Pharmacoeconomics Journal. Article Title: Health Economists on Involving Patients in Modelling: Potential Benefits, Harms, and Variables of Interest. Online Resource 1: Supplementary Detail. Authors: Stephanie Harvard and Gregory R. Werker. Corresponding Author: Stephanie Harvard, University of British Columbia Faculty of Pharmaceutical Sciences, harvards@mail.ubc.ca.

Online Resource 1 (Supplementary Detail: Methods, Results, & Discussion)*

*Portions of this document have been previously published (i.e., as worded below) as supplementary material in Harvard S, Werker G, Silva D. Social, ethical, and other value judgments in health economics modelling. Social Science and Medicine. 2020; 253: 1-9.

1. Methods

1.1. Participant recruitment

The recruitment email was sent to all individuals (approximately 110) on the Health Economics and Simulation Modelling (HESM) Methods Cluster email listserve. A description of the HESM Methods Cluster is available at https://bcsupportunit.ca/health-economics-simulation-modelling. The recruitment email stated that the research team was seeking "experts" to participate in a study and that "If you have professional experience in HESM research (e.g., decision modelling, discrete event simulation, or trial-based economic evaluation approaches) and are fluent in English, you are eligible to participate". All individuals who responded to the study invitation and who were available for interview were included in the study.

1.2. Advance Material for Participants

The Advance Material sent to participants prior to interviews is shown in Appendix 2. This material provided participants with general definitions of values in addition to the study definition of 'value judgments', along with descriptions of philosophical theory relevant to the interview topic. Advance material did address the topic of patient involvement in modelling.

1.3. Interview Conditions

Participants were invited to participate in an in-person interview at a physical location of their choosing. All interviews were conducted by the lead author (SH), a post-doctoral fellow and white anglophone woman in her late thirties. Additional details about SH and reflections about her influence are provided in this Appendix in Section 3.1. All interviews were audio-recorded and professionally transcribed. Following transcription, SH listened to the audio-recording while reading the interview transcript and corrected for error.

1.4. Interview Questions

The Interview Guide is shown in Appendix 3. As described, the majority of questions focused on value judgments in modelling, and the question about patient involvement in modelling was the only one of its kind. This question was made open-ended in order to give power to participants and encourage them to speak from their position of expertise [supplementary reference 1]. Direct questions about academic rank were not asked, as this was considered irrelevant to the inquiry and potentially distracting.

1.5. Theoretical Position and Data Analysis

In this study, the focus of data analysis was the question: "Before we close, I would like to ask your views about having patients involved in the modelling process. Do you have any thoughts about this as a potential?". We followed Braun and Clarke's approach to

thematic analysis, which encourages us to "acknowledge our own theoretical positions and values in relation to qualitative research" and to recognize analytic decisions "*as* decisions" [23, p. 80, italics in the original]. Our theoretical position is rooted in the philosophy of modelling and is well-summarized by Bokulich and Parker's "pragmatic-representational (PR) view of data" (supplementary reference 2, p.1). On the PR view, data and data models (including qualitative data models) are representations that result from a process of inquiry and "they should be evaluated in terms of their adequacy or fitness for particular purposes" (supplementary reference 2, p.1). This includes two varieties of adequacy-for-purpose that are often of interest in practice, i.e., "adequate-in-an-instance" and "adequate-given-resources" (supplementary reference 2, p.13). The PR view is consistent with the broader body of philosophical literature that argues that the primary virtue of scientific models is adequacy-for-purpose (see supplementary references 2-5). Model adequacy-for-purpose links conceptually to the values in modelling in literature, in which purposes are understood as values [8-14, 31]. Our approach to data analysis (i.e., the strategy used to develop the data model) was therefore informed by the purpose of the study, which was to inform future research into the net benefit of patient involvement in HE modelling.

