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*Developing a Framework for Public Involvement in
Mathematical and Economic Modelling: Bringing New
Dynamism to Vaccination Policy Recommendations*



Patient and public involvement in research

By public involvement we mean research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them as defined by NIHR INVOLVE

The impact of public involvement in NIHR health and social care research is defined as:

“The changes, benefits and learning gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiatives”

(NIHR INVOLVE 2019)

Why involve the public in research?

Makes research more relevant, focused on questions of importance to patients and the public

Enhances quality of research eg. ensuring a trial measures the right outcomes

A moral/ethical imperative

“Nothing about me without me”

Democratic accountability to the taxpayers

Fairness, accountability and transparency



Co-production

WARWICK

MEDICAL SCHOOL

Sharing power

Including all perspectives and skills

Respecting and valuing the knowledge of all

Reciprocity

Build and maintain relationships

Joint understanding and consensus and clarity over roles and responsibilities



Co-production in action:

The MEMVIE Study – An example of the potential of co-production in a complex area

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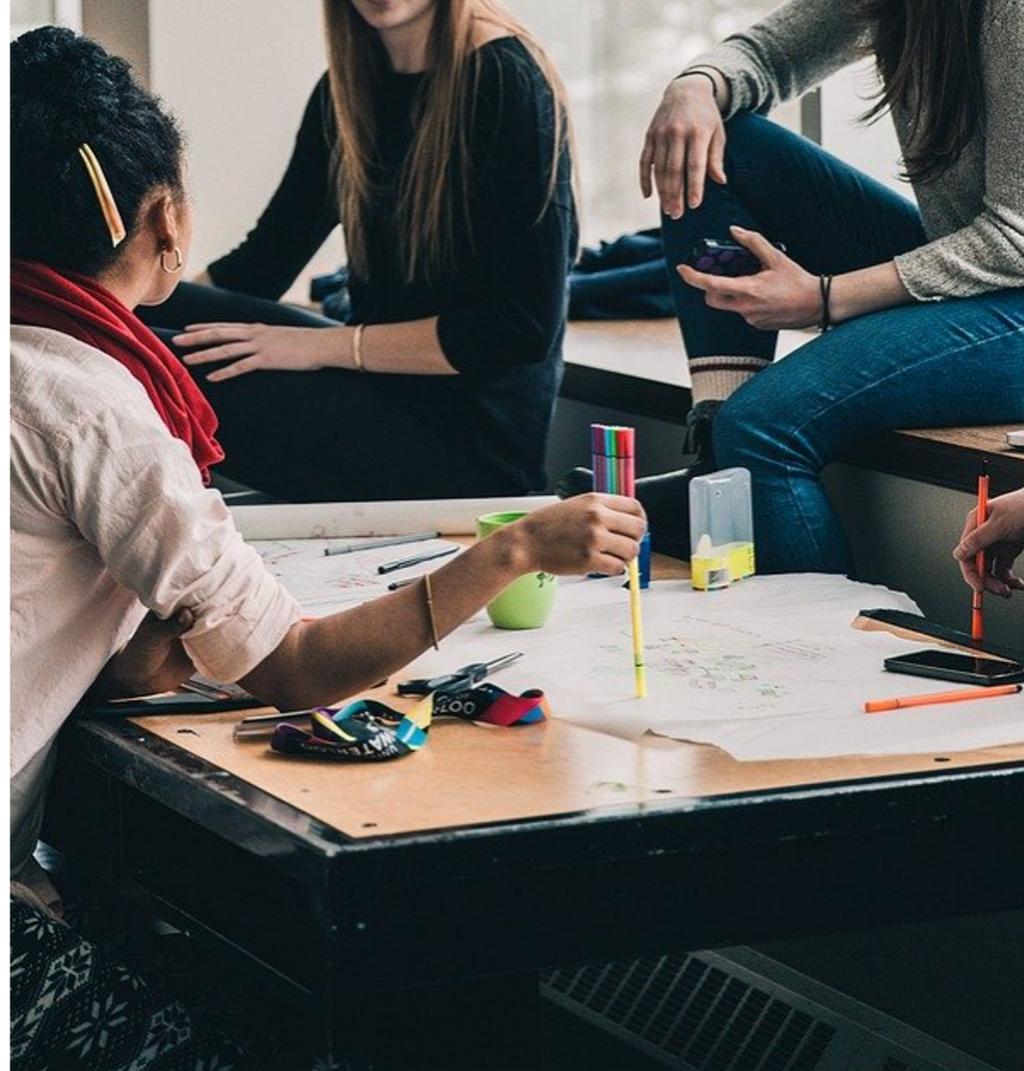
Mathematical and Economic Modelling for Vaccination and Immunisation Evaluation (MEMVIE)

- Public involvement less common in complex areas such as mathematical and economic modelling
- Modelling is important – provides decision makers with best available evidence to reach a decision
- Involving patients and public – enhance models, improve confidence and accelerate decision making
- Key outcome of MEMVIE: Identified a framework to identify the nature and type of public involvement to guide future models, identifies values, identifies conditions for implementation and provides a detailed long form version that considers involvement at each stage of the modelling process and a short form summary



What did it involve?

