“Turning mirrors into windows”: A study of participatory dynamic simulation modelling to inform health policy decisions

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Chapter 8: Discussion and conclusions

This thesis presents an in-depth exploration of the implementation, feasibility and value of a participatory approach to the development of dynamic simulation models (DSMs) that address real-world health policy questions. The participatory process utilised in these projects was novel both in terms of the methods and activities utilised to mobilise knowledge and engage participants actively (Chapters 3 to 5) and in terms of the complexity of the policy questions addressed and the sophistication of the DSMs developed (Chapters 5 to 7). The thesis research examined the participatory model development processes, and analytic objectives and decision-making involved in developing a DSM to inform policy and planning for diabetes in pregnancy in the ACT (Chapters 4, 5 and 7). It also explored the experiences and perceptions of end-user decision makers involved in participatory processes for three DSM case-studies (Chapter 6).

Each manuscript presented in the results of this thesis (Chapters 4-7) includes a discussion of findings and conclusions. Chapter 4 revealed how participatory DSM builds on best practice elements of knowledge mobilisation practice by embedding co-production principles and actively engaging key stakeholders, including end-users, as participants in the model development process. Chapter 5 revealed the iterative cycles of engagement, analysis, negotiation and refinement involved in the process of developing a DSM as a quantified decision support tool for diabetes in pregnancy. The key analytic elements of the interdisciplinary, participatory approach to develop a DSM for diabetes in pregnancy included: negotiating a focus topic that was a current priority for participants; defining the model scope; iteratively refining the model structure and logic; reviewing and synthesising evidence to quantify the main dynamic relationships within the system; ensuring that the model was focused on priority policy questions; engaging with and communicating model results; and applying the model to support evidence-informed dialogues about policy options. Chapter 6 provided new insights about the participatory process from the perspective of end-user decision makers in three case-studies. The participatory aspects were highly valued by both senior clinical and public health decision makers and were viewed as essential for ensuring that the models utilised the best available evidence and focused on priority policy questions that were locally relevant. The participatory process was also critical to building trust in the model as a decision support tool. The diabetes in pregnancy model
(Chapter 7) developed in the primary case study demonstrated a greater need for population level (over targeted) interventions focused on weight loss in order to “turn the tide” on diabetes in pregnancy. These findings from the individual papers will not be discussed again in detail in this Chapter. Instead, the main findings of the thesis are synthesised from across the included papers and discussed below as a body of work. The following sections also present the challenges and limitations of this “real-world” participatory action research study, and recommendations for future research.

Applying a participatory dynamic simulation modelling approach to public health issues

As researchers and public health professionals navigate complex health policy environments, there is growing need to engage in interdisciplinary problem solving, including creating and using a wide range of evidence and other information [1-7]. DSM is a rapidly advancing approach to decision support that can move beyond the limitations of traditional static, statistical methods to facilitate greater understanding about challenging public health issues [4, 8-10]. However, adoption of complex DSMs requires a conceptual shift for epidemiology and public health professionals [4, 11, 12]. Dynamic simulation modelling requires a shift in thinking away from statistical association models focused on effect estimates to simulations which can test scenarios under different conditions. It also relies on a synthesis of diverse evidence rather than focus on observed associations within finite and specific datasets [11, 12]. Complex DSMs do still require observational and experimental epidemiological data [11, 12]. However, these data need to be used differently, and in combination with new types of data collected and generated using innovative technologies, such as mobile device technology and machine learning. Prior research demonstrated that data from disparate sources can be synthesised and collated in order to create simulation models that enable the exploration of the key public health questions of interest [4-6, 9, 11, 12].