We note that Braun and Clarke's recommendation to acknowledge analytic decisions as decisions [23, p. 80] is consistent with the implications of the values in modelling literature [4, 8-14, 31]: both bodies of theory ultimately encourage recognizing and reflecting on value judgments made in the analytic process. We recognize several value

judgments that we made in this study: first, we used the theoretical lens of 'benefits, harms, variables' when interpreting participants' responses. To be sure, this was not the only possible lens; in fact, we considered others, such as a pragmatic 'who, how, why' framework similar to one used to analyze transparency in decision modelling [11]. Our final decision reflects our judgment that the lens chosen was of greater value, as it would result in output more closely matching the structure of models we imagine in future research (e.g., costs, benefits, independent variables). The lens we chose remains compatible with work highlighting potential risks and benefits of transparency in modelling [11]. Beyond this, we made value judgments pertaining to how to categorize, i.e., draw boundaries between, benefits, harms, and variables we interpreted participants to be referencing. Following insights from philosophy of science, we approached this task pragmatically, understanding that conceptual boundaries may be drawn differently for different purposes. As our purpose was to inform future research, we aimed to merge categories wherever we could do so without sacrificing conceptual clarity, as our experience as modellers has taught us to value parsimony. At the same time, we aimed to preserve unique insights: even if something was mentioned by a single participant, we designated it a subtheme if we perceived it to be conceptually distinct. This is akin to a decision to prioritize sensitivity, which we recognize as a value judgment [4].

2. Results

2.1. Interview Locations and Duration

In-person interviews took place at nine different locations, with the majority occurring in institutional settings (Table 1). Interviews lasted an average of 57 minutes (range 31 minutes to 1 hr, 22 minutes).

2.2. Participant Experience in Modelling

In response to the open-ended question about their work in modelling, the majority of participants described the types of models they had experience developing (Table 2). Other markers of experience provided by participants included academic degree obtained or in-progress, years of experience, number of models developed, educational background (e.g., discipline, field of study), qualitative descriptions of professional focus (e.g., modelling techniques, theoretical issues, technical issues), qualitative descriptions of experience (e.g., "many years") and qualitative descriptions of role (e.g., academic rank, role in modelling team). All participants described having expertise in one or more areas relevant to health economics modelling. Eight participants described being directly involved in model development and analysis (e.g., coding, programming, statistical analysis) but did not describe being engaged in other activities in academia. The remaining 14 participants described being engaged in one or more activities in academia in addition to model development and analysis (e.g., peer-review, supervising students, teaching classes, advising governments, holding a faculty position or post-doctoral fellowship). Among those 14 participants, two were in the course of completing their PhD.

2.3. Participant Experience Working with Patients

As shown in the Interview Guide (Appendix 3), participants were not asked about their previous experience working with patients. Four participants (P3, P4, P17, P18) made direct reference to previous experience working with patients, and three of these participants (P3, P17, P13) made comments that were explicitly based on that experience, as described in the manuscript. In the authors' interpretation, other input was given in hypothetical terms, as described in the manuscript.

3. Discussion

3.1. Potential Influences on Interviews and Results

The lead author SH conducted the interviews. SH is known to many people in the health economics community in the study setting and she had given two public presentations on values in science to that community prior to the interviews (in June 2018 and October 2018). It is possible that SH would have had an unintentional influence on participants' responses. However, to avoid this as much as possible, SH did not give her personal views during the interviews and she listened to participants' answers without leading them; she was interested to know participants' views and considered that to be the purpose of the study. It is not possible to know how SH's sociodemographic characteristics and/or social position would have influenced participants' responses to the question analyzed in this study, as data on this were not collected. However, as a post-doctoral fellow, SH does not hold a powerful professional position in the health economics community or relative to participants.

In the current study, the focus is on participants' general views on involving patients in modelling. It is possible that participants could have withheld some of their views (e.g., negative views), particularly since it was public knowledge that SH's role (and the qualitative study in general) was funded by the BC SUPPORT Unit, which supports patient involvement in health research. As this could have occurred, the findings should not be interpreted as a comprehensive representation of all of participants' views. Finally, it is possible that the earlier questions asked during the interview (on value judgments in modelling) would have influenced participants' responses to the question on patient involvement in modelling. One specific possibility is that the early interview questions would have prompted participants to frame the benefits of patient involvement in modelling in terms centred explictly around patients' values. In general, this was not observed, although (as noted in the manuscript) P17 remarked that "you need to involve everyone that’s affected in that process because their values might be different from ours". However, the results of this study should be interpreted in context, as reflecting the perspectives of participants who were briefed on the issue of value judgments in modelling and participated in interviews on this topic.

