Who is the expert? A process guide to incorporate lived/living experience into directed acyclic graphs: an applied example from HIV research

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ABSTRACT

Aim Causal inference relies on correct background knowledge, which epidemiologists generally understand to come from academic experts. Our community-engaged study augments scientific domain knowledge with lived/living experience to co-construct the directed acyclic graph (DAG) underpinning our team's research question about ageing and HIV. We outline our team's process for co-creating the community-based DAG and describe qualitative reflections from team members regarding these methods. Our overarching goal was to expand expert knowledge to include community expertise by engaging peer researchers in DAG co-development.

Methods We assembled a team of quantitative and qualitative researchers, including a diverse group of peer researchers living with HIV. The team co-constructed a DAG, illustrated by a peer researcher-artist, combining the lived/living experience of peer researchers with subject-matter expertise from academic researchers. The DAG was refined with input from epidemiologists. Qualitative researchers transcribed DAG co-development sessions to understand how peer researchers engaged with this tool.

Results Qualitative reflections allowed the study team to critically analyse our process. Peer researchers found drawing the DAG intuitive. Having a visual representation of causal relationships led to active discussion and greater understanding. The complexity of the DAG enmeshed with temporal ordering humanised the research; seeing the web of covariates resonated as a reflection of a person's life journey. One peer researcher found that incorporating diverse perspectives meant upholding unique expertise and not only platforming academic expertise.

Conclusions Co-constructing DAGs incorporating lived/living experience is reasonable and possible. Co-constructing DAGs may strengthen epidemiologic studies by reconceptualising the traditional epidemiologic definition of expert knowledge.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Causal directed acyclic graphs (DAGs) are widely used in epidemiology to illustrate causal theory and are beneficial for identifying potential confounders of the exposure-outcome relationship. DAGs rely on expert knowledge, often understood as arising from academic expertise, to outline the relationship between variables.

WHAT THIS STUDY ADDS

⇒ Errors embedded in DAGs through misspecifications of relationships between variables can bias effect estimates, prompting the need for methods to develop robust DAGs. We outline a novel method for co-constructing a community-led DAG, combining lay knowledge from people with lived/living experience and academic subject-matter knowledge, redefining expert knowledge in the process to include people with lived/living experience.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ We present qualitative reflections from this process, including recommendations and potential challenges in applying our method to other research questions; we demonstrate that the inclusion of peer researchers is possible and could strengthen epidemiological research.

INTRODUCTION

An estimated association cannot be interpreted as causal in the absence of exchangeability.[1 2] A source of non-exchangeability is confounding bias; conceptualising ways to minimise this bias is critical. Causal diagrams, such as directed acyclic graphs (DAGs), can be used to depict causal models and the theory underlying the causal structure. This allows for the identification of variables acting as sources of bias, such as the presence of common causes of the exposure and outcome (ie, confounders). However, information used to build DAGs, often referred to as expert knowledge, is limited when academics discount experiential knowledge. The addition of non-academic subject matter expertise could strengthen knowledge, in collaboration with academic and methodological experts, to build stronger causal theory. In this paper, we present an approach for engaging people with lived/living experience in co-constructing DAGs alongside academic researchers. We begin by parameterising expert knowledge, then detail the process to co-construct a DAG, reporting qualitative self-reflections.

It is imperative to appropriately depict causal theory underlying a DAG, such that researchers select confounders to best achieve exchangeability.[3 4] Generally, researchers rely on 'expert knowledge', understood to refer to academic subject expertise and published findings, and reasonable theory.[5] As detailed in guidelines for DAG-building, causal theory underlying the DAG should be developed from scientific evidence and expert knowledge gleaned from collaboration[3]; however, collaborations described are often restricted to academics and clinicians.[3 6] Similarly, some epidemiologists emphasise the importance of expert knowledge, yet stop short of defining an expert or considering from whom expert knowledge arises.[2 7] Further lacking from these guidelines are processes for engaging domain experts in DAG development.[8] Notably excluded from descriptions of expert knowledge and domain experts is reference to lived experience, or experiences that would grant expert knowledge outside of an academic context. Given the importance of expert knowledge to causal theory, and understanding that DAGs are only as good as the knowledge used to develop them,[9] a clear explication of sources of expert and subject-matter knowledge is required for strengthening DAG-building: restricting expert knowledge to academic subject expertise is a limitation.

Engaging peer researchers, meaning researchers actively engaged in a project who have lived/living experience of a health condition under study,[10 11] is crucial for adding unique perspectives to the data,[12] situating findings and disseminating results. Community-based researchers, and much of the broader research community, endorse the foundational idea that applied research embracing knowledge from lived/living experience produces higher value research outcomes than academic-driven research alone.[13–15] Peer researchers experience everyday realities that can inform questions, patterns, interpretations and limitations of statistical models used in research that might be overlooked by academic researchers without lived/living experience.[14] Epidemiologists often build DAGs using an etic perspective (ie, perspectives outside of those directly impacted by the research question), which aligns with the positivist research paradigm and the assumption that there is a single reality external to people (ontology) that can be measured and known objectively through scientific methods and quantitative data (epistemology).[16 17] Conversely, the inclusion of the emic perspective (ie, perspectives from the population under study) alongside the etic could strengthen DAGs. The emic perspective is aligned with an ontology that acknowledges that people interpret and make meaning of issues, events and health conditions and that sociopolitical forces shape ever-changing reality; further, it is aligned with an epistemology that recognises that knowledge can be generated through many ways in addition to statistical analyses (eg, personal storytelling).[14] Insider perspectives can help identify missing variables or variables conceptualised inappropriately.[16] Integrating emic and etic perspectives by including people with lived/living experience can improve research by strengthening knowledge.