The technology required for modelling complex domains is readily available and increasingly accessible to use [13]. However, for the full potential of policy-relevant modelling to be achieved, attention needs to be paid to the processes of model development and to the inhibitors and facilitators of model use [4, 13]. In the modelling case studies examined in this thesis, the models were developed in partnership with Australian jurisdictional health departments who were the primary stakeholders with key decision-making responsibilities
for the complex, public health issues being examined. Participatory modelling processes provided an opportunity for the stakeholders from a range of disciplines, including the end-user decision makers, to work collaboratively on complex and contested problems [5, 9, 13, 14]. The participatory processes adopted in the case studies facilitated the incorporation into the modelling process of participants’ extensive and rich knowledge about the focus issues. Their contributions were used by the modelling teams to inform, analyse and refine the logic and structure for the models. According to the typology of stakeholder involvement proposed by De Gooyert et. al., the role of stakeholders in our research included balancing (identifying alternative decision options and associated trade-offs), structuring (increasing knowledge about the focus issue) and involving (providing multiple viewpoints of the problem issue and potential solutions) [15]. The involvement of these primary stakeholders as partners ensured that the models targeted priority policy and program questions, increased interest and confidence in the use of the models for decision support and increased the likelihood of them being applied in practice (Chapters 4, 5 and 6).

Using co-production to convert qualitative conceptual maps into quantified simulation models

Relationships and co-production of knowledge are key elements of knowledge mobilisation and are critical to ensure that research findings are policy-relevant and can be utilised to inform decision making [16-19]. The participatory approach provided a structured process to facilitate interdisciplinary dialogue and combine diverse perspectives. This research confirmed how the developed partnerships and relationships were critical to the model development and to its likely subsequent use to inform health service and policy decisions. It was important to ensure that partners were engaged early in the project and that they were involved in deciding the priority topic to focus on. The end-user participants actively engaged in modelling decisions; they were interested in ensuring that the model was grounded in rigorous evidence and focused on their priority policy questions. This co-production was a key element for maintaining the partnership relationships throughout the process. Engagement activities and modelling team-participant interactions also occurred both within and outside of formal workshops and meetings to facilitate participants’ contribution of knowledge and their understanding of the model. Interactive activities were designed and implemented to draw out participant knowledge and expertise and to familiarise them with the model. The professional networks available through the participant groups identified and
facilitated future opportunities for the model to be applied in practice. The end-user participants all emphasised the importance of collaboration and valued the opportunity to interact with colleagues to discuss the focus issue from a range of perspectives.

Recent reviews of knowledge mobilisation and participatory DSM across health and other sectors identified the need for more knowledge about the implementation of participatory approaches to model development [13, 20, 21]. Despite acknowledgement of the importance of including end-user stakeholders in model development [13, 22-24] most participatory modelling projects have not explicitly reflected on the participatory process component of the project [23, 25]. Those that have reflected on the participatory process have concentrated on health service and facility design [26, 27] rather than population health policy development. This thesis is the first empirical research specifically focused on understanding and elaborating the participatory method in applied population health policy settings. The in-depth, empirical examination also exposed and reported the joint analytic processes involved in converting the collaborative, conceptual system map developed with participants into a rigorous quantified DSM (Chapter 5). The decision-making processes involved in the model development were highly interactive, as participants identified, reviewed and critiqued important sources of evidence to inform model parameters and assumptions, and deliberated among themselves to ensure that the model was focused on current, priority policy questions. Communication challenges commonly arise during complex modelling projects [13] and were identified in the primary case study in this thesis. For example, finding strategies to communicate a strategic view of the model logic and assumptions without swamping participants in a detailed view of the structures used in the modelling software was important. In my research of the participatory modelling process, storytelling was identified as an effective strategy to overcome these challenges and facilitate participant understanding of the structure and logic of the complex DIP model. Storytelling was also effective to communicate model results to a wider policy audience (Chapters 5 and 7). In the primary case study, the use of “case history” stories derived for individual agents in the model were a familiar method to facilitate communication with participants.
Using participatory modelling to mobilise knowledge and inform health policy decision making

Natural experiments and case-studies have been identified as important methods to facilitate learning about the future role of systems approaches to knowledge mobilisation, particularly, empirical studies of participatory modelling in applied ‘real-world’ settings [20, 28, 29]. The participatory DSM approach implemented in these case studies, and empirically analysed in this thesis, built on elements of knowledge mobilisation best practice by integrating and synthesising diverse forms of evidence into dynamic decision support tools; embedding deliberative methods that placed end-users at the centre of the process and emphasising stakeholder participation to co-produce knowledge. The perspectives of end-users on the unique benefits that participatory DSM provided over other forms of knowledge mobilisation were also identified. These unique benefits are described in Chapters 4 to 6 and included:

- increasing familiarity and trust in the model through the use of participatory, co-production methods;
- the synthesis of diverse evidence into an interactive and dynamic decision support tool;
- the facility to explore “what if” scenarios and policy options;
- exploring combinations and interactions of interventions to consider which interventions to enhance, which gaps to fill and which target groups to focus on;
- exploring the impact of new and untested interventions prior to implementing in the real world;
- and being able to forecast delays in intervention effects to modify expectations, guide implementation monitoring, and identifying and prioritising evidence gaps.

