



The 'Values in Modelling' Framework for Patient and Public Involvement in Health Economics Modelling: Development and Application in the LEAP Model Project

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Abstract

Patient and public involvement (PPI) in health economics modelling is increasingly recommended, yet formal guidance for how to structure or evaluate it remains limited. The Values in Modelling (VIM) framework was developed to address this gap by helping teams identify and deliberate on value-laden decisions in modelling. Drawing on philosophical theory, the framework defines five steps to guide collaboration between modellers and transdisciplinary participants and to document their influence on decision making: (1) identify ethical issues and perspectives; (2) characterize modelling decisions; (3) select decision-making strategies; (4) deliberate 'open' decisions; and (5) report and evaluate. We applied the VIM framework in the Lifetime Exposures and Asthma Outcomes Projection (LEAP) model project, which models the cost effectiveness of high-efficiency particulate air (HEPA) filters for asthma prevention and management. In this application, the framework helped prioritize modelling decisions for PPI, supported transparent deliberation about uncertainty, and led to concrete methodological changes—including new sensitivity analyses and revised outcome measures. These results demonstrate how a theory-informed process can enhance PPI in modelling, improving transparency, justification, and adequacy-for-purpose in health economics research.

Key Points for Decision Makers

The Values in Modelling (VIM) framework provides structured, theory-informed guidance for involving transdisciplinary participants in health economics modelling.

Applying the VIM framework in the LEAP project led to concrete methodological changes, including new sensitivity analyses and outcome measures.

The framework promotes more explicit, defensible decision making in modelling by structuring deliberation around value-laden choices and their implications.

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1 Introduction

Patient and public involvement (PPI) in health economics modelling is recommended, with the 2022 Consolidated Health Economic Evaluation Reporting Standards (CHEERS) asking authors to describe their approach to engaging patients or others affected by the study [1]. Recent contributors have reported various approaches to PPI in health economics modelling and a range of positive outcomes, including improved understanding of the decision problem, better alignment between model objectives and end-user needs, and increased transparency [2–5]. However, guidelines or ‘best practices’ for PPI in modelling have yet to be developed [2–4, 6, 7]. Progress toward this goal is complicated both by empirical uncertainties—such as the impact of PPI on model results, users’ trust in the model, and real-world capacity [8]—and normative questions, including the appropriate level of patient and public influence and the ‘right’ price to pay for the benefits of PPI [6, 9].

Pending the development of formal guidance, modelling teams must determine how to structure the PPI process, track its impact, and document challenges. This is one objective in the Lifetime Exposures and Asthma Outcomes Projection (LEAP) model project, a multi-year initiative to develop a ‘Whole Disease’ model of asthma [10–12] and involve numerous ‘participants’ [8] in modelling various asthma-related policy decisions. The LEAP project presents an opportunity to study and improve PPI over time, but also a need to justify the initial process. Given promising but varied approaches to PPI in health economics modelling [2–5], we used philosophical theory to help design and justify a PPI process to implement and adapt over time in the LEAP project.

Recently, Harvard [13] and Harvard and Winsberg [6, 9] have argued that the purpose of PPI in health economics modelling is to give patients and members of the public a role in managing value-laden decisions, i.e., decisions that are flexible from a scientific perspective and could have downstream social or ethical consequences [14]. Understanding PPI as ‘managing values’ may help unify the numerous goals and benefits linked to PPI (e.g., upholding democratic principles, improving research quality and relevance, gaining public support for funding decisions, increasing trust [15–19]) and clarify the function of PPI, fostering support for it in health economics modelling. Furthermore, this theoretical foundation [9] provides a clear justification for PPI throughout the modelling process, anticipates likely challenges, and identifies potential strategies to manage them. For these reasons, we viewed this theoretical foundation as appropriate to inform a framework to structure the PPI process in modelling and guide future work in this area.

In this article, we describe key aspects of our work in developing a theory-informed framework to structure the PPI process in the LEAP project, along with insights gained from its preliminary application.

2 Framework Development

2.1 Theoretical Foundation and Aims

Framework development was led by the first author (SH) and informed by a review and analysis of philosophical theory on ‘managing values’ in science [9]. According to theory, value-laden decisions are expected to arise in any scientific modelling process, regardless of the specific characteristics of the model [20]. Value-laden decisions have been characterized in detail elsewhere, but generally pertain to establishing the purpose of the model, deciding what should be represented in the model and how (given the model’s purpose and the problem of uncertainty), and determining whether/when to draw factual conclusions based on model results—acknowledging that these decisions have potential ethical consequences [14, 20–22]. As value-laden decisions are not ‘purely scientific’, many philosophers suggest these decisions are equally relevant and important for scientists and non-scientists to deliberate [9].

We assumed that a framework for PPI in modelling should support a ‘meta-ethical process’ in which modelling teams consider how they will make value-laden decisions and what the consequences of those decisions might be ([9] p.7). This process raises distinct questions, including (but not necessarily limited to) (i) how to identify value-laden modelling decisions and structure deliberation about them; (ii) how to select participants to join modelling teams; (iii) how to collaborate effectively with participants in modelling. Our primary aim was to address the first question specifically, by developing a theory-informed framework for managing value-laden decisions in modelling—regardless of the particular model or participants involved. This broad focus was intended to ensure the framework could be applied and refined in future phases of the LEAP project, while creating the potential to adapt the framework to contexts beyond LEAP. Formal investigation of the other questions was outside the scope of the project (see Discussion section), although we sought to describe the framework’s preliminary application in the LEAP project and record insights from the team.

We aimed to support PPI in the full range of modelling decisions, while maximizing teams’ flexibility in implementing PPI in their own context—that is, to support various levels of PPI in the modelling process, rather than require a

specific level. Our rationale was that (i) all modelling decisions are in some sense value-laden and PPI is a core strategy for 'managing' these decisions appropriately, that is, for avoiding specific problems associated with value-laden science; but (ii) PPI is not the only available strategy for this purpose, the 'right' strategy is a normative question about which there is no current consensus (nor would consensus definitively close the question), and resource limitations and other practical considerations will likely influence whether and how PPI is implemented [9]. This justifies a framework that centres the role of PPI in managing value-laden modelling decisions but avoids taking a strict view on how PPI should be implemented.

2.2 Framework Structure

The 'Values in Modelling' (VIM) framework outlines five interrelated steps for modellers (i.e., individuals with expertise in technical aspects of modelling) and transdisciplinary participants in modelling (i.e., individuals with expertise in other areas) to take when working together. Table 1 defines these five steps and their purposes, while Tables 2 and 3 describe the conceptual distinctions that inform them. Figure 1 provides a process overview.

Following the VIM framework, modellers and participants first engage in group discussion to consider relevant ethical questions, including the potential benefits and harms of the health intervention, the potential benefits and harms of the modelling project, and appropriate standards of evidence and 'adequacy for purpose' in this context (Table 1, Step 1). Next, modellers consider upcoming modelling decisions and, to the best of their ability, characterize them according to four decision types: 'Pivotal', 'Opaque', 'Guideline', and 'Informant' decisions (see Table 1, Step 2, and Table 2 for descriptions). This will inform Step 3 (Table 1), which is choosing between three previously identified strategies to inform value-laden decisions: *Democratization*, *Pre-identification*, and *Transparency* [9] (see Table 3 for descriptions). Note that each decision-making strategy is generally most appropriate for a specific type of decision (Fig. 1).

Tables 2 and 3, respectively, describe the differences between the four types of modelling decisions and the decision-making strategies highlighted by the VIM framework. Table 3 further illustrates how characterizing modelling decisions can help teams select the most appropriate strategies for managing those decisions. For example, for 'Guideline' decisions, the team is expected to use the *Pre-identification* strategy (i.e., by consulting the relevant authoritative source); this approach avoids violating well-established scientific/institutional norms and reduces unnecessary burden on participants. For 'Pivotal' decisions, the *Democratization* strategy (i.e., involving all team members in a decision) is preferable if feasible, as these decisions

are subject to considerable uncertainty/disagreement and may have important consequences. For 'Opaque' decisions, practical considerations support the *Transparency* strategy (i.e., having modellers make the decision independently, but transparently). In part because a modelling decision may fit more than one description (e.g., both 'Pivotal' and 'Opaque'), and in part because of resource considerations (e.g., there may be insufficient capacity to use *Democratization* for all 'Pivotal' decisions), the VIM framework does not prescribe the 'best' approach. Instead, it encourages teams to weigh their options thoughtfully and prepare to justify their chosen decision-making strategies.