- 21 meetings over 5 years
- Each lasted 2-3 h. Email contact in-between with the group commenting on documents
- Deliberative knowledge space and Think Aloud techniques encouraged ideas and thoughts to emerge
- Public contributors were able to challenge the data, the basis for the collection of data and the interpretation of that data, thinking outside of the box in a safe space where modellers could rework their thinking
- The meetings enabled thematic development over time as the Reference Group contributors worked with the academic contributors on continuous iterations of the emerging framework



Public contributor

“We had now picture of what public involvement would look like, and no road map to guide our journey. We also had now idea of the constraints we might need to work within. The researchers we were working with had no idea of what they wanted from us. Or even if they could add anything useful to their model. The first year really felt like we were working in the dark, not even sure what we were trying to achieve.”

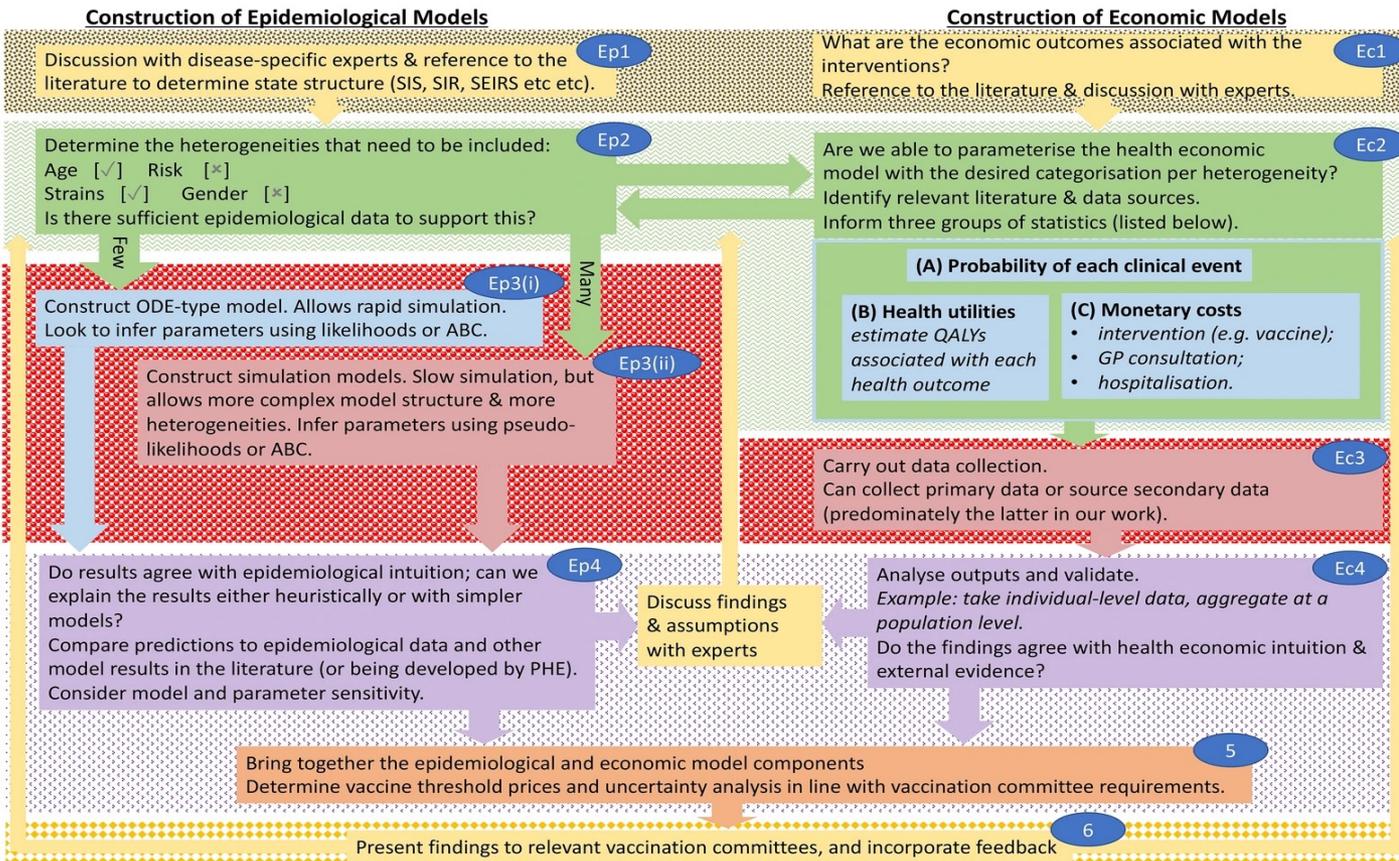
Public contributor

“A key breakthrough was the pictorial representation of the Epidemiological and Economic Model. For the first time we understood modelling as a process and provided a framework through which we could start to organise and structure our contributions”