As new technologies enable greater model transparency, increasingly participatory processes can combine the significant knowledge of domain experts with the expertise of modellers to develop complex, dynamic decision support tools [9]. Participants in the case studies examined in this thesis reported that it was especially valuable to learn how decisions in one part of the system impact on other parts i.e. to understand the focus issue from a systems perspective. However, the participatory approach was resource intensive and required a structured and rigorous process to ensure it added value to the modelling process and built
trust in the modelling outputs (Chapters 4 to 6). Being involved in the participatory modelling projects involved a significant time investment for participants. The policy makers who engaged in the projects reported that they had carefully weighed the benefits and costs before agreeing to participate. A significant factor contributing to their decision to participate was that the focus topic was a current, local priority for which effective policy and intervention options were unclear or contested (Chapter 4 and 6). In this context, participants were motivated to explore both the issue in depth and new methods for supporting decision making because the models were developed specifically to address their local priorities and decision needs.

Interrogation of the model logic and model results is important to facilitate refinement of the model and understand the implications for policy [13, 30]. Engaging with and discussing the model findings was a critical phase in the participatory model development process in the primary case study. Participants were encouraged to challenge and question the model and critically review the data used to inform it. Unexpected results generated from the three case study models provided opportunities to explore and challenge both the model assumptions and the assumptions held by the participants in relation to the focus issues (Chapter 5 and 6). Reviewing and discussing model results also provided an important opportunity to elicit further participant knowledge prompted in this context.

Managing Uncertainty

Quantitative modelling methods including scenario analysis, system dynamics, agent based modelling and discrete events simulation are useful to both identify and manage uncertainty [25]. Management of uncertainty is an important element of good practice in model development [31]. The types of uncertainty that are of particular importance for simulation modelling in the health domain include: stochastic uncertainty - the random variability in health outcomes between identical patients; parameter uncertainty - the uncertainty in estimation of the parameter of interest; heterogeneity – the variability between patients that can be attributed to characteristics of those patients; and structural uncertainty - the assumptions inherent in the decision model [32]. The participatory modelling process facilitated transparency of and robust discussion about the uncertainties inherent in the models. The participants comprehensively reviewed and refined the evidence used to inform model parameters and, through this process, identified key parameters that had higher levels
of uncertainty as priorities for future research (Chapters 5 and 6). As described in Vignette 1, Chapter 5, heterogeneity of both disease aetiology and outcomes for different population groups was an important source of uncertainty that was acknowledged and explored at length in the DIP model case study. Through the participatory process, knowledge about individual characteristics that were likely to contribute to differential risk of disease or effectiveness of interventions was elicited and shared between domain experts and the modelling team. These discussions were viewed as providing important information to guide which individual characteristics were represented in the model logic and structure (Chapter 5). Close involvement of participants in the model development process provided opportunity for structural model assumptions to be made transparent and tested against expert domain knowledge to ensure the assumptions were valid and robust. Statistical methods, including drawing parameter values from known probability distributions and calibrating parameters against retrospective data, were used in these case studies for parameter estimation and to reflect stochastic uncertainty about individual differences in health outcomes [9, 32]. Multiple simulations were used to assess variation in model outputs between runs and the variation was measured and reported using 95% confidence intervals for scenarios.