Following the VIM framework, modelling decisions to be made following either *Pre-identification* or *Transparency* are labelled 'Closed' decisions, while modelling decisions to be made following *Democratization* are labelled 'Open' decisions, i.e., to indicate that they will receive input via PPI (Table 3). In deliberating about 'Open' decisions (Table 1, Step 4), the VIM framework encourages modelling teams to consider overlapping epistemic issues (e.g., quality of scientific evidence) and ethical issues (e.g., social consequences of modelling decisions) from different team members' perspectives, while centring the goal of model *adequacy-for-purpose* [23]. In its final step, the VIM framework invites modelling teams to describe the results of the process, including who was involved and who had the highest level of decision-making power (Table 1, Step 5). It further asks participants to address questions relevant to evaluating the model and PPI process (Table 6). The questions reflect the core assumptions that i) to ensure adequacy-for-purpose, models demand a level of critical scrutiny capable of detecting relevant weaknesses if they exist (cf. [24]) and ii) PPI in modelling introduces diverse perspectives that help probe for relevant weaknesses in models, particularly around values, priorities, and real-world implications that might be overlooked in purely technical assessments. Currently, Step 5 of the VIM framework addresses only a subset of issues relevant to reporting and evaluating the model and PPI process—further development is needed (see Discussion section).

3 Preliminary Application in the LEAP Project: Key Aspects

3.1 Context, Selection of Participants, and Process Overview

In 2023, work began to use the LEAP model to estimate the cost effectiveness of high efficiency particulate air (HEPA) filters for asthma prevention and management. To support this effort, five transdisciplinary participants were invited to join the LEAP team: four members of the Legacy for Airway

		STEP 1: identify ethical issues and perspectives	STEP 2: characterize modelling decisions	STEP 3: select decision-making strategies	STEP 4: deliberate 'Open' decisions through <i>Democratization</i> strategy	STEP 5: report and evaluate—PPI process and model
Key action	Modellers and transdisciplinary participants engage in group discussion	Modellers characterize upcoming modelling decisions according to relevant conceptual distinctions (see Table 2)	Team lead determines how each modelling decision will be made and why (see Tables 2–3)	Modellers and transdisciplinary participants consider alternatives and aim to identify and justify preferred method(s)	Demonstrate to what extent value-laden modelling decisions received input from transdisciplinary participants	Summarize Steps 1–4. Report model weaknesses or other concerns raised through PPI
Key purpose	Orient team to ethical significance of decision making in modelling and encourage group reflection and debate	Inform selection of decision-making strategies and prioritize decisions for PPI	Prepare to communicate and justify which decisions will and will not be informed by PPI	Consider alternative methods from diverse perspectives, including potential consequences and adequacy for purpose. Finalize decisions and/or record outstanding disagreements	What is the quality of the evidence and the nature of the uncertainty affecting the decision? Does uncertainty pertain to a 'correct' value or the 'right' question to be asking? Where a relevant 'correct' value is unknown, what are the downstream social/ethical consequences of over- vs under-estimation and how do team members value them? Where there is uncertainty over the 'right' question to be asking, what are the downstream social/ethical consequences of the alternatives and how do team members value them?	Who was involved in the PPI process? What was the nature of the modelling decisions that participants were involved in? How did participants engage with the decision? What input did they give? Who had the highest level of decision-making power? Did participants flag any decisions they wished to be involved in?

Table 1 The Values in Modelling (VIM) framework

Table 2 Conceptual distinctions between modelling decisions following the Values in Modelling (VIM) framework

Modelling decision	VIM framework definition	Considerations	Example(s)
Pivotal decisions	Modelling decisions where the best choice is uncertain, it is expected to have a significant impact on results, and/or team members are expected to suggest different courses of action	Identifying Pivotal decisions is not a precise or algorithmic process—team members may disagree on which decisions qualify. However, by reflecting on the degree of uncertainty, expected impact on results, and likelihood of disagreement, modellers can identify decisions that warrant greatest attention. Decisions that modellers characterize as 'Pivotal' are a priority for PPI	Choosing the data source and method to project future PM _{2.5} levels from wildfire smoke, given deep uncertainty, expected impact on model results, and potential for ethical disagreement (i.e., preferences for over- vs under-estimating impact of climate change)
Opaque decisions	Modelling decisions that are expected to be difficult to communicate about and understand among transdisciplinary groups. The features and significance of these decisions may remain partly unknown to some participants in the modelling process	Identifying Opaque decisions relies on anticipating communication capabilities among modellers and participants—again, team members may disagree on which decisions qualify. Where the significance of modelling decisions is truly hard to explain, PPI may not be feasible. However, modellers should recognize that unexplained model features can undermine trust. For decisions classified as Opaque, participants should be asked how these features influence their trust in the model	Selecting calibration targets for tuning a microsimulation model such as LEAP, as the nature of the decision, rationale for and impact of alternative methods may be difficult to communicate among all participants
Guideline decisions	Modelling decisions where the best course of action is constrained by an authoritative source. Guideline decisions are either i) supported by long-established, well-credentialed scientific consensus or public record and subject to little to no empirical uncertainty; or ii) informed by published guidelines reflecting strong institutional consensus	Guideline decisions should be easy to agree on, as they are characterized by clear, authoritative sources and broad consensus, with little or no uncertainty. If team members disagree about whether a decision counts as a Guideline decision, it should not be treated as one. Modellers should be prepared to cite a published guideline or source that demonstrates well-established scientific or institutional consensus	Setting the caloric value of 1 g of glucose to 4 kcal or using national life table values to predict baseline mortality, as these rely on uncontested scientific facts/statistical methods.
Informant decisions	Modelling decisions that are expected to require input from one or more individual informants (e.g., a person with lived experience of a health condition, clinical experience, or other tacit knowledge), as the relevant evidence is unlikely to have been systematically collected in a reliable way	Team members should generally agree on which decisions count as Informant decisions, as these are defined by a clear lack of scientific evidence. Such decisions are best informed by input from multiple informants and, given their inherent uncertainty, should be priorities for deliberation and sensitivity analyses to assess their impact on the model.	Selecting the discount rate(s) for costs and health outcomes, as the range of appropriate values is well established by national and international health economic evaluation guidelines

PPI patient and public involvement

Table 3 Decision-making strategies within the Values in Modelling (VIM) framework

Decision-making strategy	VIM framework definition	Considerations
Democratization	Involve all team members in a decision. Facilitate deliberation and invite all participants to give their reasons to pursue or avoid a certain course of action. Decisions made using ‘Democratization’ are described as ‘Open’ decisions as they will receive input via the PPI process	<p>Strongly recommended for Pivotal decisions, wherever feasible—Prioritize <i>Democratization</i> for decisions with highest uncertainty, expected impact, and/or potential for disagreement.</p> <p>May not be feasible for Opaque decisions—Deprioritize <i>Democratization</i> for Opaque decisions unless other considerations apply.</p> <p>Not generally appropriate for Guideline decisions—Using <i>Democratization</i> to inform Guideline decisions requires extraordinary justification.</p> <p>Generally more appropriate for Informant decisions than Pre-identification—Consider using <i>Democratization</i> to make final decisions after input from multiple informants</p>
Pre-identification	Identify in advance the ‘right’ values to inform a decision, such as by following modelling guidelines or another authoritative source. Decisions made using ‘Pre-identification’ are described as ‘Closed’ decisions as they will not receive input via the PPI process	<p>Generally expected for Guideline decisions—Use <i>Pre-identification</i> to avoid violating well-established scientific norms and reduce unnecessary burden on participants.</p> <p>Aim to avoid using <i>Pre-identification</i> for Informant decisions based on input from a single informant—Prioritize receiving input from multiple informants and use <i>Democratization</i> instead, wherever feasible</p>
Transparency	Invite modellers to make the decision independently, but to be transparent about their decision and the reasons behind it. If modellers consider it difficult to be transparent about the decision (e.g., because technical details are difficult to explain), ask them to be transparent about that difficulty. Decisions made using ‘Transparency’ are described as ‘Closed’ decisions as they will not receive input via the PPI process	<p>Generally the default decision-making strategy in health economics modelling—Use <i>Transparency</i> with discretion and provide justification. Invite transdisciplinary participants to review and flag decisions that should be revisited using <i>Democratization</i></p>