While some research teams globally embrace this idea by working to engage various stakeholders when constructing DAGs (table 1), most studies default to engaging clinical experts: only three[16 18 19] of 10 studies identified through a brief literature review explicitly included people with lived/living experience. Further, when considering the spectrum of community engagement in research,[20] none of the identified studies were community-led (table 1), emphasising a need to incorporate community leadership into DAG methodology.

We hypothesise that parameterising expert knowledge to include perspectives from people with lived/living experience will strengthen the underlying causal theory in a DAG. In this manuscript, we propose a process for engaging people with lived/living experience in the creation of DAGs and describe qualitative reflections from team members, with the goal of developing novel methods for community engagement in studies using administrative health data. As an example, we present a DAG that our team drew in the context of HIV research, pertaining to the research question: to what extent does an initial cardiovascular (CVD) event impact recurrent CVD events among people with HIV?

METHODS

Study background

Our team developed this DAG through a community-led research project using administrative health data.[21] The parent project aims to examine the recurrence of CVD events among people with HIV in British Columbia, Canada, to improve healthy ageing.[22] The team, led by five peer researchers who are older adults with HIV, includes epidemiologists, data scientists, social scientists and HIV clinicians. The project was committed to de-centring academic subject matter expertise, whereby community members' knowledge is regarded as valid expertise.[23] Team formation is detailed in online supplemental 1.

DAG co-construction

The DAG was fully co-developed, including research questions. We summarise below the process for constructing a community-based DAG, with details outlined in table 2. Each phase, including the entire study team, was conducted in sequence. Concrete steps to de-centre academic expertise are presented in table 2; in brief, we aimed to provide peer researchers with the training and tools needed for this work.

Step 1: training

We planned an in-person retreat at an off-site location, enabling the team to spend 2 days co-creating the DAG. An epidemiologist provided a video tutorial explaining DAGs (key concepts outlined in online supplemental 2). Training was important to engage all team members in meaningful, collaborative research. Peer researchers led the conceptualisation of research questions, settling on: to what extent does an initial CVD event impact recurrent CVD events among people with HIV? (table 2). The team discussed how adding variables allows researchers to visualise the complex web of causation, framing causal theory.

Step 2: drawing the DAG

The collective hands-on process of drawing a DAG and talking through the relationships was essential to understanding its value for research. A peer researcher-artist drew the DAG on a sheet of paper taped to the wall (figure 1). Team members recalled variables of interest and discussed how they could be related (or not) to the exposure and outcome. An initial draft of the DAG is depicted in figure 2.

Step 3: refining the DAG

After the retreat, an epidemiologist facilitated the translation of the DAG into the Daggity software (online supplemental 3)[24] and refined the DAG (online supplemental figure S1). We iterated the DAG during online conversations, which allowed the team to spend time considering relationships between variables and include additional confounders. During this phase, we identified sources of unmeasured

Table 1 Examples of peer-reviewed research outlining methods for engaging a variety of stakeholders while creating a directed acyclic graph (DAG)