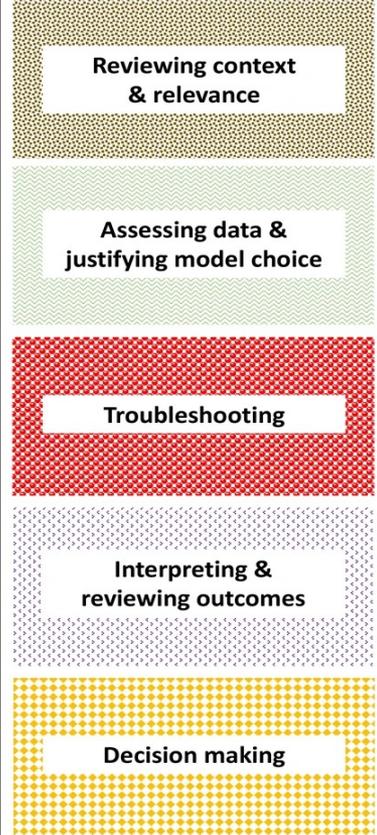
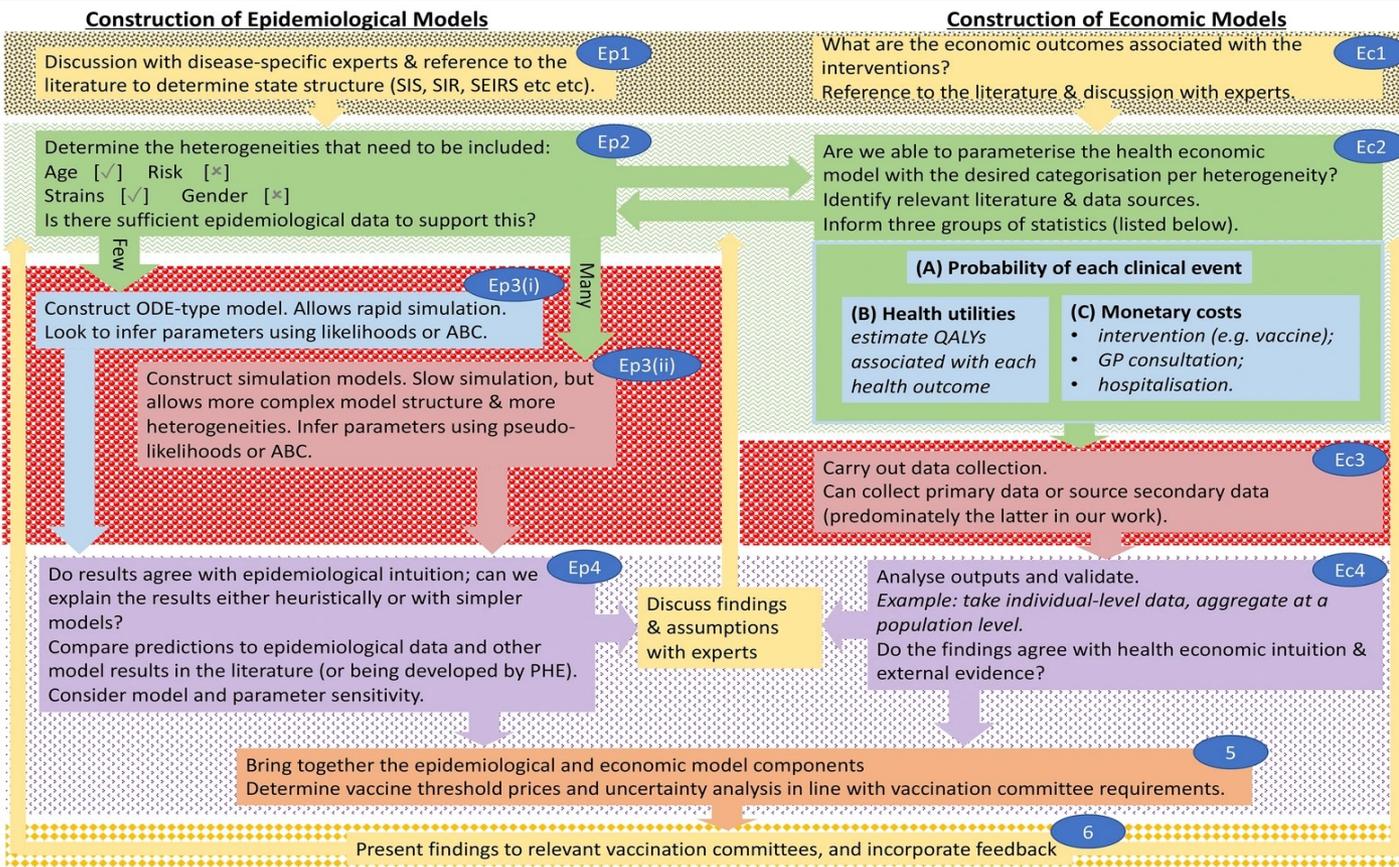
Academic contributor

*“When I joined midway through the duration of the MEMVIE project, I had not had any previous exposure to public involvement as part of the research process. I found it extremely beneficial to have an additional forum to describe our modelling process, discuss model assumptions and examine data. **From my perspective, being given the opportunity to convey the work to public members through reasoned discourse, ensured justification of modelling aspects, aiding model integrity and validity.** In addition, public involvement generated broader discussion surrounding data curation and data collection (such as questionnaire content), producing recommendations that can be used to inform future developments.”*