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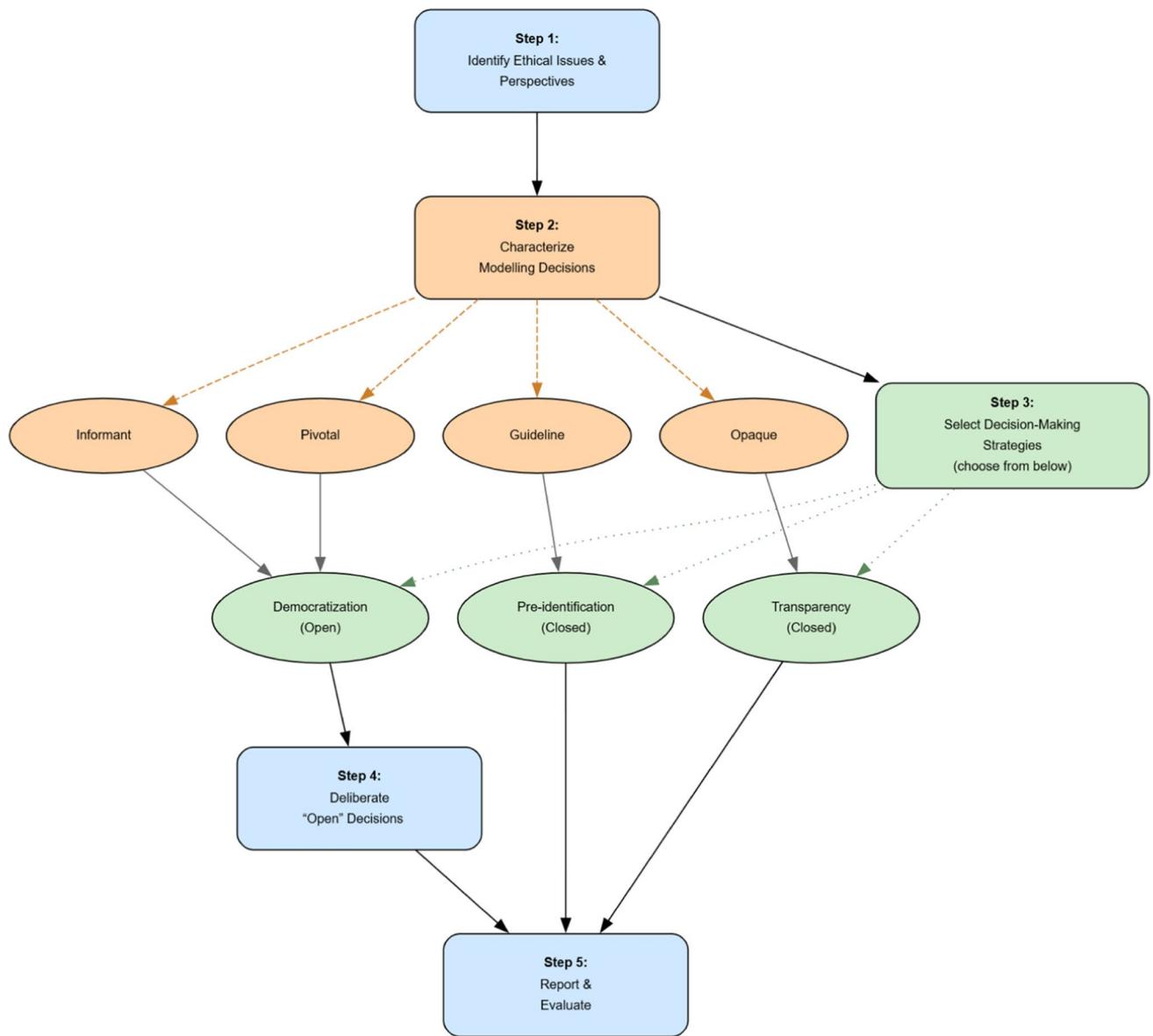


Fig. 1 Overview of the Values in Modelling (VIM) framework process. Rectangles denote the five sequential steps within the framework. *Blue rectangles* indicate steps that do not require explicit choices between options. The orange rectangle shows the step in which modellers must characterize modeling decisions by distin-

guishing among four decision types (orange ovals). The green rectangle marks the step where modellers select among different decision-making strategies (green ovals). Solid lines show the step-by-step process, while dotted lines connect steps to their respective decision type or decision-making strategy

Health (LAH) Community Partner Committee (CPC), all of whom have lived experience of asthma (RC, SHC, TL, ZZ), and one government knowledge user with expertise in air quality, who departed the project early due to a professional role change (MR—see Acknowledgements). This project was the first application of the VIM framework. All team meetings occurred online to increase accessibility—meeting dates and attendance notes are provided in Supp. Mat. 1 (see electronic supplementary material [ESM]). Participants were invited to meet with the facilitator (SH) if they had questions or comments following team meetings.

In the following, we describe selected aspects of the VIM framework's application and its influence on the modelling process. Due to space constraints, results of Step 1 are not presented.

3.2 Identification and Justification of 'Open' Decisions

Following Step 2 of the VIM framework, KJ, SH, and EW met to characterize modelling decisions, with KJ ultimately responsible for determining how decisions would be made

in modelling the cost effectiveness of HEPA filters. A total of five decisions were designated as ‘Open’ decisions, that is, to be made using the *Democratization* strategy (Step 3, decisions are listed in Table 4). The first decision concerned what data sources and methods should be used to project future air pollution attributable to wildfire smoke (specifically ‘PM_{2.5}’, particulate matter with a diameter of 2.5 micrometers or less). This decision was designated as ‘Open’ for two reasons. First, consultations with environmental scientists reinforced the published view that current data/methods are not adequate for projecting future wildfire [25, 26]; the choice of which scenarios to model is ultimately ‘unforced’ by scientific evidence [27, 28] and all modelled scenarios will be subject to significant uncertainty. Second, the choice of data sources/methods, including which scenarios to model, could be anticipated to significantly affect model results and/or provoke ethical disagreements among participants (e.g., because of the differing values individuals place on over- versus under-estimating the impacts of climate change, which include changes to wildfire patterns). Given these features, the decision was considered to be ‘Pivotal’ and prioritized for PPI. The four other ‘Open’ decisions concerned what data sources and methods should be used to represent the impact of PM_{2.5} on asthma outcomes, including asthma control, moderate exacerbations, severe exacerbations, and asthma incidence. Not only were these decisions also considered to be ‘Pivotal’, modellers anticipated that participants with lived experience of asthma could have special knowledge relevant to the decisions.

3.3 Deliberation 1: Methods for Projecting Future Wildfire-Attributable PM_{2.5}

The first ‘Open’ decision concerned the process to project future levels of PM_{2.5} due to wildfire smoke. Because this decision involves considerable uncertainty, methodological complexity, and potential consequences for model results and policy recommendations, it shares features with many health economics modelling decisions. PPI in such decisions is supported by theoretical arguments but is often approached hesitantly for a variety of reasons, including doubts about participants’ interest, capability, and influence [8]. This section describes how participants were engaged in deliberations, illustrates that participants raised relevant questions and considerations, and demonstrates their influence on the management of uncertainty.

Prior to deliberation, participants were informed about the nature of the decision and why it presents a methodological challenge with ethical significance, including the implications of over- versus under-estimating one of many possible impacts of climate change (see Table 4). Briefly, the facilitator (SH) explained that the first task would be to choose between two data sources to examine historical

averages of PM_{2.5} in Canada. One source is the Canadian Optimized Statistical Smoke Exposure Model (CanOSSEM), a machine learning model which estimates historical PM_{2.5} levels using numerous predictor variables [29]. Another source is the Regional Air Quality Deterministic Prediction System (RAQDPS), whose purpose is to produce 3-day air quality forecasts across Canada based on meteorological inputs, emissions, and chemical transport, but which ultimately provides records of forecasts that can be used to estimate historical PM_{2.5} levels [30]. Although both CanOSSEM and RAQDPS provide estimates of historical PM_{2.5} levels, only RAQDPS is capable of distinguishing PM_{2.5} caused by wildfire specifically. The second task would be to choose a method for representing the increase in PM_{2.5} attributable to wildfire smoke over time. One way to do this would be to model a range of possible levels of increase (e.g., 0%, 10%, 25%, 100% etc.), without grounding these numbers in empirical estimates or projections. Another way would be to incorporate the results of one or more modelling studies that attempt to project increases in wildfire and resulting smoke according to climate change scenarios, such as the study by Xie et al. [31]. A third possibility would be to combine these methods, extending the range around projections informed by climate change scenarios.

To foster group discussion, the facilitator described potential strengths, limitations, and downstream implications of these different methods, informed by KJ’s consultations with environmental scientists and an expert in climate modelling ethics (EW). Group discussion began with questions, which participants raised regarding sources of uncertainty affecting the model. These included questions concerning the level of agreement between CanOSSEM and RAQDPS and the latest data incorporated into RAQDPS. In discussing methods for modelling future increases in PM_{2.5}, one participant spoke in favour of incorporating evidence-informed projections (rather than hypothetical assumptions), but another asked for clarification regarding the source of evidence-based projections. This prompted discussion over the desirability of using Canada-specific projections, and the group asked modellers to search for wildfire projection studies that use data from areas close to British Columbia (BC), where the LEAP project is based. Ultimately, participants suggested using a variety of approaches to estimate future PM_{2.5} and being transparent about what additional data would be required to reduce uncertainty.