Author	Title	Country*	Stakeholder composition	Methods for engaging stakeholders
Andleeb *et al*[18]	Age-at-migration, ethnicity and psychosis risk: Findings from the EU-GEI case-control study	Brazil, England, France, Italy, the Netherlands, Spain	Four people with lived experience of migration and psychosis and/or mental health problems from ethnic minority backgrounds	► Identified confounders with input from a Lived Experience Advisory Group during project meetings
Cardoza *et al*[38]	Heat-Related Illness Is Associated with Lack of Air Conditioning and Pre-Existing Health Problems in Detroit, Michigan, USA: A Community-Based Participatory Co-Analysis of Survey Data	USA	Representatives from five not-for-profit organisations	► The research group (including academic partners) created an initial DAG ► The research team provided community partners with background on the utility of DAGs ► During a meeting of the community-academic partnership, the group co-selected potential confounders and expanded on the original DAG
Dang *et al*[39]	Developing DELPHI expert consensus rules for a digital twin model of acute stroke care in the neuro critical care unit	USA	Clinical experts (ie, clinicians from neurology, neurocritical care, emergency medicine and pulmonary critical care medicine)	► A steering committee composed of clinicians drafted the initial version of the DAG ► The DAG was iterated and revised by the same committee
Hasani *et al*[40]	Constructing causal pathways for premature cardiovascular disease mortality using directed acyclic graphs with integrating evidence synthesis and expert knowledge	Malaysia	Twelve experts: public health specialists, epidemiologists, a nutritionist and clinicians	► The research team began by constructing a DAG using evidence synthesis ► The research team used a Delphi method and interviewed each expert individually, presenting them with the proposed DAG in an in-person meeting ► After collecting feedback from the initial interview, the research team then conducted a second round of interviews using an online form to achieve consensus on the proposed causal pathways ► The online form used a Likert scale to score agreement regarding the included causal paths ► Researchers then applied the Fuzzy Delphi Method to the data from the online form to reach the final DAG
Hinwood *et al*[41]	Do P2Y12 receptor inhibitors prescribed poststroke modify the risk of cognitive disorder or dementia? Protocol for a target trial using multiple national Swedish registries	Sweden	Clinical experts	► Consulted clinical experts when creating the DAG to gain a better understanding of prescription patterns of the exposure
Houghton and Paniagua-Avila[16]	Why and How Epidemiologists Should Use Mixed Methods	UK, Bangladesh	Participants from qualitative interviewing	► Provide examples for how to incorporate knowledge gained from qualitative interviewing into DAGs, to inform the causal structure
Magrini *et al*[42]	A probabilistic network for the diagnosis of acute cardiopulmonary diseases	Italy	Clinical experts (physicians)	► Clinical experts identified variables to be included in the DAG ► Variables considered were grouped ► Edges were drawn between groupings of variables ► Additional edges drawn by clinical experts
Mascaro *et al*[43]	Modeling COVID-19 disease processes by remote elicitation of causal Bayesian networks from medical experts	Australia	35 domain experts defined as medical specialists (eg, respiratory and infectious disease specialists, clinical immunologists, cardiologists, renal specialists, primary care physicians)	► Literature review to identify necessary areas of expertise ► Recruitment of domain experts and an initial online survey to inform the potential causal model ► Sent participants background information on the models to be discussed during a workshop ► The goal of the online workshop, which ran for ~2 hours, was to produce a causal DAG ► Asked a standard set of questions about relevant variables in the proposed DAG and causal relationships between variables ► Ran an internal debrief for 0.5–1 hour, to refine the proposed DAG ► If additional clarification was needed, or disagreements were resolved, researchers scheduled individual meetings with domain experts ► If needed, the researchers scheduled additional meetings with supplementary experts ► Sent all refined models to domain experts

Continued

Table 1 Continued

Author	Title	Country*	Stakeholder composition	Methods for engaging stakeholders
Ramsay *et al*[35]	Urinary tract infections in children: building a causal model-based decision support tool for diagnosis with domain knowledge and prospective data	Australia	A range of clinical experts involved in treatment of children with UTIs (eg, experts from paediatric emergency medicine, microbiology and infectious diseases, general paediatrics, nephrology, epidemiology and medical laboratory science)	► Began with an initial causal model to present to domain experts ► Throughout workshops and collaborative meetings, domain experts provided feedback on the initial model. ► Relationships between variables were confirmed, corrected or expanded. ► Found causal relationships depicted to be intuitive and not controversial, such that moderated discussion was sufficient and allowed consensus to be achieved ► Final DAG refined by the core research team, with any further areas of uncertainty resolved via written feedback, individual expert meetings or internally within the core research team
Rodrigues *et al*[19]	Reflection on modern methods: constructing directed acyclic graphs (DAGs) with domain experts for health services research	England	20 domain experts including three patients, six healthcare professionals, six researchers, three commissioners from the NHS, two representatives from industry	► Ran an online workshop for 2.5 hours with 20 domain experts and three facilitators ► Began with a short presentation about the project and DAG methodology ► Split participants into three breakout rooms, with a set of discussion questions ► Ran two 30-minute breakout sessions, one with a 'brainstorming' phase, to create the first draft of the DAG, and the other with a 'refinement' phase, to refine the initial draft ► Regrouped for 15 min after each phase to present and discuss DAGs from each group ► After the workshop, the research team sent out a DAG informed by the literature they had drawn, and reconciled features across DAGs to create a final set of DAGs for consideration ► Used Microsoft PowerPoint to draw DAGs

Country from which the data are derived. Note: We searched PubMed to find relevant articles using the following search terms, connected with Boolean operators: directed acyclic graph, DAG, DAGs, expert knowledge, expert opinion, community, lived experience, living experience, stakeholder*, domain expert*, qualitative, mixed methods and delphi. We also searched through the reference section of identified articles for relevant studies.
EU-GEI, EUropean network of national schizophrenia networks studying Gene-Environment Interactions; NHS, National Health Service; UTI, urinary tract infection.

confounding, as we discussed limitations of administrative data.

Qualitative self-reflection

We applied qualitative methodology (ie, self-reflection) to understand how DAG co-construction resonated with the team. We examined our process through participant observation and reflexive critical analytical dialogue. These methods draw on reflexive studies about navigating the ethical and methodological dynamics of community-based research[25–27] and are increasingly used in examining community engagement in research.[28 29]

Our team collectively conducted participant observation, observing ourselves (ie, the entire team) as we created the DAG. Key to participant observation is the recording of activities, interactions, conversations and thoughts.[30] We took field notes and recordings at in-person and remote gatherings. Recordings were transcribed verbatim. Social scientists (KI and CW) led reflexive, critical analytical dialogue about the DAG work organically in real time, and through planned discussions immediately following a DAG session or periodically (eg, once a month). This allowed the team to voice their experiences and thoughts about the process.[31] Prompts for discussion are outlined in table 2. Initial content and thematic analyses were conducted by a qualitative researcher and an epidemiologist (KI and MEM), who brought potential themes to peer researchers for discussion to identify additional themes, strengthening our team-based analysis.[32]

RESULTS: QUALITATIVE SELF-REFLECTION

Overall, we found the process of co-constructing the DAG to be possible and reasonable; peer researchers were active throughout the process, showing that this method is a way to meaningfully engage people with lived/living experience in administrative health data research. We describe key qualitative reflections during each step of the DAG co-construction below.