MEMVIE framework for PI



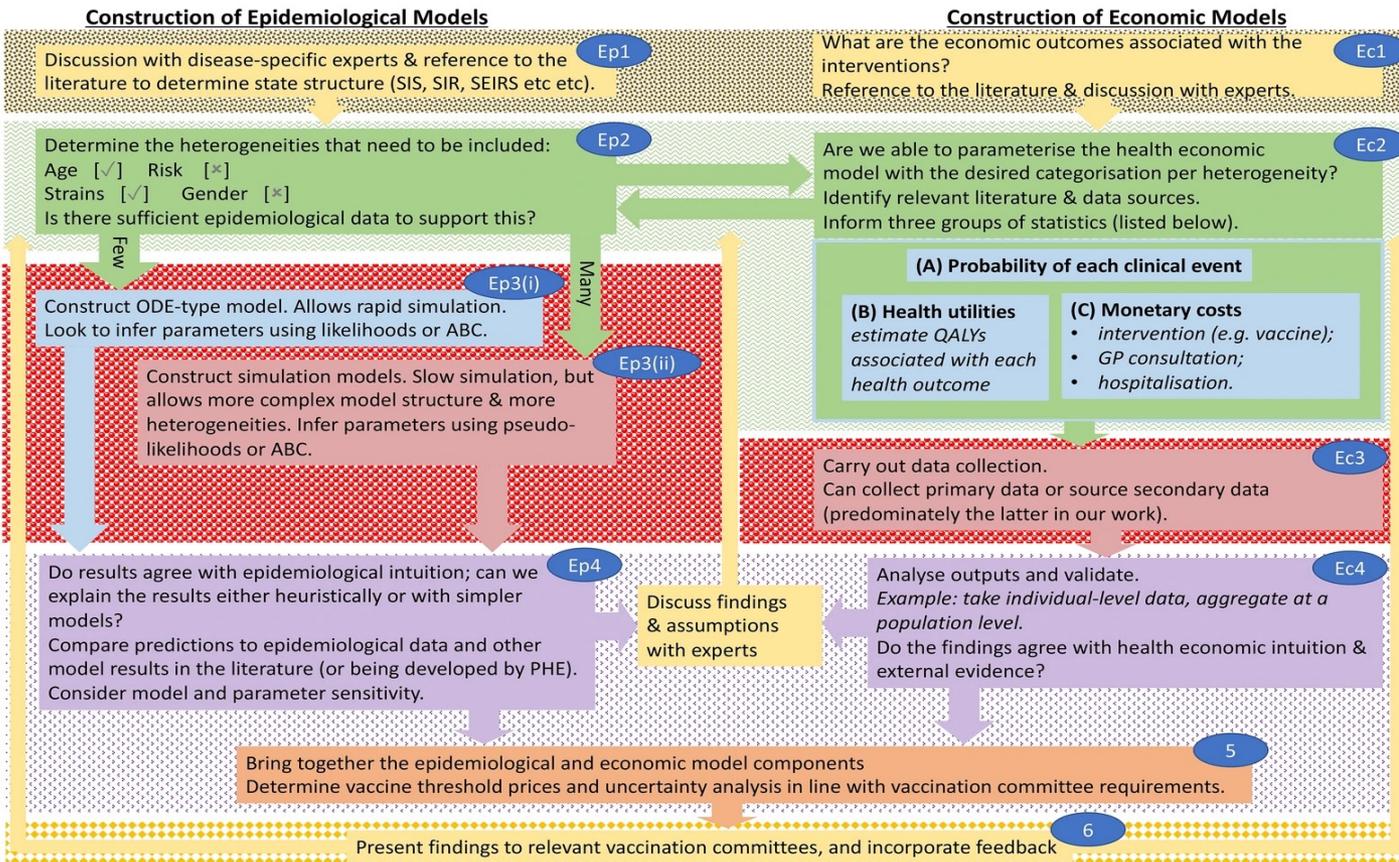
MEMVIE framework for PI



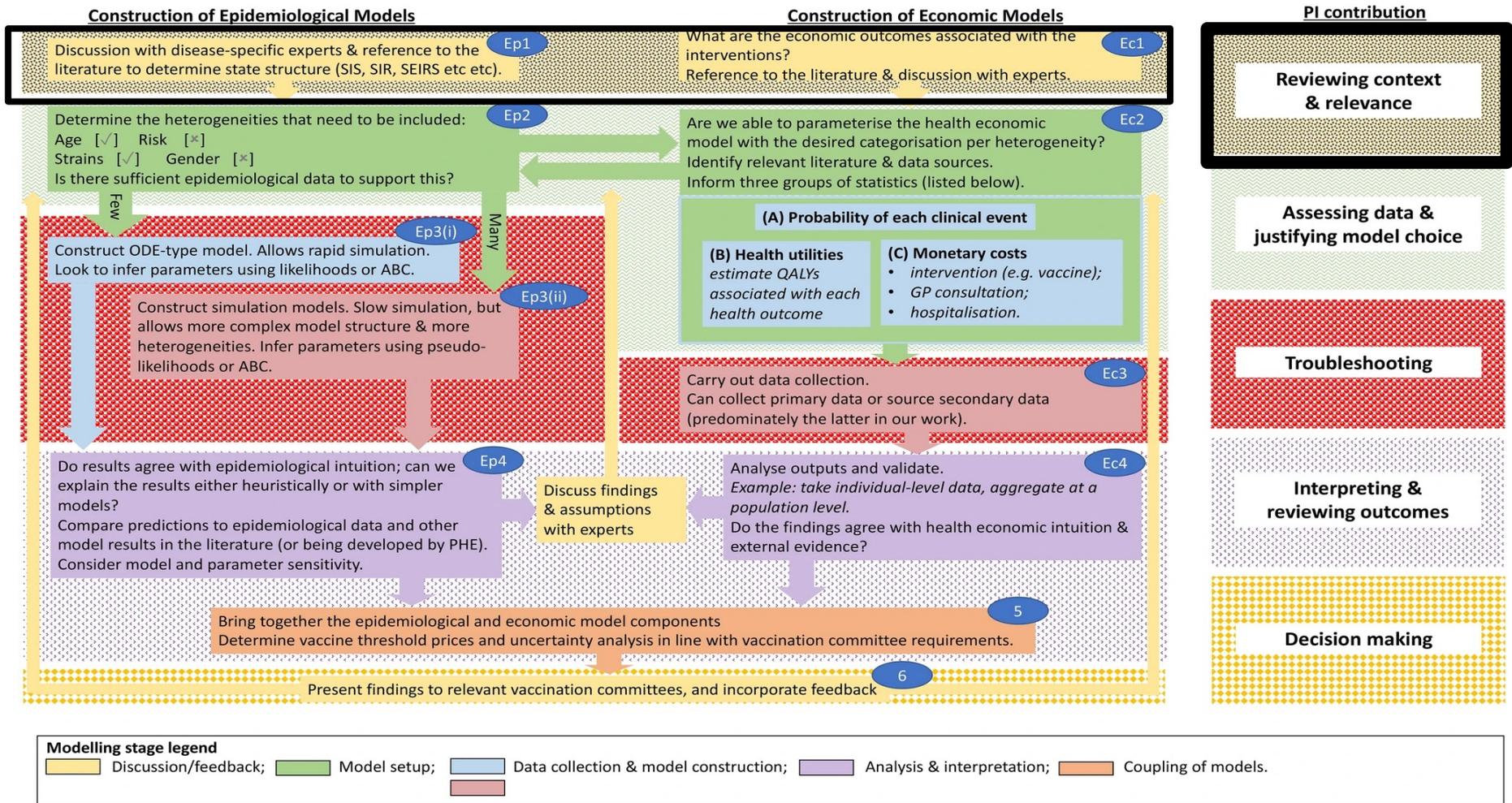
Modelling stage legend

- Discussion/feedback;
- Model setup;
- Data collection & model construction;
- Analysis & interpretation;
- Coupling of models.