At the next meeting, modellers responded to outstanding questions, confirming that the latest RAQDPS data are from 2023 and the agreement between CanOSSEM and RAQDPS is 0.72, as assessed by Pearson’s correlation coefficient. Reflecting on this level of agreement, modellers noted that the most common interpretation among experts is that RAQDPS overpredicts peak exposure to PM_{2.5} during wildfire events but underpredicts baseline exposure compared

Table 4 'Open' decisions in the LEAP model project: summary and impact of patient and public involvement (PPI) following the Values in Modelling (VIM) framework

'Open' decision	Summary of 'value-ladenness' (scientific flexibility, potential social/ethical consequences)	Impact of PPI following VIM framework
<i>Deliberation 1:</i> Select data source(s) and methods for projecting future wildfire	Scientists warn that deep uncertainty surrounds future wildfire, though it will be influenced by climate change. Selecting data sources and methods for wildfire projection cannot be determined by evidence alone and implicitly involves judging the ethical significance of various possible outcomes (e.g., representing future wildfire as being more severe or less severe than it really will be; signaling to the public that scientists can predict future wildfire to high degrees of accuracy; signaling to policy makers that future wildfire will be determined exclusively by climate change and not by environmental policies, etc.)	Change to uncertainty management strategy —Increase attention to disagreement between data sources and expand sensitivity analyses beyond what was initially planned
<i>Deliberation 2:</i> Select data source(s) and methods to represent the impact of PM _{2.5} on asthma control	There are multiple ways to define and measure asthma control in the literature (e.g., medication use patterns, self-reported symptoms, functional tests). What outcome is chosen may impact how policy makers and others perceive the severity of the disease. Existing data on the impact of PM _{2.5} on outcomes linked to asthma control may over- or underestimate the true impact of PM _{2.5} on people with asthma	Change of outcome measure —Avoid using salbutamol dispensations to represent asthma control as initially planned and use Asthma Control Test (ACT) instead
<i>Deliberation 3:</i> Select data source(s) and methods to represent the impact of PM _{2.5} on moderate asthma exacerbations	Moderate asthma exacerbations can be defined and measured by various clinical criteria/tests and other self-reported and observed outcomes. Choosing between them involves judging what is important and may influence perceptions of asthma burden and downstream resource allocation decisions. Health care utilization may represent moderate asthma exacerbations but could over- or underestimate them	Change to error-checking process —Verify that care from a range of practitioners will be captured before using primary care visits to represent moderate asthma exacerbations
<i>Deliberation 4:</i> Select data source(s) and methods to represent the impact of PM _{2.5} on severe asthma exacerbations	Like other exacerbations, severe to very severe asthma exacerbations can be defined and measured by various outcomes and choosing between them has downstream consequences. Using asthma-related emergency room visits is practical but could fail to capture the link between PM _{2.5} and asthma exacerbations due to the limitations in current knowledge (e.g., the timing of the effect of PM _{2.5} and its complex determinants)	Expansion of model outcomes —Model a range of 'lagged' effects to draw attention to heterogeneity among people with asthma and acknowledge that asthma exacerbations due to increases in PM _{2.5} may occur at different points after the exposure
Select data source(s) and methods to represent the impact of PM _{2.5} on asthma incidence in children and adults	Impact of PM _{2.5} on asthma incidence has been studied using different methods in different settings, resulting in a range of 'concentration response functions' (CRF) identified in meta-analyses. It is unknown which CRF most accurately represents the impact in different parts of Canada and over- or underestimation could have policy implications	Change to uncertainty management strategy —Increase attention to disagreement between data sources and expand sensitivity analyses beyond what was initially planned

with CanOSSEM. In most contexts where the goal is to establish a causal inference, 0.72 is considered on the border between medium and high correlation, but one may or may not consider it 'adequate' agreement between two tools that aim to measure the same phenomenon; therefore, one might still wonder about the impact on the model results of using RAQDPS to estimate historical PM_{2.5} due to wildfire. If the group wished to explore this source of uncertainty, the facilitator noted, one possibility would be to perform a sensitivity analysis by taking the wildfire-attributable fraction of PM_{2.5} derived from RAQDPS and multiplying it by the CanOSSEM total PM_{2.5}, which would reduce reliance on RAQDPS. Asked whether modellers should perform this additional analysis, all participants agreed that they should do so, if feasible, to strengthen the methods. The modelling team considered this additional sensitivity analysis a result of the PPI process.

Addressing participants' question concerning projection studies using more local data, modellers confirmed that such studies are lacking. However, modellers identified a wildfire projection study of Western USA [32], which incorporates the propensity of different regions to burn, given historical wildfire activity, fuel availability, and fire weather conditions, and links observed fire behaviour to near-future trends, making it better suited for the LEAP model's near-future timeframe (2023–2036). Using this study would result in the LEAP model representing an 11% increase in wildfire-attributable PM_{2.5} between 2023 and 2036 in the base-case analysis; modellers would then choose 0% as a lower bound for the confidence interval and the midway point between 0 and 11% as the intermediate scenario, i.e., a 5.5% increase from 2023 to 2036. Asked whether modellers should apply any additional scaling factors (e.g., exploring the impact of assuming even greater levels of increase in wildfires, or of absolute reductions in wildfires), participants all indicated that modellers should *not* apply additional scaling factors, as none had reasons to support doing so (see Discussion section).

3.4 Deliberations 2–5: Methods for Representing the Impact of PM_{2.5} on Asthma Outcomes

'Open' decisions 2–5 concerned how to represent the impact of PM_{2.5} on asthma outcomes. This section describes how participants were engaged in deliberations about these decisions, including considerations when choosing a 'concentration response function' (CRF) to represent these impacts (see Supp. Mat. 2 in the ESM). We note that 'Open' decisions 2–5 all had a clear connection to participants' lived experience of asthma, unlike 'Open' decision 1 (see Discussion). Discourse on PPI in health economics modelling has emphasized that participants' lived experience is an important source of factual knowledge relevant to model

development, raising the question of whether this knowledge is the most important or even only thing to be sought through PPI [2, 6]. Here, we describe how participants contributed not only factual knowledge that may have otherwise been inaccessible to modellers, but also their personal, normative perspectives on what questions the model should address, what potential sources of error should be investigated, and how modellers should represent uncertainties.

'Open' decision 2 concerned how to represent the impact of PM_{2.5} on asthma control. Participants were briefed on the decision and informed that KJ's independent suggestion was to use a BC study that examined the effect of PM_{2.5} on salbutamol dispensations [33]. To encourage deliberation about this choice, participants were asked "*Are salbutamol dispensations an adequate proxy for asthma control?*". All participants expressed significant doubts, noting that, in their experience, salbutamol lasts a long time, they often have back stock, and sometimes share within the family (i.e., where more than one member has asthma), meaning they may not see a doctor or pharmacist during a period of high PM_{2.5} despite being affected. Given these considerations, KJ provided two alternative sources of CRFs to consider, one for adults [34] and one for children [35], both of which use the Asthma Control Test (ACT) as a direct measure of asthma control. KJ summarized the limitations of these studies from her perspective, including that both were conducted in settings considerably different from BC (e.g., weather, housing stock, rural/urban mix), which could affect the relationship between PM_{2.5} exposure and asthma outcomes. In discussions, it was noted that while salbutamol dispensations would likely underestimate effect of air pollution on asthma control, it was unclear whether or to what extent the studies using ACT scores would underestimate or overestimate impact of air pollution on asthma control in BC. Discussions resulted in unanimous agreement among participants that the ACT is a superior measure of asthma control and in the decision to model the relationship between PM_{2.5} and ACT scores, rather than salbutamol dispensations. Modellers reflected that participants had contributed factual knowledge about salbutamol use that was otherwise inaccessible to them. This input, along with participants' negative assessment of methods expected to underestimate the effect of PM_{2.5} on asthma, persuaded the team to model asthma control differently than originally planned.