3.2 Other Considerations

In this study, we analyzed participants' responses to a single open-ended question on patient involvement in modelling, and it is a limitation of the study that it included no additional questions on this topic. This includes certain questions that could have

provided additional context for participants' responses, such as a direct question regarding whether participants had previous experience working with patients. As noted in Section 2.3, where participants' comments were explicitly based on previous experience working with patients, this was noted in the manuscript. However, as a direct question about participants' experience working with patients was not included, the relationship between participants' input and their previous experience was not a focus of the analysis. This is a limitation of the current study and readers are encouraged to interpret the results with this in mind, e.g., conservatively, as largely hypothetical. In our view, given that patient involvement in HE modelling is not yet a widespread practice, even HE modelling professionals' hypothetical views relevant to this potential are an important contribution to the literature.

Although the current analysis was based on a single question, we note that the question was highly open-ended, which helps to alleviate the potential concern that participants' responses lacked essential context. That is, participants were invited to register any insights they considered to be relevant to the question, including whatever context they deemed to be important. For this reason, although the results of this study should be interpreted as having more breadth than depth, we believe the risk of important misinterpretation is minimal. As noted in Section 1.5, this study was carried out from a theoretical position rooted in the philosophy of modelling, in which models' primary virtue is understood as being adequacy-for-purpose, which includes adequacy in the context of available resources (supplementary reference 2). The purpose of this study was

to inform future research on the net benefit of patient involvement in HE modelling, using data from a larger qualitative study in which a small portion of resources were devoted to exploring the idea of patient involvement. We believe this is an important purpose and our findings are adequate to inform future research.

Table 1. Interview Locations

Location	Number of interviews
Health Economics Research Group (Hospital-Based, University-Affiliated) A	3
Health Economics Research Group (Hospital-Based, University-Affiliated) B	4
Health Economics Research Group (University-Based) A	3
Health Economics Research Group (University-Based) B	6
Health Sciences-Related Department, University A	1
Health Sciences-Related Department, University B	1
Private home	1
Specialized Research Institution (Hospital- and University-Affiliated)	2
Specialized Research Institution (Hospital-Based, University-Affiliated) B	1

Table 2. Participant Descriptions of Experience: Model Types

[Disease-specific] models
Big Data; statistical models; disease-progression models
Big Data; statistical models; machine-learning algorithms
Cost-effectiveness analysis; simulation modelling; conventional regression modelling
Cost-effectiveness models
Decision-modelling; trial-based evaluation
Decision-tree; individual-level simulation modelling; cost-effectiveness analysis; HTA
Decision-tree; Markov
HTA; Markov
HTA; Markov models; decision-trees; microsimulation
Individual-level simulation modelling; trial-based cost-effectiveness
Markov modelling; discrete-event simulation; micro-simulation; reference modelling
Markov modelling; statistical modelling
Markov models
Markov models; discrete-event simulation; decision-modelling; policy-intervention modelling
Population-level models
Semi-Markov cohort models; dynamic transmission models; agent-based models;
Simulation modelling; preference-based measurement
Simulation modelling; Whole Disease Modelling
Trial-based cost-effectiveness analysis; model-based cost effectiveness analysis
Trial-based economic evaluations; model-based economic evaluations
Whole Disease Model

Supplementary References

1. Grbich, C. 2013. Qualitative Data Analysis: an Introduction. Sage Publications, London.

2. Bokulich A, Parker W. Data Models, Representation, and Adequacy-for-Purpose. 2021. [Preprint, forthcoming in European Journal for Philosophy of Science]. Available at: http://philsci-archive.pitt.edu/18530/

3. Alexandrova A. Adequacy for Purpose: The Best Deal a Model Can Get. The Modern Schoolman 2010; 87 (3/4): 295–301.

4. Parker, WS. Scientific Models and Adequacy-for-Purpose. The Modern Schoolman 2010; 87 (3/4): 285–293.

5. Parker, WS. Model Evaluation: An Adequacy-for-Purpose View. Philosophy of Science 2020; 87 (3): 457–477.