

Expert knowledge from living experience: Applications to Directed Acyclic Graphs

Megan E. Marziali¹, Peggy Frank², Kathleen Inglis³, Wayne Campbell⁴, Sandy Lambert, Patience Magagula⁵, Valerie Nicholson, Michael Budu⁶, Melanie Murray^{7,8}, Silvia Guillemi⁶, Catherine Worthington³, Robert S. Hogg^{2,6}

INTRODUCTION

- Causal inference is not possible without background knowledge
- We rely on background knowledge being correct, as it is encoded in identifiability assumptions
- It is generally understood this **knowledge comes from academic subject matter experts**
- However, **people with living experience should also be considered experts**, providing unique and novel insights to causal questions

AIMS

- 1 To blend living experience with scientific domain knowledge and construct a directed acyclic graph (DAG) underpinning our research question about aging and HIV

Through approaching DAGs in this way, we hope to **challenge the notion of what constitutes "expert" knowledge**

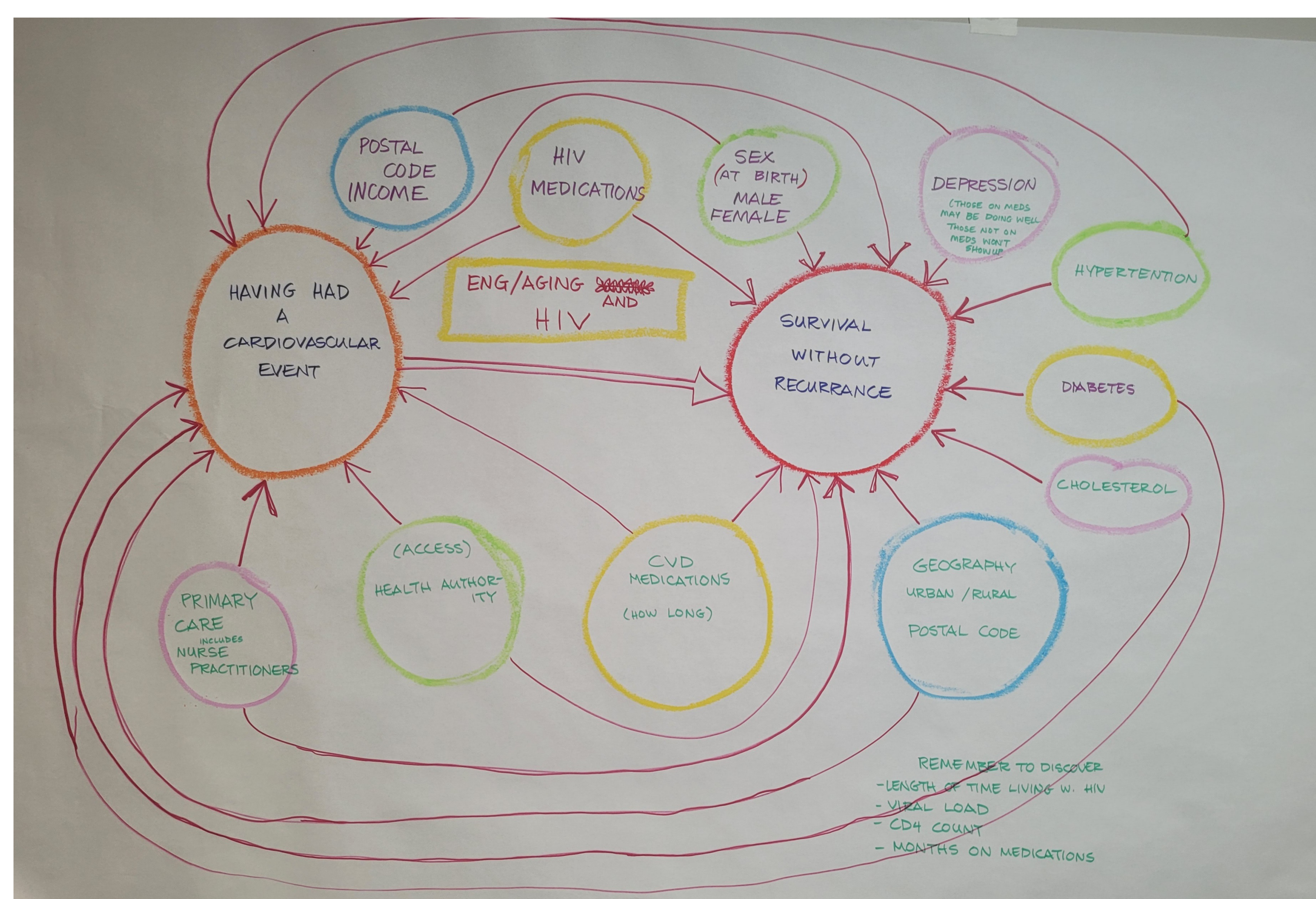
METHODS

- We organized a retreat where peer researchers watched short tutorials on building a DAG, to train peer researchers and other team members unfamiliar with DAGs
- Quantitative research team members created these tutorials to define types of bias (e.g., confounding, selection bias) and outline DAG rules
- The team worked together to create a DAG illustrated by a peer researcher-artist, combining the living experience of peer researchers with scientific and medical knowledge from quantitative researchers
- The DAG was refined with input from epidemiologist
- Qualitative researchers transcribed the process of learning about and drawing the DAG to understand how peer researchers engaged with this tool

Incorporating expert knowledge from living experience into Directed Acyclic Graphs (DAGs) is feasible, strengthens epidemiological studies, and humanizes our research.