'Open' decision 3 concerned how to represent the impact of PM_{2.5} on moderate asthma exacerbations. Participants were briefed on this decision and informed that KJ's independent suggestion was to use a BC study which examined the effect of PM_{2.5} on asthma-related physician visits [33]. To encourage deliberation about this choice, participants were asked "*Are asthma-related physician visits an adequate proxy for moderate asthma exacerbations?*" The central concern raised by participants was whether the billing codes

used in the study would capture visits to nurse practitioners, walk-in clinics, and urgent care. Participants stressed the importance of capturing these visits, given a perceived reduction in access to primary care physicians since 2010. Upon confirmation that these visits would normally be captured (so long as the visit was billed correctly), participants agreed that the suggested study [33] was an adequate source to obtain a CRF for moderate asthma exacerbations. Modelers observed that participants had drawn their attention to the issue of reduced access to regular primary care physicians and prompted them to verify that their method would capture other episodic primary care visits. The PPI process had therefore resulted in an additional check for potential error that would not have occurred otherwise.

'Open' decision 4 concerned how to represent the impact of PM_{2.5} on severe to very severe asthma exacerbations. Participants were briefed on the decision and informed that KJ's independent suggestion was to use a recent meta-analysis, which stratified the effects of PM_{2.5} on asthma-related ER visits into 'lags' of 0–4 days [36]. To encourage deliberation, participants were asked to consider the assumption that exposure to PM_{2.5} has a 'lagged' effect on asthma exacerbations (i.e., exacerbations due to increases in PM_{2.5} do not occur immediately, but 1, 2, 3, or 4 days after exposure) and "*How should this lag be represented in the LEAP model?*" At the outset, the facilitator flagged one reason to avoid modelling the 4-day lagged effect, that is, the corresponding evidence was considered 'low certainty', unlike other effects for which evidence was generally considered 'moderate certainty'. Most participants expressed that lagged effects of 2 or 3 days were the relevant ones to model, as they often try other symptom-control strategies first before resorting to visiting the ER. However, one participant said they tend to visit the ER fairly quickly when experiencing a sudden exacerbation. In light of this discrepancy, participants suggested asking a physician whether it is more common for symptoms to gradually worsen, or whether patients often present to the ER from sudden symptom onset. The physician consulted (see Acknowledgements) suggested that the inflammatory reaction usually occurs within 24 hours but people differ in self-management, comfort, home environments, etc. Given the physician's input, participants unanimously suggested modelling a range of lagged effects from 1 to 3 days. Modelers noted that, prior to participants' input, they were unsure what lagged effect to model (i.e., 0–4 days), but they were inclined to select just one of the four options as this would simplify model results and downstream policy discussions. The PPI process therefore effectively encouraged addressing a greater number of questions, despite the complexity this introduces, and representing a wider array of asthma outcomes relevant to a diverse patient population.

'Open' decision 5 concerned how to represent the impact of PM_{2.5} on asthma incidence in children and adults,

respectively. Participants were briefed on the decision and informed that KJ's independent suggestion was to use two separate meta-analyses, both of which compiled evidence from diverse geographical settings [37, 38]. At the first two meetings, participants were asked to consider: (1) asthma is difficult to diagnose in children under 5 and what is considered asthma in this age group could vary across studies included in the children-focused meta-analysis; (2) asthma diagnosis was often self-reported, and could therefore be uncertain, in studies included in the adult-focused meta-analysis. A follow-up brief circulated by email highlighted additional considerations and asked "*Do you think we should use the two meta-analyses above as the sources for the CRFs for asthma incidence in adults and children, respectively? If we do use them, will you trust the model results?*" The brief also provided examples of alternate/complementary strategies that modellers could take, such as using only Canadian studies or studies meeting other important criteria, conducting sensitivity analyses around the CRFs obtained from meta-analyses, and/or taking extra measures to communicate the uncertainty in the CRFs. At the final meeting, the facilitator presented additional information concerning the quality of evidence included in the meta-analyses.

Contemplating this decision, participants expressed different perspectives. Two participants said the decision should be made by modellers familiar with the meta-analyses in question and that they were not qualified to decide which option is best and why. However, one expressed the view that CRFs from meta-analyses should be adequate, as researchers who conducted the meta-analyses would 'weed out' poor studies so that the average would be appropriate. Conversely, another worried that meta-analyses would not reflect actual asthma incidence, noting that many children may remain undiagnosed due to barriers in accessing specialized care and self-reported asthma could introduce inconsistencies based on differences in healthcare access, cultural factors, and awareness levels across regions. This participant also questioned whether variability in study locations would affect how well the CRFs from meta-analyses would reflect asthma risk in BC/Canada. Accordingly, the participant expressed a preference to use specific studies selected to represent the local context. While they thought it was reasonable to use the CRFs from meta-analyses, they said they would feel more confident in the model's results if additional steps were taken to account for uncertainty.

Given these differing opinions, deliberation gravitated towards using a range of CRF values and presenting multiple results. One participant suggested asking the modeller most familiar with the meta-analyses to identify specific studies that would be particularly suitable for representing BC/Canada. For the CRF among adults, this modeller recommended two large, high-quality cohort studies with PM_{2.5} concentrations comparable to Canada [39, 40]. Considering

the various suggestions made, KJ made the final decision to model not only the CRFs obtained from the meta-analyses but the CRFs from the two previously recommended studies as well [39, 40]. Modellers reflected that the PPI process, following the VIM framework, prompted the team to consider the complexities of selecting a single CRF to represent the impact of PM_{2.5} across all policy settings that may be informed by the LEAP model. This effectively encouraged modelling a wider range of uncertainty.

3.5 Reporting and Evaluation

As described in Table 1 (Step 5), the VIM framework invites modelling teams to describe their process and demonstrate to what extent value-laden modelling decisions received input from transdisciplinary participants. While model results are outside the scope of this article, Table 5 describes the decisions required to model the cost effectiveness of HEPA filters and indicates which decision-making strategies were followed to make each one, including who was involved in specific decisions and who had greatest decision-making power. Table 5 shows the proportion of decisions designated as ‘Open’ versus ‘Closed’, highlighting that the PPI process involved participants in a very small proportion of total decisions in this phase of LEAP model development. Table 6 describes participants’ answers to VIM framework questions relevant to evaluating both the model and PPI process (see Discussion). As VIM framework questions do not cover personal experiences, participants were also asked to complete the Patient Engagement in Research Scale [41] (see Supp. Mat. 3, ESM). This was done to obtain a general impression of participants’ experiences and identify any serious issues that should be addressed before undertaking future work using the VIM framework. The results indicated that one participant had criticisms of the process (see Discussion), but feedback was generally interpreted as positive and encouraging of future work.

4 Discussion

This article described the VIM framework’s process, rationale, and initial application. Here, we reflect on its strengths, implications, and limitations, and outline future research directions for evaluating and refining the VIM framework.

The VIM framework was developed following an extensive review and analysis of literature on ‘managing values’ in science [9]. This process identified both philosophical and practical considerations relevant to structuring PPI in health economics modelling. The analysis concluded that any PPI process will remain subject to criticisms and the benefits of involving all team members in every decision

are unlikely to outweigh the costs. Accordingly, the VIM framework encourages modelling teams to prioritize PPI in key modelling decisions and promotes a transparent and systematic process for doing so.

In practice, health economics modellers already set priorities for PPI. For example, Gibbs et al. [3] report prioritizing questions about unfamiliar cultural contexts and decisions about data sources and assumptions expected to greatly influence results. One of the strengths of the VIM framework is it provides a theoretical justification for implementing intuitive solutions like this. Moreover, the framework offers theory-informed guidance for how to prioritize decisions for PPI and what information to record throughout the modeling process. This includes whether decisions can be readily informed by uncontested science and/or well-established institutional guidelines, whether individual informants are required due to lack of systematic evidence, whether decisions pertain to ‘opaque’ model features that could influence user trust, and whether decisions are flexible from a scientific perspective and carry significant downstream social/ethical implications. By identifying these considerations, the VIM framework has provided the LEAP team with concrete guidance for structuring the PPI process and reporting it using the CHEERS (items 21 and 25) [1] and GRIPP2 checklist [47].

Key questions concern the evaluation of the VIM framework. While the current study provides only limited insight into these questions, it presents an opportunity to reflect on their importance and how they may be addressed in future research. Here, we briefly consider five distinct questions, which suggest different objectives and evaluation methods.