Step 1: training

For most team members, this retreat was the first introduction to DAGs. During the training, questions from peer researchers involved adjustment for variables to avoid confounding. Since most of the research experience among peer researchers was qualitative, and qualitative researchers are trained to account for the intersection of factors influencing health, adjustment to isolate the causal pathway seemed contrary (table 3).

Many team members unfamiliar with DAGs shared an initial misconception that blocking backdoor paths meant dismissing them as part of the causal relationship. Quantitative researchers were able to reiterate the importance of the identification of confounders in the web of causation. This process was important to the team members' conceptual shift.

Table 2 Summarised process guide for our approach to creating a community-led DAG, with each phase conducted in sequence

Phase	Summary	Leading questions	Recommendations and potential pitfalls
Preliminary	Team formation ► Prior to drawing the DAG, we convened a team of researchers with a shared interest in ageing and HIV, including peer researchers, epidemiologists, data scientists, social scientists and HIV clinicians. ► This project was led by five peer researchers, who are older adults and long-term survivors of HIV.	NA	► Construct a timeline outlining time commitments, to ensure that the research team is respectful and upfront in communicating the steps that will be involved in co-constructing a DAG. ► A research team with varying expertise is important. It is critical to include academics with expertise in community-based participatory research to navigate this process and to help facilitate discussions. ► A team with diverse perspectives is essential. Understanding that people with lived/living experience are not a monolith is needed to challenge assumptions in the DAG. We recommend assembling a team of peer researchers with diverse sociodemographic characteristics relevant to the overarching research question. ► Building and establishing relationships and trust with community members and organisations will help to enable involvement of peer researchers. ► Engage community members/peer researchers in decisions around team composition. It is important to learn from community members which people and stakeholders are valuable to have on the team. Shared decision-making power is also key to building trust and relationships among team members.
	Introducing the cohort study ► We introduced the team to the basics of administrative health data and the overall objectives of the study through several team meetings. ► We created plain language PowerPoint presentations and materials.	NA	► Co-create content with at least one peer researcher to ensure accessibility and relevance. ► Make hard copies of content (eg, booklets) for team members to reference on an ongoing basis. ► If possible, space out presentations and discussions over several meetings, with substantial time for questions. This will help ensure a safer, ethical and reciprocal co-learning/co-teaching space, important to bridging capacity[44] for a community-led DAG.
	Preliminary brainstorming ► In one meeting, we discussed our interests regarding ageing and HIV.	► What is your biggest concern about this topic and why?	► Methods based on creative modes of expression are encouraged. These help to elicit experiential knowledge from team members. For instance, our team had 'homework' individually to show an object or picture that represented the topic. ► Pre-DAG discussion about interests keeps ideas open, provides opportunities to share experiential knowledge and builds team relationships and rapport, all of which help to effectively set up the next phases.
Step 1: training	Deeper understanding of the cohort study ► At a 2-day off-site retreat, our team gained a deeper understanding of administrative health data. ► At the retreat, an epidemiologist provided a PowerPoint presentation with more technical explanations and additional plain language materials (eg, glossary of terms) related to the study. ► We continued providing plain language materials in response to individual needs and requests on an ongoing basis.	NA	► When content becomes more technical, use plain language and graphics as much as possible. ► Build in time for questions and discussion. ► As training continues, conduct group and individual check-ins with team members, particularly peer researchers. Ask them what concepts they would like to learn more about and what learning style or format they would prefer. ► Based on the point above, create and/or find learning materials. Ideally, co-create or review the material with at least one peer researcher.
	Brainstorming ► At the retreat, peer researchers led the conceptualisation of research questions. ► Areas of inquiry were formed by peer researchers' experiences ageing with HIV, which were conversations begun in the preliminary phase (see above). ► Research questions were selected based on their importance to the peer researchers personally, to the wider HIV community (known by the peer researchers), and whether study design was possible.	► What issue is most important to you and why? ► Can we turn our interest(s) into a research question? How? What could that look like? ► What variables/data in the cohort study can help us answer this? ► What do you hope to accomplish in this research? Why?	► Have a hard copy list of interests for each team member prepared ahead of time, if the group had a preliminary discussion (see phase above). Team members can add to the list when more ideas arise. ► Alternatively, the team could list ideas in real time (e.g., on a whiteboard, poster, etc.). We found the exercise of crossing out or circling ideas to help in understanding administrative health data and epidemiology. ► If you have several research question possibilities, use a collaborative decision-making method like 'Dotmocracy' (sticky dot, Post-It Note, etc is used to vote on a sheet of paper with research question, variables, ideas).
	Introducing DAGs ► An epidemiologist created a video tutorial to explain the purpose of DAGs in plain language, using examples. ► The tutorial defined confounders and other types of bias and outlined the rules for drawing a DAG. ► With the guidance of another epidemiologist, the group discussed how DAGs are drawn using a set of rules.	► What was clear about this video? Interesting? Unclear? How (if at all) is it different from your way of thinking?	► Begin with introducing basic DAG concepts, focusing on confounding. If appropriate for the team, additional concepts can be added, but this may need to be considered in future sessions. This will likely depend on the level of research experience within the team. ► Emphasise that there is no 'right' answer when drawing a DAG, as we are doing our best to outline assumptions. This may also stimulate discussion, by reiterating that there isn't one 'right', predefined solution we are trying to reach. ► Create a hard copy of the DAG tutorial, with a plain language glossary of terms. Team members found the hard copy as a helpful resource they continually referenced.