Embedding decision makers in the model development process, and making this process as transparent as possible, facilitated their knowledge about the uncertainty associated with the models. Participants emphasised that this increased their awareness of the limitations of the models, the need to ensure that model outputs were interpreted appropriately, and for non-participant end-users to be aware of the assumptions and limitations of the model (Chapter 6). Issues relating to uncertainty are discussed throughout the thesis, however the term “uncertainty” was not frequently used in the published papers. The audience for published papers included health professionals and policy makers who were less likely to be familiar with this modelling terminology. Therefore, the concepts were mainly discussed using more accessible language such as when describing the tensions inherent in identifying and negotiating quality evidence and prioritising evidence gaps, evaluating outputs and deciding when the model was “fit” for use (Chapters 5 and 6).
Summary of implications for future participatory modelling projects

There were a range of implications and suggested implementation strategies for future modelling projects arising from this thesis: including strategies to facilitate the recruitment and ongoing engagement of policy makers; ensure that the participatory process activities were efficient and engaging and ensure that the models remained policy relevant and focused. These have been outlined in detail in Chapters 4 to 6, however key implementation strategies drawn from across the thesis are summarised in this section. In summary, the engagement of senior clinicians and policy makers in the participatory approach provided many benefits which justified the time and resources required for implementation. The sense of ownership of the models and commitment from policy makers to use what they came to view as ‘their’ model was an important outcome of the participatory process that facilitated the use of the models to inform decision making. It was evident that senior policy makers were selective about their involvement in research activities and would only engage and participate if there was flexibility in the project to set focus questions based on their current priority policy needs, and to revise the questions as needed. Having a known colleague already involved in the project was also a useful strategy to encourage engagement.

The active engagement of stakeholders helped to parameterise and provided face validity checks for the models. The collaboration facilitated the dynamic and continuous integration of significant knowledge and a rigorous evidence base into the models. Through collaboration, the modellers were informed about the complexities of the system they were aiming to represent, and equally, the participants were educated about the capabilities and limitations of the model that they were helping to develop. The participants perceived and valued their role as knowledge contributors to the process and it is important that this is emphasised in the participatory activities. When planning participatory workshops, emphasis should be placed on structuring activities, such as those described in this thesis, that engage participants actively to contribute their expertise. Translation of information between disciplines emerged as an important challenge in these case studies and it is recommended that ‘translator’ roles be implemented, preferably embedded within the policy environment, to facilitate communication between participants, particularly between the primary policy partners and the technical modelling team.
The development of knowledge translation products was also identified as an important phase of participatory modelling research projects. The participants in the primary case study facilitated communication opportunities and identified key messages of interest to a broader policy audience. It is recommended that knowledge dissemination be considered part of the participatory process to elicit and leverage participant expertise. The DSMs developed in these case studies provided an opportunity to explore priority public health issues from a quantified and rigorous, systems perspective. This facilitated the mobilisation of knowledge and generation of policy insights that would not have been possible using more traditional statistical techniques.

Building on the 4 p’s framework for reporting participatory modelling projects in an applied health setting

The detailed examination of the participatory process reported in this thesis has added significant value and new understanding to a recently proposed framework [33] for reporting participatory modelling projects. This framework was developed in the environmental science modelling domain; and provides a useful template to facilitate reporting and communication by structuring the description of participatory modelling projects [33]. The manuscript in Chapter 5 demonstrated how the ‘Process’ component of Gray et al’s framework is relevant to health modelling projects, and can be applied to foster learning across sectors. The Process component explores how participants were involved in the model development, describes the level of participation, and the relationship between the process and decision making.

However the Gray framework also identifies ‘Purpose’, ‘Partnerships’ and ‘Products’ as key components of participatory modelling projects and practices [33]. The Purpose component defines the issue being modelled, describes the justification for building the model and for using a participatory process (the why). The Partnerships component describes the stakeholder partnerships that formed around different parts of the process (the who), defines the owner of the process and the criteria for including participants. The Product component describes the outputs resulting from these efforts (the what) including the policy insights. I have applied these four components to the primary case study, the DIP model, in Table 1 to provide an overview of all of the case-study findings, and to demonstrate how the framework can be used as an interdisciplinary method to report on and facilitate learning.
from participatory modelling projects across sectors. On reviewing this application of the 4P categories to the findings in my thesis, I have proposed that two additional components be added to the 4 P’s framework: i.e. consideration of research ‘imPact’, and ‘Prioritising’ future research. These potential new components have also been added to Table 1 and are explained and discussed below.