MEMVIE framework for PI

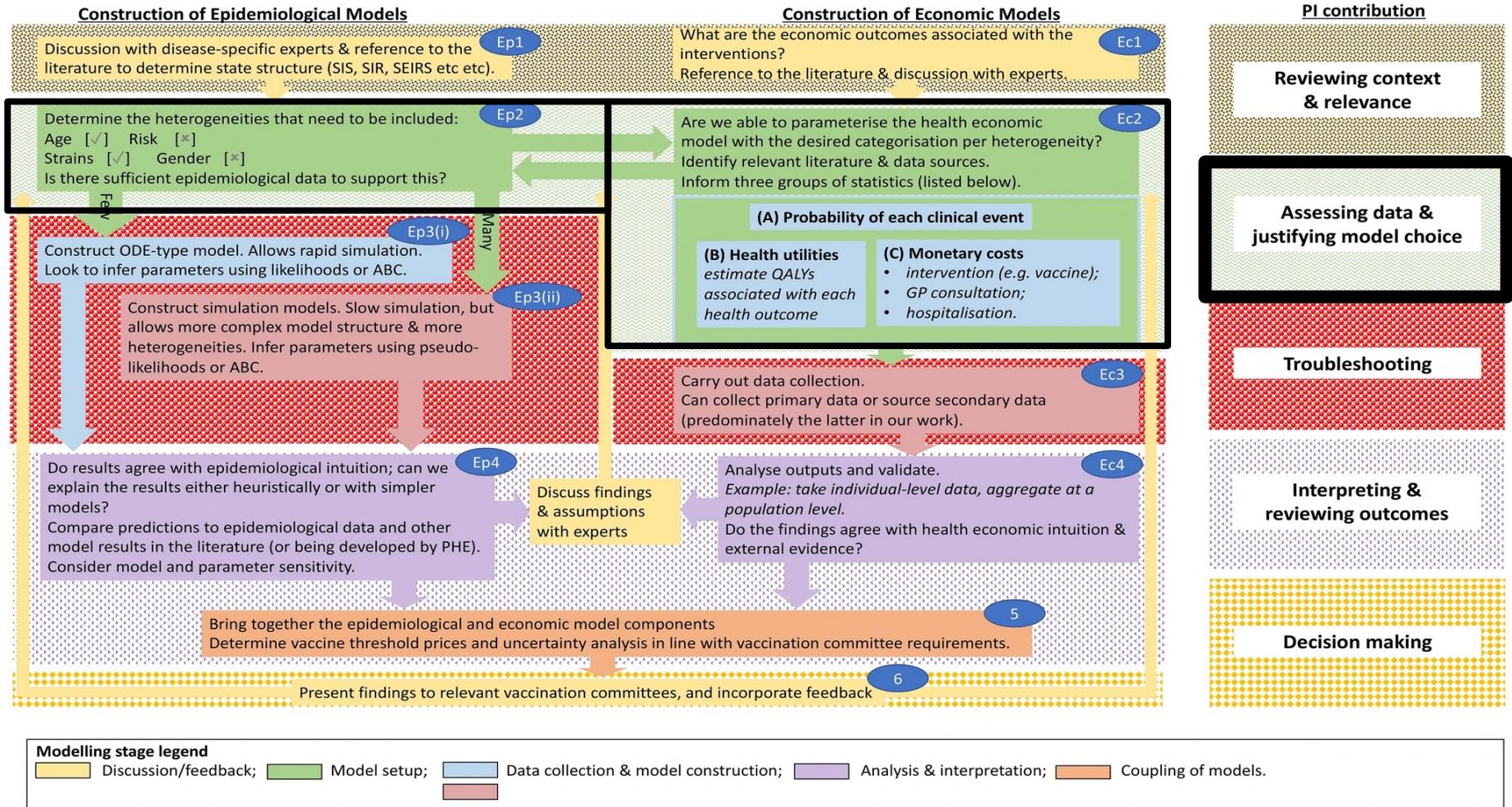


MEMVIE framework for PI



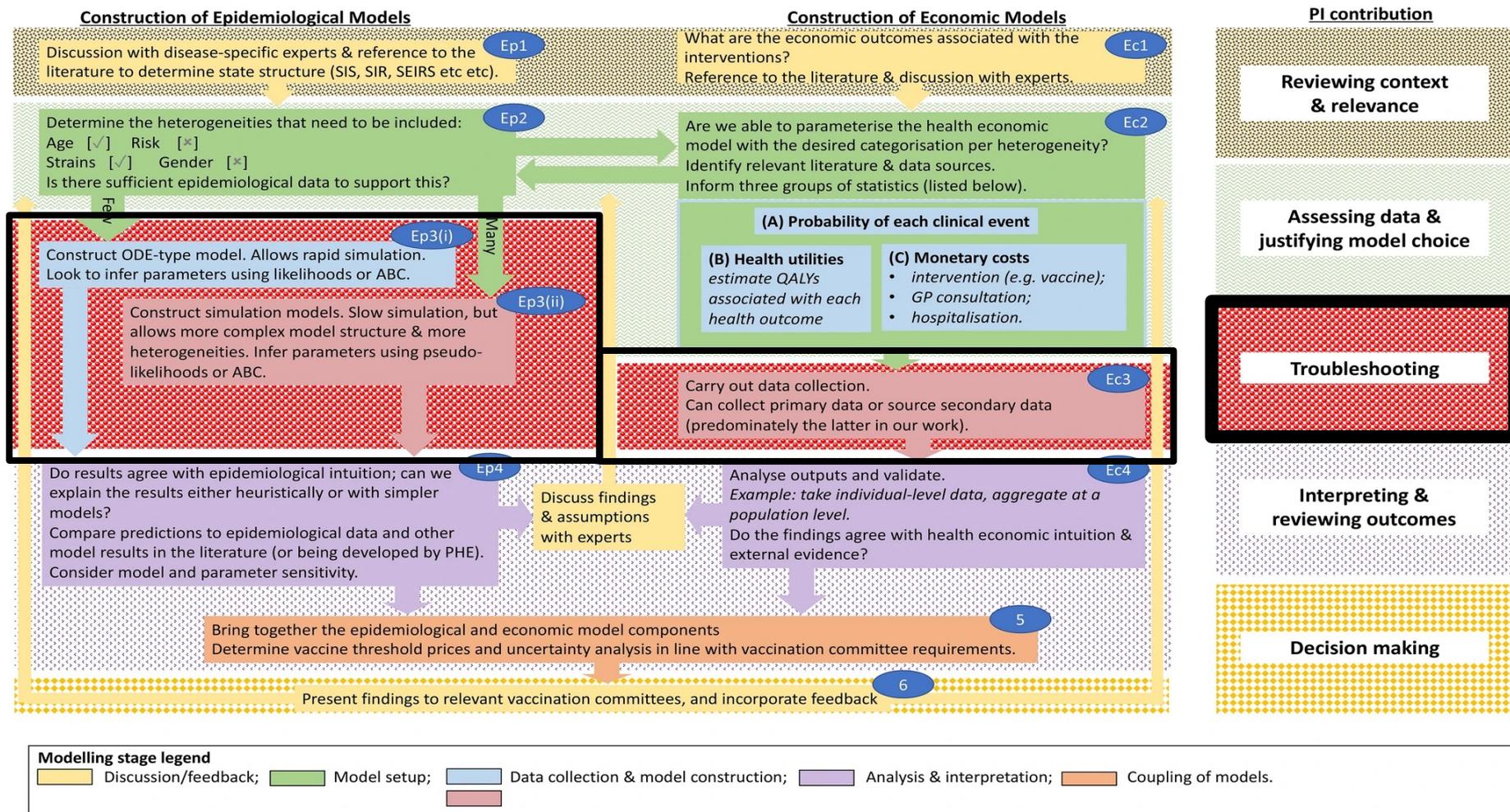
- Determining what should go into the model, with inputs from disease-specific experts and through reference to relevant literature.