RESULTS

Figure 1. Community-led Directed Acyclic Graph, drawn during the retreat, capturing ongoing conversations.

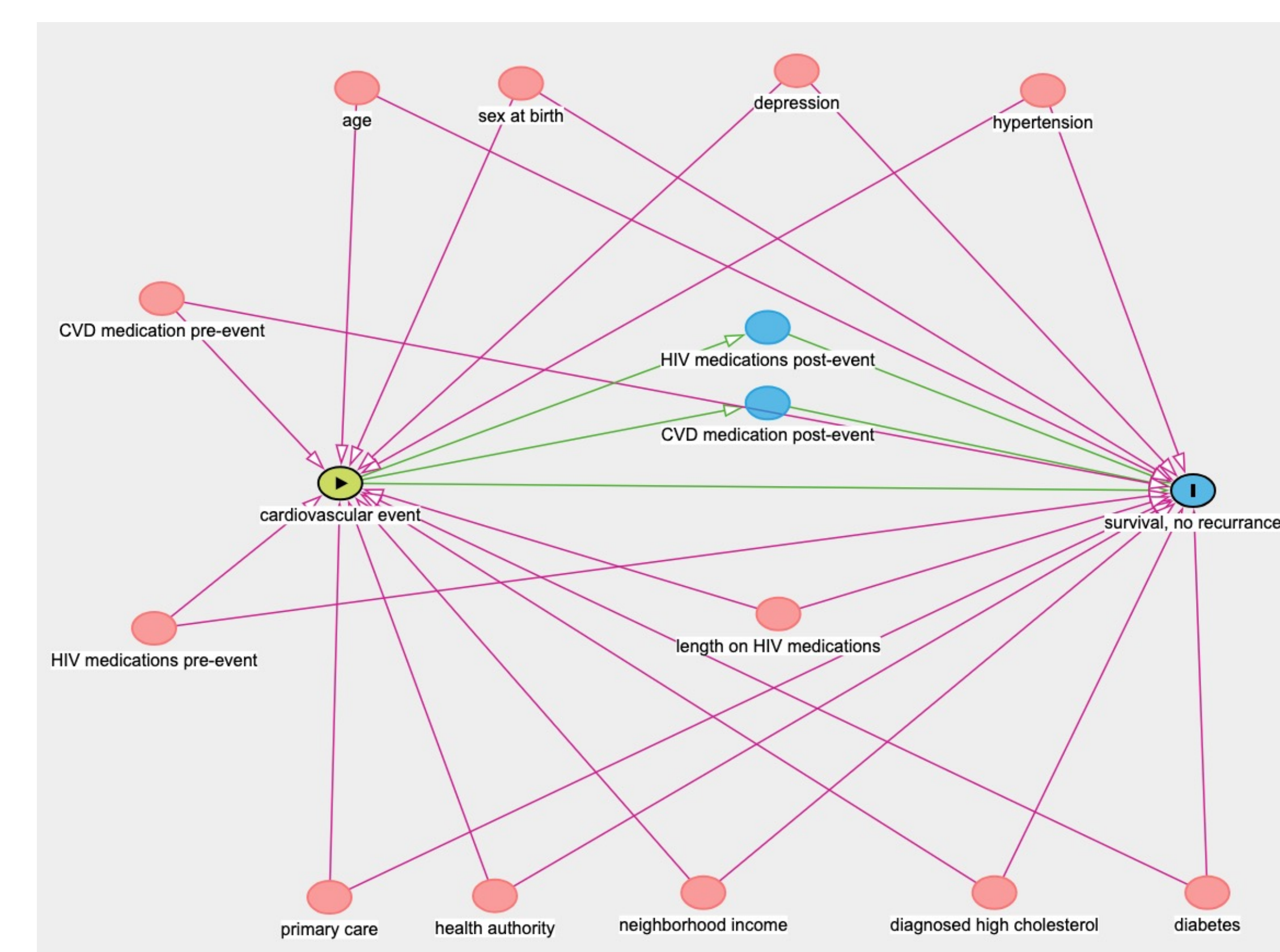


RESULTS (cont'd)

We present the community-drawn DAG in Figure 1 and the final DAG in Figure 2.

- Peer researchers found drawing DAGs intuitive
- Visualizing the temporal ordering of variables was a crucial moment in understanding the causal structure for peer researchers
- The complexity of the DAG enmeshed with temporal ordering humanized the research; **seeing the web of covariates resonated as a reflection of a person's life journey.**

Figure 2. DAG translated into Daggity



CONCLUSIONS

Administrative health data research often lacks a community engagement component. In addition, expert knowledge encoded in DAGs is often understood to encompass academic knowledge and not living experience.

We found that constructing DAGs incorporating living experience is feasible, ethical, and strengthens epidemiologic studies by reconceptualizing our definition of background knowledge and humanizing research.

Future research should consider appropriately incorporating living experience from peer researchers as expert knowledge when constructing DAGs.