Perceived value of proposed PPI procedure First, does the VIM framework propose the right procedure for PPI in health economics modelling generally? In this work, we built on the assumption that social procedures (e.g., scientific, legal, democratic) have intrinsic value, which can only be assessed subjectively by the individuals with an interest in the process. Features like perceived transparency, inclusiveness, fairness, accountability, deliberativeness, and legitimacy can all influence what value individuals ascribe to a procedure [42–46]. Informed by philosophical theory [9], the VIM framework was developed with the goal of enhancing these perceived features of the modelling process. However, we did not examine whether this goal was achieved. In the future, the potential exists to systematically assess the perceived value of the VIM framework—including compared with alternatives [4]—through formal surveys of patients and the public, decision makers, and other members of the health economics community. One potential objection to the VIM framework’s proposed procedure (suggested by a reviewer of this article) is that it does not explicitly aim to ensure that modelling decisions receive appropriate guidance from relevant domain experts *before*

Table 5 Cost-effectiveness of HEPA filters: representational decisions and decision-making strategies in the LEAP model project

Parameter	Description	Decision-making strategy	Team members involved in decision	Base case	DSA	PSA	Source
Fixed model inputs							
Start year		Closed (Transparency)	KJ*, SL, AA	2010			
Childhood cohort age at start, y		Closed (Transparency)	KJ*, SL, AA	5	5, 10		
Adult cohort age at start, y		Closed (Transparency)	KJ*, SL, AA	25	20, 30		
Discounting (annually)	Guideline decision	Closed (Pre-identification: Guidelines)	KJ*, SL, AA	1.5%			
Air cleaner unit lifespan (y)		Closed (Transparency)	KJ*, SL, AA	5			
Air cleaner filter lifespan (mo)		Closed (Transparency)	KJ*, SL, AA	9			
All-cause annual mortality		Closed (Transparency)	KJ*, SL, AA	Varies by age (y)			Statistics Canada life tables [49]
Exposure inputs							
Historical monthly PM _{2.5} concentrations (2010–2022)	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	Various			CanOSSEM [26, 29]
Projected monthly PM _{2.5} concentrations attributable to wildfire (2023–2036)	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	Various			RAQDPS [27, 30]
Projected monthly PM _{2.5} concentrations attributable to non-wildfire sources (2023–2036)	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	Various			GEM-MACH model [50]
Climate scaling factor (2023–2036), annual increase in PM2.5 attributable to wildfire	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	0.42%	0%, 0.84%		Liu et al. [32]
Infiltration efficiency	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	0.61	± 20%	Normal	Barn et al. [51, 56]
HEPA filter effect	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	0.48	± 20%	Beta	
Proportion of time spent at home	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	0.89 (≤ 12 y) 0.88 (> 12 y)	± 20%	Beta	Matz et al. [52]
Rates, probabilities, and risk							
Asthma control							

Table 5 (continued)

Parameter	Description	Decision-making strategy	Team members involved in decision	Base case	DSA	PSA	Source
Proportion of well-controlled asthma at baseline		Closed (Transparency)	KJ*, SL, AA	0.506 (≤ 18 y) 0.560 (> 18 y)	$\pm 20\%$	Beta	Kennedy et al. [53] Sadatsafavi et al. [54] O'Byrne et al. [55]
Proportion of not well-controlled asthma at baseline		Closed (Transparency)	KJ*, SL, AA	0.494 (≤ 18 y) 0.440 (> 18 y)	$\pm 20\%$	Beta	
Probability of well-controlled asthma to not well-controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	0.244	$\pm 20\%$	Beta	Sadatsafavi et al. [54]
Probability of not well-controlled asthma to controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	0.140	$\pm 20\%$	Beta	
<i>Asthma exacerbations</i>							
Relative risk of exacerbations in not well-controlled asthma (vs well controlled)		Closed (Transparency)	KJ*, SL, AA	1.20	$\pm 20\%$	Log-normal	Pollack et al. [56]
Rate of moderate exacerbation (annually)		Closed (Transparency)	KJ*, SL, AA	0.10 (≤ 18 y) 0.090 (> 18 y)	$\pm 20\%$	Beta	Adams et al. [57] Bateman et al. [58] Pollack et al. [56]
Rate of severe exacerbation (annually)		Closed (Transparency)	KJ*, SL, AA	0.068 (≤ 18 y) 0.011 (> 18 y)	$\pm 20\%$	Beta	
Rate of very severe exacerbation (annually)		Closed (Transparency)	KJ*, SL, AA	0.019 (≤ 18 y) 0.009 (> 18 y)	$\pm 20\%$	Beta	
Risk of death due to moderate exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	0.00027	$\pm 20\%$	Beta	Watson et al. [59]
Risk of death due to severe exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	0.001733	$\pm 20\%$	Beta	
Risk of death due to very severe exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	0.001801	$\pm 20\%$	Beta	
<i>Effects of PM_{2.5}</i>							
RR incident asthma (per 5 ug/m ³ PM _{2.5})	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	1.16 (≤ 18 y) 1.07 (> 18 y)	1, 1.20	Log-normal	Lee et al. [11] Kreis et al. [37]

Table 5 (continued)

Parameter	Description	Decision-making strategy	Team members involved in decision	Base case	DSA	PSA	Source
RR for loss of asthma control (per 10 $\mu\text{g}/\text{m}^3 \text{PM}_{2.5}$)	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	1.04	1, 1.20	Log-normal	Yao et al. [33]
RR for moderate exacerbation (per 10 $\mu\text{g}/\text{m}^3 \text{PM}_{2.5}$)	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	1.06	1, 1.20	Log-normal	Yao et al. [33]
RR for severe exacerbation (per 10 $\mu\text{g}/\text{m}^3 \text{PM}_{2.5}$)	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	1.07	1, 1.20	Log-normal	Borchers et al. [60]
RR for very severe exacerbation (per 10 $\mu\text{g}/\text{m}^3 \text{PM}_{2.5}$)	Pivotal decision	Open (Democratization)	KJ*, AA, SL, SH, RC, SHC, TL, ZZ	1.06	1, 1.20	Log-normal	Borchers et al. [64]
Air cleaner costs							
Air cleaner unit rebate (every 5 y)	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	\$150.00	$\pm 20\%$	Gamma	Retail cost assumption
Annual electricity cost for air cleaner (continuous use)		Closed (Transparency)	KJ*, SL, AA	\$10.08	$\pm 20\%$	Gamma	
Filter replacement (every 9 mo)	Pivotal decision	Closed (Transparency)	KJ*, SL, AA	\$30.00	$\pm 20\%$	Gamma	
Asthma direct costs							
Well-controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	\$24.41	$\pm 20\%$	Gamma	Sadatsafavi et al. [54]
Not-well controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	\$170.07	$\pm 20\%$	Gamma	
Moderate exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	\$185.04	$\pm 20\%$	Gamma	Sadatsafavi et al. [61]
Severe exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	\$585.41	$\pm 20\%$	Gamma	
Very severe exacerbation (per event)		Closed (Transparency)	KJ*, SL, AA	\$11,211.59	$\pm 20\%$	Gamma	
Asthma indirect costs							
Well-controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	\$161.16 (≤ 18 y) \$1268.49 (> 18 y)	$\pm 20\%$	Gamma	Sadatsafavi et al. [54] and Kennedy et al. [53]
Not well-controlled asthma (monthly)		Closed (Transparency)	KJ*, SL, AA	\$886.37 (≤ 18 y) \$1364.34 (> 18 y)	$\pm 20\%$	Gamma	Sadatsafavi et al. [54] and Kennedy et al. [53]

Table 5 (continued)

Parameter	Description	Decision-making strategy	Team members involved in decision	Base case	DSA	PSA	Source
Moderate exacerbation	Closed (Transparency)	KJ*, SL, AA	\$591.90	± 20%	Gamma	Sadatsafavi et al. [61]	
Severe exacerbation	Closed (Transparency)	KJ*, SL, AA	\$1183.81	± 20%	Gamma		
Very severe exacerbation	Closed (Transparency)	KJ*, SL, AA	\$1775.71	± 20%	Gamma		
Utilities							
General population	Closed (Transparency)	KJ*, SL, AA	0.95 (5–11 y) 0.89 (12–17 y) 0.86 (> 17 y)	± 20%	Beta	Yan et al. [62]	
Disutility of well-controlled asthma (monthly)	Closed (Transparency)	KJ*, SL, AA	0.0042 (\leq 18 y) 0.013 (> 18 y)	± 20%	Beta	Lee et al. [11] and Lee et al. [63]	
Disutility of not well-controlled asthma (monthly)	Closed (Transparency)	KJ*, SL, AA	0.0067 (\leq 18 y) 0.017 (> 18 y)	± 20%	Beta		
Disutility of moderate exacerbation	Closed (Transparency)	KJ*, SL, AA	0.0057	± 20%	Normal	Lloyd et al. [64]	
Disutility of severe exacerbation	Closed (Transparency)	KJ*, SL, AA	0.0075	± 20%	Normal		
Disutility of very severe exacerbation	Closed (Transparency)	KJ*, SL, AA	0.0092	± 20%	Normal		

AA Amin Adibi, KJ Kate Johnson, RC Rachel Carter, SH Stephanie Harvard, SHC Sian Hoe Cheong, SL Spencer Lee, TL Tony Lanier, ZZ Zainab Zeyan

CanOSSEM Canadian Optimized Statistical Smoke Exposure Model, *DSA* deterministic sensitivity analysis, *GEM-MACH* Global Environment Multiscale-Modelling Air Chemistry, *PSA* probabilistic sensitivity analysis, *RAQDPS* Regional Air Quality Deterministic Prediction System, *RR* Relative risk

*Highest decision-making power

being opened to PPI. In the LEAP project, all modelling decisions—including those related to the projection of wildfire—received input from relevant domain experts prior to PPI and we expect this to be the procedure that would be most widely endorsed. However, future work is needed to establish whether and how the VIM framework should more explicitly describe recommended procedures regarding the consultation of domain experts.