MEMVIE framework for PI



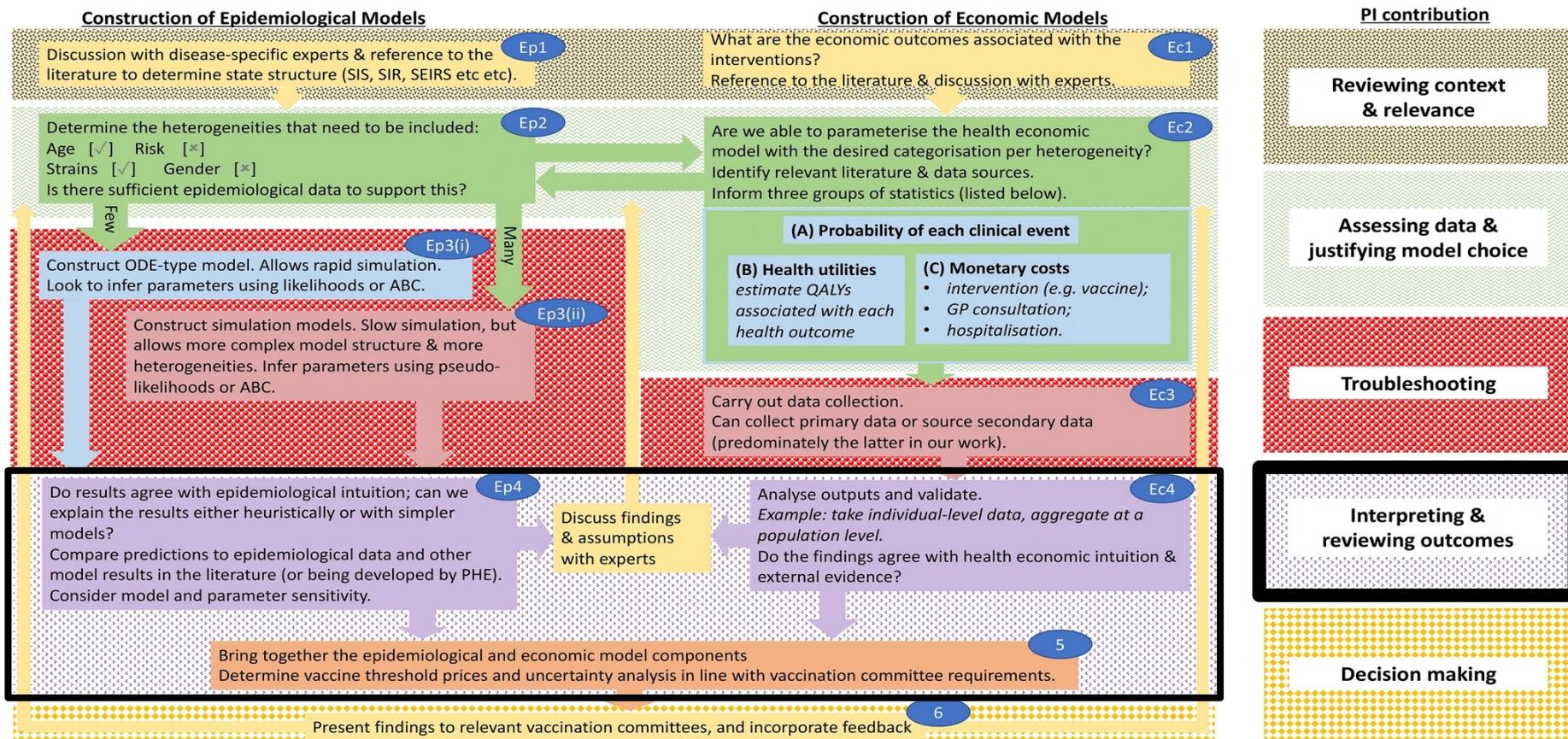
- Farther-reaching benefit of PI through querying the robustness of a tool or questionnaires that have been used to collect data.