Considering imPact

The first additional component arising from this thesis is imPact. There are increasing demands to demonstrate the beneficial impact of research in terms of the social, economic and domain specific outcomes e.g. health outcomes [34-38]. Research impact can be direct or indirect and short or long term [36] and it is acknowledged that it can be difficult to measure and demonstrate, particularly when reporting in short term policy and grant application cycles [35, 36, 38]. However, it is important to consider and report examples of the impact of simulation models beyond the generation of policy insights, where possible, to both provide practical demonstration of their value and promote their ongoing use for policy discourse. Research impact has been defined as the intended positive impact of a research activity or an intervention [38, 39]. A systematic review conducted in 2017 identified 26 research impact frameworks for health care research [37]. The authors synthesised the research impacts that were common across the frameworks into short, mid and long term impact outcomes in five domains including primary research related outcomes (short term), influence on policy making, health service impact (mid term), health and societal and economic impact (long term) [37]. Impact reporting frameworks need to be flexible, not impose onerous reporting requirements and able to be tailored to fit the diverse range of research projects conducted [37]. The following question is proposed to be included in the reporting framework - “What was the imPact of the modelling process?”. Three sub-domains are proposed for this component; process impact, forecast impact and policy impact. These are explained below and are applied to the primary case study in Table 1:

1. Process impact: Describe the outcomes arising from the co-production, participatory process and the model, such as capacity building and knowledge exchange, that increase the likelihood of impact. Provide examples of products used to communicate insights from the model.
2. Forecast impact: Describe how the model outputs can be used to forecast the impact of policy or program interventions. For example, the DIP model outputs forecast the need for population level weight reduction interventions over interventions targeted at high risk groups to impact on the incidence of DIP.

3. Policy impact: Describe how model outputs are being used to inform decision making. For example, the DIP model is being applied to inform the development of a diabetes plan for the ACT.

Prioritising future research

The second additional component is Prioritisation. Identifying and Prioritising gaps in the existing evidence base is an important component of the model development and maturation process (Chapter 6) [4]. Lack of data should not preclude the use of modelling, particularly when the model development applies an iterative, participative approach that allows data needs to be identified and ways of addressing these to be developed [13]. The participatory process in these case studies mapped the causal factors and explored the impact of interventions for each focus topic in these case studies which facilitated the identification, clarification and prioritisation of gaps in current knowledge and evidence which can be used to guide future research. A core factor in policy makers’ motivation for participating in the projects was that the case studies focused on priority topics which had aspects that were not currently well understood and had contested policy alternatives that could be explored using the simulation models. The knowledge gaps identified and prioritised as an important focus for future research in the primary case study included understanding the individual heterogeneity of aetiology of diabetes in pregnancy and the impact of differing levels of glycemic control during pregnancy on maternal and perinatal outcomes (Table 1). The negotiation and prioritisation of evidence gaps was a highly valued benefit of the participatory process for end-user and researcher participants (Chapter 6) and is important to communicate to the broader research community when reporting on participatory modelling projects.
Table 1: Extended 4 P's framework for reporting participatory modelling projects applied to the primary case study