Continued

Table 2 Continued

Phase	Summary	Leading questions	Recommendations and potential pitfalls
Step 2: drawing	► We used paper and coloured markers for the initial DAG. ► We began by taping a large sheet of paper to the wall, with a peer-researcher artist leading the drawing. ► There was open discussion of how variables relate to the exposure and outcome. ► Messiness was allowed, with double-sided arrows included to ensure that all voices were heard and that everyone understood the relationships between the exposure, outcome and potential confounders.	► Based on our research question, what is the health outcome? What is the exposure? ► Based on your personal experience and knowledge, what do you think causes this outcome? How does x cause y in your opinion? How can we represent that in the DAG? ► Does anyone have differing experiences or insights? ► How might other community experiences (among people not represented in this room) be similar or different? ► To what extent do you think the DAG (draft) represents your experiences and concerns?	► Convening in person was essential for drawing the initial DAG, as reflected in relevant quotes. Physically drawing the DAG on paper helped make the process more engaging. ► It may be possible to carry out this step remotely, depending on team dynamics and personal preferences. Based on our experiences, drawing the DAG in person was beneficial for everyone's learning and understanding. ► It is productive to have a team that is comfortable challenging each other and each other's assumptions; having a team with diverse perspectives is conducive to opportunities where assumptions are challenged. ► Using arrows (in lieu of straight lines) and encouraging the team to think about cause and effect was described as making the research more complex but also clearer. Emphasising the purpose of using arrows when drawing an initial version of the DAG may help stimulate discussion. ► Be encouraging. Inform the team that DAGs are complicated even for epidemiologists. It allows for a safe space for exploration and sharing of lived/living experience. ► Use plain language descriptors alongside key terms like exposure, outcome, confounders. For instance, 'block' alongside 'adjust'. Metaphors also resonated; for instance, 'water pipes' and 'blocking the water'.
Step 3: refining	► After the retreat, we translated the hand-drawn DAG into Daggity, keeping double-ended arrows. ► Through iterative meetings over Zoom, we refined the DAG by discussing directions of arrows and the inclusion of additional confounders. ► At this stage, we discussed sources of unmeasured confounding, as some of the confounders identified initially, or through follow-up discussions, were not available in the administrative health data.	► Let's think more about how variables relate to each other. Do you think the x variable directly impacts the x outcome? Do you think the x variable indirectly impacts the x outcome through another variable? ► What do we mean by this variable exactly? Why did this variable come to mind? ► What is missing on the DAG? What else should we consider? ► To what extent does the DAG represent what you want to know?	► If possible, continue meeting in person, to facilitate engagement and ensure the DAG remains community-led. This was not possible for our team due to material resources and availability; we conducted these sessions remotely. ► Team members needed to be reminded about the data we had access to, as potential confounders identified and discussed were not measured in our data. ► Temporal ordering was a reoccurring conversation. This was described as making the research feel more three-dimensional. ► Moving variables around in Daggity in real time spurred discussion and decision-making about whether variables were directly impacting the outcome or were confounders. Visually walking through different possible pathways allowed the team to compare and contrast different scenarios, providing another opportunity to share experiential knowledge. This would be possible through paper as well (drawing different possible pathways). ► Revisit the meaning of variables for team members. Through discussion, we discovered that team members thought some variables were important for different reasons (which led to additional areas of inquiry in future projects). ► Future work could explore the development of multiple DAGs and reconciling versions of the DAG in subsequent sessions. ► Reflection during or after each meeting would be helpful for gauging progress. At times, people felt like we went too far 'into the weeds' in a way that was not necessary for peer researchers. Reflection would help learn how much to teach and how in-depth teachings should be. ► It is unlikely that the entire team will be available for each meeting. If a team member is absent from a session, it may be helpful to prepare the team member ahead of the next meeting in a 1:1 meeting. This is particularly relevant if dealing with emotionally charged health outcomes.

DAG, directed acyclic graph; NA, not available.

Step 2: drawing the DAG

Drawing the DAG aided in visualising the research question for the team. The process addressed concerns and confusion regarding the research question, described by a peer researcher in table 3. People called out reminders of variables of interest followed by, "*Is that an exposure? Outcome? Confounder?*" A senior demographer reiterated the research question, exposure and outcome. The following day, the team took in the full DAG, voicing approval and pride, demonstrating that the team connected with this method.

