed acyclic graph" with input of peer researchers behind her (out of frame)

**Figure 2**: Peer researchers, Peggy Frank, Elder Sandy Lambert, Patience Magagula, Valerie Nicholson, with Dr. Melanie Murray, writing out the team's research interests.

## NEXT STEPS

- As we continue our community-led administrative data research on "recurrence-free survival rates" among People Living with HIV in comparison to people living without HIV in BC, we will further our critical examination of our research process.
- We will bring our findings—about both our cardiovascular events research and our process of community-led big data research—back to the wider HIV community through Town Hall meetings. These discussions will help inform a framework for community-engaged big data HIV research, which can contribute to the practice of data science research more broadly.

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