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<thead>
<tr>
<th>Component</th>
<th>Questions / Dimensions</th>
<th>Application to DIP model</th>
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<tbody>
<tr>
<td>Purpose</td>
<td>Why model? And Why participatory?</td>
<td>The decision rationale for modelling Diabetes in pregnancy (DIP) for ACT Health was as follows. DIP is a complication of pregnancy that is defined as carbohydrate intolerance resulting in hyperglycaemia (abnormally high blood sugar). It includes women for whom the first recognition or onset of the condition occurs during pregnancy, as well as women with pre-existing type 1 and type 2 diabetes mellitus [40]. There has been a dramatic increase in the prevalence of DIP both in Australia and internationally [41] alongside increases in identified risk factors including high maternal body weight, physical inactivity, increasing maternal age, increasing parity and ethnicity [42-44]. There are short- and long-term health risks for both mother and baby, including increased risk of birth injury in the short term and development of diabetes later in life [45-48]. The available evidence does not definitively guide health services on how best to prevent and manage DIP with policy and program questions crossing the spectrum from population health interventions to complex clinical management issues [49-52]. Sophisticated analytical tools, developed using an interdisciplinary approach, such as participatory DSM, are needed to inform policy and health service planning decisions.</td>
</tr>
<tr>
<td>Component</td>
<td>Questions / Dimensions</td>
<td>Application to DIP model</td>
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<tr>
<td>Process</td>
<td>How were stakeholders involved in the model development?</td>
<td>The participatory process centred around three face-to-face workshops where participants interacted to collaboratively map a qualitative conceptualisation of the focus issue; prioritised and mapped interventions to be tested in the model; prioritised and defined the outcomes to be measured; and reviewed and refined iterations of the model. Multiple additional forums e.g. web meetings, emails, and small group meetings, were used to engage participants throughout the process. A diagrammatic overview of the activities involved in the participatory process was included in Chapter 5. The activities were fully described in Chapters 3, 4 and 5. The model was developed to test policy intervention scenarios.</td>
</tr>
<tr>
<td>Partnerships</td>
<td>Who participated and why?</td>
<td>A diverse range of domain experts, including clinicians, public health specialists, researchers, and computer scientists engaged in the participatory process to collaboratively conceptualise the complex issues relating to diabetes in pregnancy and to co-produce a DSM to support decision making. The members of the participatory modelling consortium were listed in Chapter 7.</td>
</tr>
<tr>
<td>Products</td>
<td>What was produced by the modelling process?</td>
<td>The core product was a multi-scale DSM of diabetes in pregnancy in the ACT that can explore policy and health service scenarios to prevent and manage DIP. The model incorporated the complex and interrelated causal factors that contribute to the development of DIP and explored intervention options and combinations, spanning the spectrum from clinical to population health interventions. The model brought together the best available evidence and data with integrated complex systems modelling approaches to inform policy decision making for diabetes in pregnancy and is described in Chapter 7. Associated products were developed to facilitate communication of model results to a broader non-technical audience. These included a plain language factsheet about the model, a podcast and an interactive results dashboard (Chapter 7).</td>
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### Component

<table>
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<tr>
<th>Questions / Dimensions</th>
<th>Application to DIP model</th>
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<tr>
<td><strong>ImPact</strong></td>
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| What was the impact of the modelling process? | Process impact: Capacity building and knowledge exchange was a key impact of the participatory modelling. The process enabled significant knowledge about both dynamic simulation modelling and diabetes in pregnancy to be combined to develop a decision support tool for policy and practice decision making. Professional academic, clinical and information sharing networks were established through the process. The model and the participatory process have been presented in multiple clinical, simulation modelling and knowledge mobilisation forums.  
Forecast impact: High weight status is an important and modifiable risk factor for DIP, and the impact of prevention interventions targeting weight were prioritised for first testing in the model. Model results forecasted that population level interventions would be necessary to make an impact on DIP incidence in the ACT. Targeted interventions for high risk women delivered either pre- or post-pregnancy were simulated to have a positive impact for individuals but would not substantially impact on population DIP incidence. The model also demonstrated that prevention interventions need to overcome BMI increases associated with increasing maternal age and parity.  
Policy impact: These findings are currently being used to support and inform a diabetes prevention and management plan for the ACT. The model findings have been used to emphasise the importance of including diabetes in pregnancy as a central focus for the service plan. |
| **Prioritising**       |                          |
| What future research priorities arose from the process and/or the model? | Two research priorities that arose from the process included firstly, improving knowledge about the dynamics and heterogeneity in the aetiology of glycemic dysregulation and diabetes mellitus development and secondly, understanding the impact of glycemic control during pregnancy for women diagnosed with DIP on maternal and perinatal outcomes. |
Research in a real-world context – reflections on the challenges, strengths and limitations of this participatory action research

In this section I will reflect on the participatory action research (PAR) approach employed as a conceptual framework to investigate the research objectives, and discuss the associated challenges, strengths and limitations. PAR differs from conventional research in three ways [53]. Firstly, the focus of PAR is to both study and enable action. As described in the Chapter 1, the action is decided through a reflective cycle, whereby participants collect and analyse data, then determine what action should follow. The resulting action is then further researched, and an iterative reflective cycle perpetuates data collection, reflection, and further action [53]. Secondly, participants become partners in the research process: including selecting the research topic, data collection, and analysis and deciding what action should happen as a result of the research findings [53, 54]. Thirdly, PAR contrasts with less dynamic approaches that separate data and information from their contexts, PAR is embedded within the research context [53]. The PAR framework of action orientation, collaboration, reflection, iteration and involvement of researchers as participants was applied on two levels in this thesis. Firstly, within the core research cycle investigating the development of the DSMs for diabetes in pregnancy; and secondly, as part of the reflective research cycle examining the participatory approach to model development in both the primary and the two additional case studies.