The materiality of the pen-and-paper mode was stimulating in a way not possible if the team were, as one peer researcher said, "huddle[d] around a [computer] screen." In addition, it eliminated the requirement to understand how to operate Daggity[24] or other software, making it easier for a peer researcher to draw the DAG, which empowered all peer researchers. The peer researcher-artist reflected, "It felt like I was everyone's pencil that they could see." The initial drawing facilitated the peer researchers' active role in the DAG, necessary to incorporate their lived/living experiences into the DAG.

Refining the DAG

Throughout virtual meetings, the team met and continued conversations that arose during the retreat and developed new understandings of the utility of DAGs to our research group. We summarise two key points of reflection below: the importance of incorporating diverse positionalities while co-creating a DAG, and the value of using more visual methods, such as DAGs, to encourage community engagement.

Importance of diverse positionalities

Community-led DAG work adheres to ethical research principles addressing 'Nothing About Us Without Us', according to a peer

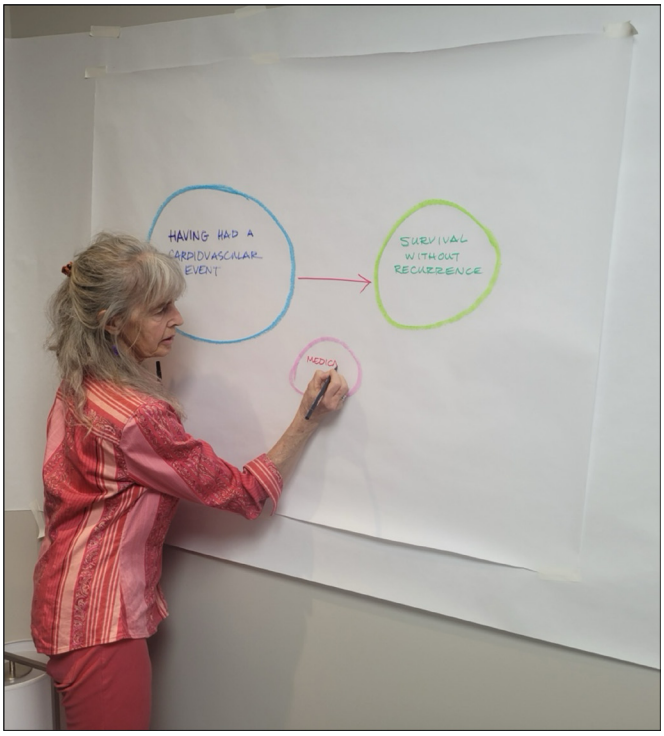

Figure 1 Peer researcher-artist working on developing an initial DAG. The team is sitting and standing around the peer researcher-artist out of frame, co-producing the DAG. DAG, directed acyclic graph.

researcher. This motto, rooted in activism,[33] is invoked to call for the active involvement of People Living with HIV (PLHIV) in HIV research.[34] As explained during one of the research meetings by a peer researcher (table 3), centring lived/living experience when co-creating the DAG forces academics to reconsider sources of expertise.

This same quote by a peer researcher in table 3 exemplifies the long-held position in community-based research that engaging people with lived/living experience as research experts improves science by holding academics accountable for their assumptions. For instance, peer researchers challenged the deficit-based assumption that PLHIV will have poorer CVD outcomes using lived experience that PLHIV may have greater healthcare engagement than people without HIV in BC (organically considering the concept of surveillance bias). This discussion also led to a reconceptualisation of primary care engagement (a confounder), including HIV specialists in addition to general practitioners, which some academic team members did not consider. Peer researchers explained that these are providers they see regularly, including for non-HIV-related care. HIV specialists on our team confirmed this. Diversity of experience and expertise was key to DAG co-construction.

Unique positionalities gave rise to careful thinking of causal relationships. Diversity among our peer researchers deepened considerations of the data. For example, one peer researcher who migrated from Africa emphasised the importance of ethnicity as a confounder. Our data cannot reliably capture ethnicity, prompting the team to conceptualise ethnicity as a source of unmeasured confounding. This led to a larger discussion