Process benefits in the LEAP project Second, what impact did the VIM framework have on the modelling process in the LEAP project? When focusing on ‘process benefits’ [8], one key question is whether the VIM framework led to PPI in the ‘right’ modelling decisions, irrespective of the content of participants’ input or its impact on the final model. Addressing this question requires judging what constitutes appropriate inclusion and exclusion of participants from modelling decisions—and future research is needed to

shape these judgments. However, questions asked of participants at the end of this project provide some insight into their perspectives (Table 6). Importantly, none of the four participants felt their involvement in specific decisions was unnecessary or not appropriate. When asked if there were any modelling decisions they were not involved in where they felt their input would have been valuable, three out of four participants said no. However, one participant remarked that they were not fully aware of the relevant details and therefore could not answer the question. The same participant questioned whether the costs included in the model truly reflect the financial burden experienced by people living with asthma and suggested that “additional context from lived experience may have been beneficial”.

This critical feedback shows that not all participants felt they were adequately informed and included in the full scope of relevant decisions. This could be interpreted as a

Table 6 Questions for participants in the LEAP model project

Question	Partner A	Partner B	Partner C	Partner D
Of the modelling decisions you participated in, were there any where you felt your involvement was unnecessary or not appropriate?	No. I don't think unnecessary or not appropriate, but there were some decisions that felt they needed a little more knowledge of the modelling than I had, so I could share my thoughts, but didn't feel like I could participate in the final decision.	No. There was at least one element of the decision-making that the team reverted the decisions to the mgmt team. Otherwise they were all appropriate.	No. I believe the research team was very intentional and thoughtful about when to include us in modelling decisions and when to refrain. Of the modelling decisions I participated in, I always felt that my involvement was meaningful and appropriate. I clearly understood the role I played in contributing to those discussions, particularly when the decisions directly benefited from the insight of our lived experiences with asthma. At no point did I question why I was being asked for input, which speaks to how well the team aligned our participation with decisions that genuinely required our perspective.	No. I think the patient partner involvement was appropriate
Of the modelling decisions you participated in, were there any where you felt your input should have had a greater impact on the final decision made by the modelling team lead?	No.	No. The process was fair and respectful	No. In my experience, the modelling team consistently made an effort to ensure our input was meaningfully considered in the final decisions. They regularly checked in with us to confirm that the outcomes felt reflective of our insights and lived experiences. If there were ever concerns that a decision didn't fully capture what had been shared, the team was open and accommodating in revisiting the conversation.	No. The researchers and other patient partners were very engaging ... we had good discussions and decisions were made based on evidence, consensus, informed-decision making.

Table 6 (continued)

Question	Partner A	Partner B	Partner C	Partner D
Thinking about the modelling decisions you participated in, do you have any outstanding concerns about data limitations or other issues that affected those aspects of the model?	No.	Unsure. No actually outstanding concerns but the continual concern that the completed model (with the information available to us all) may show some inaccurate assumptions that could skew the messaging. That said, we have been careful to work as best we can to reduce less-dependable data while also clarifying sources and why those sources we used.	No. Initially, I had some concerns about the method used to choose the concentration-response function (CRF) for PM2.5 and asthma incidence. However, after voicing my thoughts and listening to the perspectives of the rest of the team, I felt reassured by how the modelling team approached the discussion. They took the time to understand our varying viewpoints and guided us toward a mutually agreed-upon conclusion. I appreciated that they not only ensured our lived experiences were accounted for but also made sure we fully understood the research terminology and rationale behind the modelling decisions, allowing for a more informed and meaningful discussion.	No. We discussed various options including the "weaknesses"/limitations and decided the best option
Were there any modelling decisions you were not involved in where you feel your input would have been valuable?	No.	No. It is a great practice to segment the work based on what is reasonable in terms of input.	Unsure. I trust that the modelling team was intentional in involving us as patient partners in decisions where our lived experience could provide meaningful insight. When reviewing Table 1, many of the closed decisions appear to be primarily quantitative and based on existing data, where qualitative input may not have been as relevant. That said, I'm not fully aware of the specific details behind each of those closed modelling decisions, so I can't confidently say whether my input would have added value in those areas. Overall, I felt the team made thoughtful choices about when to engage us.	No. The researchers were great in engaging us if the topics required patient partners' perspectives
If any of these decisions are revisited in the future, would you like to be invited to contribute?	Yes. If the team thinks it appropriate for me to contribute, I would like to be invited. But I trust the team in their making and communicating their decisions in these matters.	Yes. Always interested in the outcomes and where we may have made errors.	Yes.	Yes. Open to being involved again - part of the continuity (i.e. easier on everyone :))

Table 6 (continued)

Question	Partner A	Partner B	Partner C	Partner D
Taking into account your experience with the modelling process and the information provided in Table [4], do you have any concerns regarding the decisions you were not involved in?	No.	Unsure. While I trust that the modelling team made thoughtful decisions about when to engage patient partners, I'm not fully aware of the specifics behind each of the closed modelling decisions, so I can't confidently assess whether my input would have been valuable in those areas. That said, I did notice that most decisions related to Relative Risk (RR) for increased asthma risk due to PM2.5 exposure were open, with the exception of the RR for exacerbations. This stood out to me, as I believe our lived experiences, particularly with both well-controlled and poorly controlled asthma, could have offered useful context in understanding exacerbation patterns. Similarly, under the Asthma Costs section, I'm curious about what those costs encompass and whether the figures used truly reflect the financial burden and indirect costs experienced by people living with asthma. These are areas where additional context from lived experience may have been beneficial.	No.	No concern

Table 6 (continued)

Question	Partner A	Partner B	Partner C	Partner D
Do you have any additional comments or reflections that you feel are relevant to evaluating the LEAP model?	none, i think the team has been great.	It was a great experience.	One thing that stood out to me throughout this process was how open and collaborative the modelling team was. As someone without a technical background in modelling, I appreciated how they took the time to explain concepts and walk us through their reasoning. It made it easier to engage meaningfully and feel like our input had value. Looking ahead, I'd be interested in seeing how the LEAP model could continue to grow, especially in incorporating more social determinants of health, like socioeconomic status or housing conditions, which often intersect with asthma outcomes. I think accounting for those realities could make the model even more representative and actionable.	Can't think of now
In its current state, for what purpose(s) do you think the LEAP model should be used for?	not sure, sorry	The LEAP model can be used to create other models in health research. Specifically how the material was delivered to the team.	Given my understanding of the model, the LEAP model integrates risk factors, particularly air pollution, alongside interventions and health cost outcomes over time to support health economic evaluations and inform asthma-related policy. Its predictive nature makes it especially valuable for projecting future asthma incidence and prevalence based on environmental exposures like PM2.5. This can guide decision-makers on the potential impact and cost-effectiveness of interventions, such as air cleaners, in reducing asthma-related outcomes. Overall, I see the model being a powerful tool for policy planning, resource allocation, and evaluating the long-term benefits of public health interventions.	Using the model for public health advocacy and (prevention) health policy development

Table 6 (continued)

Question	Partner A	Partner B	Partner C	Partner D
Do you have any additional comments or reflections on patient and public involvement (PPI) in health economics modelling, including the approach to PPI that was taken in this project?	I think the approach to PPI has been thoughtful and thorough. The approach and decisions have been communicated clearly and transparently. It really feels like the team have done their best to maximise PPI wherever it's been possible and appropriate.	Amazing approach. The plan used in delivering materials to the team can be used as best practices for engaging patient/family partners.	Being part of this project really showed me the value of patient and public involvement (PPI) in health economics modelling. Traditionally, modelling has been viewed as highly technical and data-driven, but this project demonstrated that lived experience can meaningfully inform decisions, even in quantitative spaces. The team's approach to PPI was intentional and inclusive. They clearly identified where our input would be most impactful and ensured we were prepared to contribute and always took the time to explain things so that we felt confident participating meaningfully. They also created space for open dialogue, treated our insights with respect, and were open to revisiting decisions based on our feedback. This experience showed me that PPI, when done thoughtfully, doesn't just make modelling more inclusive, it makes it more grounded in reality and, ultimately, more relevant and ethical.	If was an honour to be invited as a patient partner to be part of the health economics modeling research! I had never thought a patient partner such as myself would be involved in such a research (as I am not a PhD, statistician etc.). The researchers (Stephanie, Kate) were very helpful, patient in facilitating the sessions ... from providing an overview of the topics to guiding us what they need from us as a patient partners! I learned so much ... so thanks again for the opportunity!

shortcoming of the VIM framework process, whereby modellers characterize decisions and the team lead determines which decisions will receive input via PPI. This process assigns considerable power and accountability to the team lead; although nothing in the VIM framework prevents asking participants which decisions they think they should be involved in, it is not a required step. Having modellers and participants co-identify decisions for PPI would further empower participants but could also raise concerns. For example, participants might assume their role is limited to decisions with obvious connections to their lived experience, overlooking their legitimate contributions to seemingly ‘technical’ (but value-laden) decisions. Notably, we observed that participants were willing and able to contribute to both types of decisions. Although not addressed here, numerous considerations deserve careful attention before adapting the VIM framework to encourage co-identification of decision-making strategies.