MEMVIE framework for PI



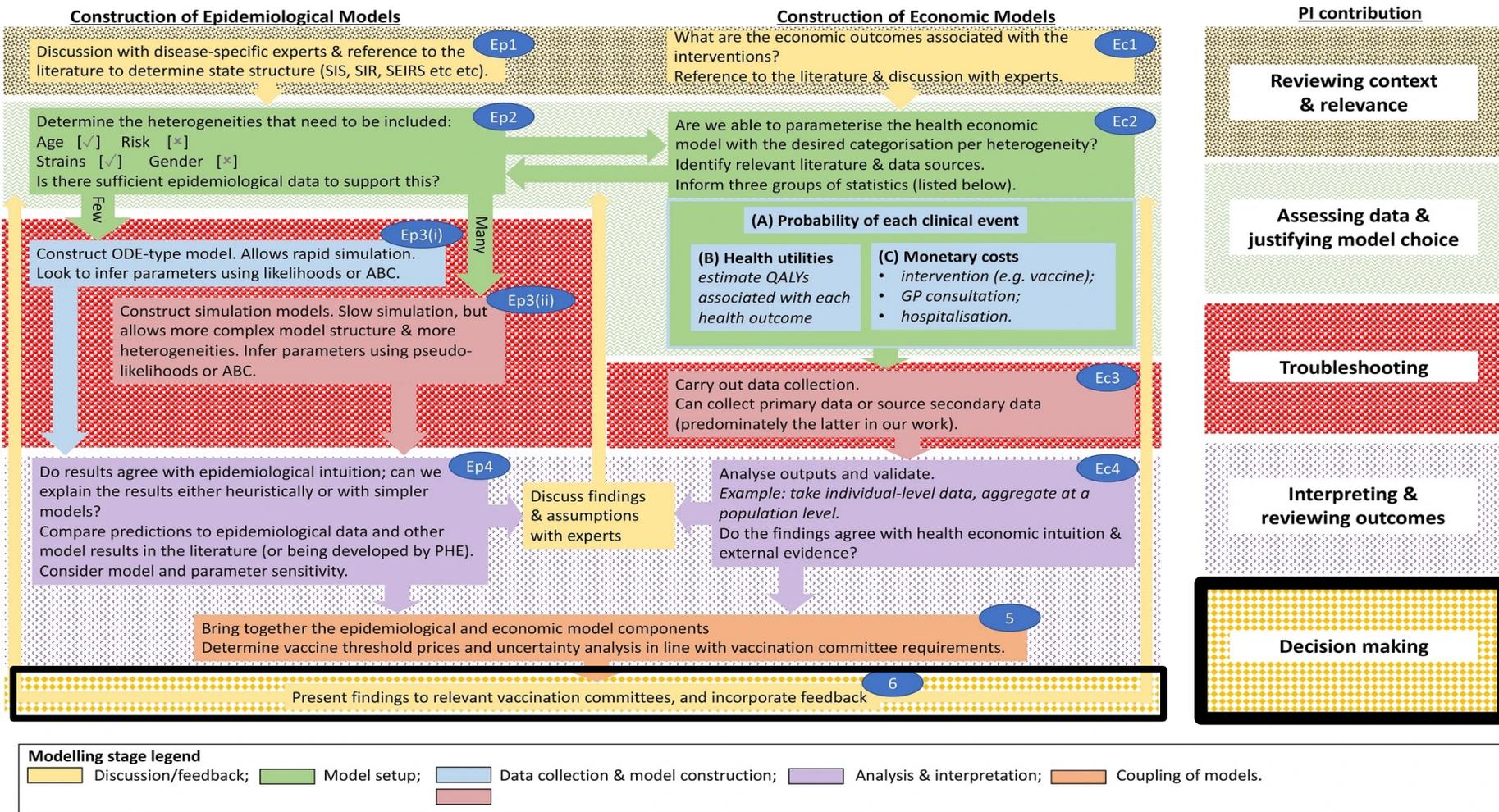
- Preliminary findings from the models can be presented to the PI group and the influence of some of the factors thought to be contributing to uncertainty discussed.

MEMVIE framework for PI



- Opportunity for the PI group to review the models and consider the sensitivity of the results in relation to the parameters used, and to critique the model assumptions.

MEMVIE framework for PI



• PI contribution could be in the form of a report detailing group findings, considered alongside the model or presented by public representation on relevant committees.

A summary of MEMVIE

MEMVIE includes:

The context for implementation: what do you need to have in place

The values that underpin PPI in modelling

Short Form MEMVIE Framework

Long Form MEMVIE Framework

Conclusion

- Our MEMVIE Framework is ready for application and refinement
- Our work shows that PPI in methodologically complex area such as modelling is feasible
- However, PPI is more common in the content of a research study and less common in methodological development
- The advantages of PPI in methods thinking is that we can unravel a method, explore where PPI can contribute and co-produce a framework to guide future work
- However funding for PPI in methodological work is very rare
- Future development of PPI and its underpinning evidence base requires that we maximise the contribution studies can make methodologically
- This requires changes in funding and requires funders to acknowledge that PPI can be evidence informed and evidence generating, both in the content of research and in the methods used to acquire knowledge

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