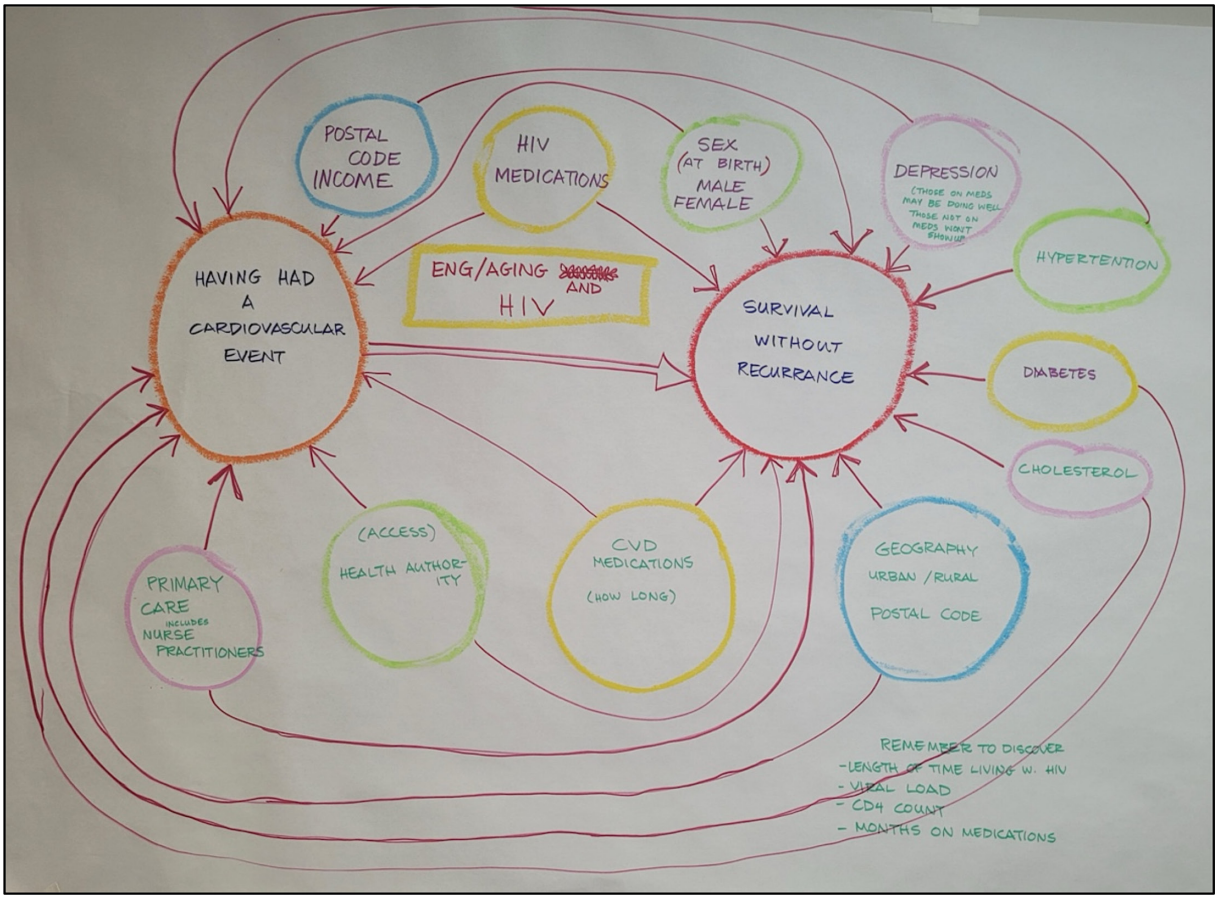

Figure 2 The DAG produced during the retreat, drawn by one of the peer researchers with team input, without strict DAG rules incorporated. DAG, directed acyclic graph.

Table 3 Quotes from research team members during qualitative reflection

Phase	Team member role	Quote
Step 1: training	Social scientist	"I feel like oftentimes, where the confusion comes in, is because real life is messy. And all these things are happening at the same time. And really, in the real world, we're interested in how everything interacts. But when you have a research question, say around housing policy, you really just want to know about that one bit. And so what the statistics allows you to do is kind of take away the effects of all the other things, even though in real life, we know they're all influencing each other, which is what the DAG is helpful to see."
Step 2: drawing the DAG	Peer researcher	"We need our exposures, we need an outcome that we're going to strive for. So, I mean, I'm sitting here looking at this [DAG] during this presentation, trying to figure out what is where and I realized that I don't have a question that I'm working toward. Is this, like, survival rates? Or is this [cardiovascular event] reoccurrence rates? Or are people experiencing these at a younger age? I don't know where we're really aiming for, so…"
Step 3: refining the DAG	Peer researcher	"We're not guinea pigs anymore. People Living with HIV have mulled things around in their heads for a long time without it being called research; they're researching every step of their life, almost. Doing the DAG together puts the epidemiologists into the world of human ethics somehow. Incorporating peer researchers into DAG works means you [academics] can't assume expert knowledge, you have 'a face to the disease' right in the room… Everybody has their own expertise. Epi people have a specific expertise that's really important, but no more important than anyone else's."
Step 3: refining the DAG	Peer researcher	"For me, being visual, this is really helping… For me, this one looked better than the other one, it [the other one] looked like OMG [less clear]…I love having the pre [event]-stuff… on the left hand side."

DAG, directed acyclic graph.

regarding available measures in the data. The peer researcher's expertise grounded our understanding that we cannot assume that a person's home postal code (akin to a zip code) indicates where they receive care or the distance to care, which were potential confounders of interest. First-hand accounts of experiences with racism, stigma and discrimination from local healthcare sites forced longer travel times to seek compassionate care. This peer researcher also described similar experiences by other Afro-Caribbean community members, who are forced to rely on caregivers who are not in their home area. Disclosing this experience prompted others to share their knowledge of PLHIV living in rural areas who will travel great distances to major centres for care. While academics are likely aware of data limitations, they may not have knowledge informed by the intersection of cultural, social and structural conditions that affect people with lived/living experience. Real-world perspectives, like those shown above, equipped the research team with a nuanced understanding of the limitations of our assumptions and broader limitations of the data in future analyses.