Impact on the LEAP model Third, how did the VIM framework affect the final model? An important limitation of this article is that it excludes model results, due to scope and space constraints. However, we described several changes to the model that resulted from PPI, including the addition of sensitivity analyses, the exclusion of a potentially misleading variable (salbutamol dispensations), and the expansion of model outcomes (Table 4). This adds to the growing body of literature that demonstrates that PPI triggers changes to health economics models [2–5]. A difficult question is whether these changes make the models ‘better’. There is no gold standard to answer this question, which must be assessed subjectively by model developers, decision makers, and citizens with an interest in model results. In our view, PPI in ‘Pivotal’ decisions identified through the VIM framework resulted in *prima facie* improvements to the final model, perhaps the most compelling of which is the exclusion of salbutamol dispensations as an outcome of interest. The LEAP team agreed that, given participants’ insights into why salbutamol dispensations may be insensitive to changes in asthma symptoms, this outcome was arguably irrelevant to the decision problem and its inclusion could be criticized by others down the road. One limitation of the present study is that we did not ask others to evaluate the changes to the model that resulted from PPI. Crucial areas for future research include broader, in-depth, systematic analysis of how decision makers and other public groups value changes to health economics models driven by PPI, including PPI structured by the VIM framework.

Impact on participants Fourth, what impact did the VIM framework have on the participants involved in LEAP? Focusing on this question, at least two distinct outcomes should be considered. The first is participants’ *perceptions of the model*; for example, did the PPI process structured by the VIM framework influence participants’ trust in the

model or views of how it should be used? The second is participants’ *personal experiences*; for example, how did the process affect participants’ sense of empowerment, burden, satisfaction, etc.? We aimed to generate preliminary insights by asking participants questions about the LEAP model (Table 6) and administering the Patient Engagement in Research Scale (PEIRS) (see Supp. Mat. 3, ESM). However, in-depth, systematic evaluation of these outcomes was out of scope, which is an important limitation. Further research is needed to better understand how to collaborate effectively with participants in modelling and improve their perceptions of the final model. Although feedback received from participants was generally positive, one participant was relatively critical of the process (see Table 1, Supp. Mat. 3). Follow-up with this participant (a co-author) suggests future work should strengthen communication between modellers and participants. In their words: “While I trusted the modelling team’s intentions and appreciated the inclusive environment, I sometimes found it difficult to tell whether my input had a meaningful impact on certain decisions. This uncertainty, along with my limited expertise in technical modelling and moments where I felt unsure about my contributions during meetings, may have influenced my lower scores on the PEIRS. Greater clarity on how decisions were made and how feedback was integrated could have helped me feel more confident and valued in the process.” In the future, it may be beneficial to schedule routine follow-up meetings between participants and the facilitator, rather than make them available upon request. Despite this constructive criticism, feedback generally suggested that our process was successful in upholding best practices for participatory research. This includes fostering relationships based on mutual trust and respect and ensuring that meetings and facilitation materials are accessible to all [47, 48].

Impact on decision making Finally, an important question is whether downstream policy decisions based on the LEAP model will be influenced by the implementation of PPI following the VIM framework. We did not address this question, which is an important area for future research as LEAP model results become available. Formal qualitative research, including interviews with policymakers, would be valuable.

In addition to raising key evaluation questions, implementing the VIM framework pointed to areas for improvement at the conceptual and practical levels. For one, team members found it challenging to identify ‘Pivotal’ decisions as defined by the VIM framework, as ultimately every modelling decision could potentially be classified this way. A closely related criticism of the concept of a ‘Pivotal’ decision (raised by a reviewer of this article) is that the impact of a modelling decision cannot be known in advance. In the future, the VIM framework may be refined to better guide modellers through these challenges in characterizing modelling decisions. This may require more carefully

distinguishing between decisions where a significant impact on model results can be anticipated with high confidence and decisions where the impact will not be known until the model is run. It may also require the addition of other decision 'types'. As shown in Table 6, many decisions in the current project were not marked as belonging to any of the four decision 'types' defined by the VIM framework. There is room for conceptual development to characterize decisions that do not clearly fit the descriptions currently highlighted by the VIM framework—or else have features of more than one decision 'type'. For example, some decisions labeled 'Pivotal' in this study also had features of 'Informant' decisions, such as the one informed by participants' lived experience of salbutamol use. As the VIM framework recommends that modelling decisions be assessed in advance to determine the relative importance of PPI, further work is needed to clarify the significance of decisions with overlapping 'Pivotal' and 'Informant' features and better guide those assessments.

Another issue that was not addressed here is how to select individuals to participate in the modelling process. Participant characteristics are expected to influence the results of PPI in modelling and concerns surround the possibility of over- and under-representing specific public groups and sets of values in the process. Although this problem is emphasized in the literature that informed the VIM framework, the framework itself does not aim to solve it. Rather, it rests on the simplifying assumption that some level of PPI in modelling is better than none. In this study, all four participants involved for the duration of the project were members of the LAH CPC with lived experience of asthma and they do not represent all members of the general public. Notably, all four participants agreed with modellers' original proposal to use scaling factors obtained from an external source that estimates a ~50% increase in wildfire in Western USA from 2001–2010 to 2050–2059 [29]. This choice reflects, at least in part, shared values around model 'signalling' effects [45] and raises the question of whether other transdisciplinary participants would provide the same or different direction to model development. For example, EW pointed out that members of communities who are investigating strategies to control wildfire might want to model a scenario in which wildfire activity actually decreases in the future—an outcome that is optimistic, but not impossible, and whose representation would signal to model users that reducing wildfire is itself a relevant goal [45]. As norms develop surrounding the selection of participants in modelling, the VIM framework should be adapted to reflect them.

Last, the resource implications of implementing the VIM framework should be considered. In this project, the PPI process was supported by numerous personnel, including four researchers at the professor or senior scientist level and four Masters-level trainees. The four participants received

compensation dictated by the Legacy for Airway Health (LAH) Community Partner Community (CPC), which at time of writing is CDN \$40 per hour. While detailed reporting of resource use is outside the scope of this article, PPI clearly carries significant financial costs. Further research should clarify PPI's benefits, helping funders weigh them against costs.

Grounded in philosophical theory, the VIM framework aims to help identify and deliberate about value-laden modelling decisions, regardless of the particular model or participants involved. This high-level focus creates the potential to adapt the framework to contexts beyond the LEAP project. As the LEAP project continues, ongoing refinement and evaluation of the VIM framework will help determine the value of broader adaptation.

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Data availability The model code and supporting files are publicly available on GitHub 447 (https://github.com/resplab/hepa_ce_v3).

Declarations

Competing interests The authors have no competing interests to declare.

Author contributions Stephanie Harvard: conceptualization, methodology, project administration, writing—original draft; Rachel Carter: methodology, writing—review and editing; Sian Hoe Cheong: methodology, writing—review and editing; Tony Lanier: methodology writing—review and editing; Zainab Zeyan: methodology, writing—review and editing; Amin Adibi: methodology, software, formal analysis, writing—review and editing; Spencer Lee: investigation, software, formal analysis, writing—review and editing; Cristina Novacovik: investigation, visualization, writing—review and editing; Mark Ewert: software, formal analysis, writing—review and editing; Eric B. Winsberg: conceptualization, writing—review and editing; Kate Johnson: conceptualization, methodology, supervision, project administration, funding acquisition.

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