Leveraging community engagement through visualisation

Our team found that the visual nature of DAGs makes them an extremely effective tool to leverage the power of community engagement. Part of the visual appeal was due to temporality invoked in DAGs. During a remote session following the retreat, we began moving variables to different sides of the screen to make temporality clearer, which a peer researcher immediately described as being helpful (table 3).

Considering cause and effect over time prompted us to imagine a potential life trajectory through the DAG. We realised we needed to untangle causal relationships of certain variables (ie, HIV, CVD medications) before and after a CVD event. Creating our DAG in alignment with time-instigated recollection among peer researchers; for instance, medications they were prescribed (or medications clinical team members prescribed over time), and when/how medications could change before or after a CVD event. Treating the DAG as a temporal exercise elicited rich discussion of the evolution of antiretroviral therapy (ART) in British Columbia and health effects over time, which furthered the team's understanding of measuring ART effects. Using the DAG to visualise a life trajectory took it, as one peer researcher stated, "from being one-dimensional to three-dimensional….it makes [the research] more real."

Tensions and recommendations

A complete list of recommendations is presented in table 2. We did not encounter a situation where the group strongly disagreed on the inclusion of a variable or directionality, with uncertainties resolved through discussion. Similar experiences have been reported[35]; research groups could consider multiple DAGs if strong disagreements arise. Developing multiple DAGs could be used for sensitivity analyses. Online supplemental 4 provides a more in-depth discussion on this topic, where we compare our method to examples from the literature (online supplemental Table S1). Alternatively, research teams could consult experts (with experience relevant to the specific source of disagreement) not involved in the co-construction of the DAG. Additionally, we did not explain complex epidemiologic methods, such as mediation, during the initial training stage; we were wary of adding too much complexity too early in the learning process. If

a research question includes these concepts from the outset, our approach may need to be altered to account for additional time and resources. Thoughtful consideration of the expectations and potential burden on peer researchers and other collaborators is needed prior to beginning this process. We consider our process in comparison to other methods of stakeholder involvement in DAG construction in online supplemental 4.

DISCUSSION

We propose an expansion of the definition of expert knowledge to include ways of knowing by people with lived/living experience. Overall, peer researchers found working with DAGs to be intuitive, underscoring that it is possible to apply this technique in future work.

The process of visualising ideas through the DAG was valuable to our team. Creating the DAG on-site and in real-time, using paper and pens, elicited a lively discussion. Studies have shown that drawing in science stimulates interactive, inquiry-based learning, enhancing engagement.[36] Drawing diagrams is a way to make one's thinking explicit and to monitor one's own understanding and assumptions,[36 37] which 'leads to opportunities to exchange and clarify meanings between peers'.[36]

While we centre our work in the context of HIV, the process for co-creating a community-based DAG is applicable across epidemiology. We believe there are opportunities to expand this work, including a wider spectrum of people with experience of an outcome under study, and creating opportunities for meaningful engagement. Other work has thoughtfully argued the importance of mixed methods in epidemiologic research by providing an example of qualitative components in a DAG pertaining to adolescence and puberty,[16] cementing the applicability of these methods in various settings.

Though we focus on parameterising expert knowledge to include lived/living experiences, there are rich sources of lay knowledge that should be considered as expertise. We need not limit our operationalisation of community-based DAGs to include academics and people with lived/living experience. For example, research with a cohort in Detroit, Michigan, leveraged a community-academic partnership by first having academics create a DAG and subsequently presenting the DAG to community partners (eg, representatives from not-for-profit organisations).[38] Community partners provided lay knowledge expertise, resulting in the expansion of the DAG[38] and, thus, a more complete causal model.

A strength of this study lies with our team. Peer researchers engaged in this work had some familiarity with academic research, largely pertaining to qualitative research, and were willing to explore epidemiologic methods. General familiarity with research meant that peer researchers were aware that research is time-intensive; they were open to additional training, which allowed this project to take shape. Our process could require modifications if applied in a setting with peer researchers who are newly involved with research methods. However, most peer researchers were not familiar with administrative data research; thus, we demonstrate that this method is applicable for those new to this field.

Limitations are noted. Our process was time- and resource-intensive. We outline suggestions for trialling this process in settings with fewer resources (table 2; online supplemental 4). We completed this process once—future iterations may provide a concrete understanding of necessary components. For example, during self-reflection, some team members voiced an overemphasis on methodological details that clouded understanding. Lastly, we did not seek to compare the community-based DAG with one solely created by academics. This would provide valuable insight into the benefit conferred through lived/living experience. Future work should consider comparing a community-based DAG with one constructed solely by academics.

CONCLUSIONS

Constructing DAGs incorporating lived and living experience with a team that includes and is led by peer researchers is both possible and reasonable. Co-creating community-based DAGs could strengthen epidemiologic studies by expanding and reconceptualising our definition of background knowledge. Most importantly, our broader definition of expertise allows us to meaningfully engage peer researchers in administrative data research.

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