Researcher position is critical to consider in participatory action research as the action researcher impacts on the process being examined and exerts influence on the study [53, 55]. My position in the participatory action research was as a participant observer; I both enabled and examined the process of developing the DIP dynamic simulation model using participatory methods and studied the value and utility of the participatory modelling process as perceived by end-user decision makers. As outlined in Chapter 3, my role in the primary case study (DIP model) was highly visible as the project lead, core modelling team coordinator, and primary conduit between the technical modellers and the stakeholder participants. My central role as both project enabler and PhD candidate/researcher was an important consideration when interviewing the end-user decision makers to elicit their perceptions of the value and utility of participatory modelling for decision support. Firstly, I was explicit about seeking participants true perceptions of the process and invited them to
genuinely reflect on both pros and cons. Secondly, the participants were all senior research, policy and practice professionals who were also aware of my status as a PhD candidate and less likely to feel the pressure of providing a socially desirable response than perhaps less experienced study participants may have been. Finally, the potential for interviewees to limit the disclosure about negative aspects of the process was further mitigated in the research design with the inclusion of two additional case studies. This allowed me to collect data from projects where I had not played a visible role in facilitating workshops and developing the model. The additional interviews provided opportunity to compare across interviews to examine whether there was some caution among participants from the primary case study to fully disclose their views on the value of the process. The level of interviewee openness was found to be similar across all case studies. The senior policy makers and clinicians interviewed were comfortable to openly discuss both the negative and positive aspects of their experience with the participatory model development process and the benefits and limitations of using the models to inform decision making (Chapter 6).

A core characteristic of participatory action research is that it is embedded in a real-world context [53]. As described above and in Chapters 4 to 6, this can strengthen the research by providing opportunities for it to be directly applied to addressing real issues. However, real-world policy making can also result in challenging and unexpected circumstances that delay or impact on the implementation of the research [55]. This thesis examined the in-depth collaboration of senior clinicians, policy makers and researchers from multiple Australian jurisdictions that addressed priority public health issues. Engaging the very senior and highly busy participants in the model development processes provided access to a significant knowledge base, and opened doors to opportunities for the models to be applied in practice. However, these senior domain experts also had many competing commitments and a significant challenge of implementation was ensuring that interactions with them were focused and efficient, met their expectations, minimised the risk of overburdening them and therefore facilitated their ongoing engagement in the process. An additional, practical challenge was finding suitable times to bring all the participants together. For the DIP case study for example, it became apparent as the project progressed that long lead times would be essential when booking workshops and meetings to ensure that as many key participants as possible were able to attend. It was therefore necessary to estimate when each development stage of the model would be ready for presentation to participants well in advance. Most times, these estimations were reasonably accurate, and meetings went ahead
as scheduled, however sometimes unexpected delays occurred and some meetings had to be postponed resulting in further, lengthy negotiations regarding scheduling.

The core modelling team for the primary case study also had other priorities to balance during the study period. For example, the head of the technical modelling team based in Canada, Professor Nathaniel Osgood, a highly skilled and experienced modeller with substantial teaching and research commitments, relied on much of the detailed programming being completed by his post-graduate students, working under his supervision. All these modellers needed to balance their time on the DIP model development with other commitments. There were also two personnel changes among the student modellers as each person primarily responsible for model development moved on in their own studies. The DIP model is a highly sophisticated and complex model and each new modeller required time to become familiar with it and learn the next steps for its development under the guidance of Professor Osgood. The development of an Australian-based programming workforce who specialise in health sector modelling has been an ongoing challenge and priority for The Australian Prevention Partnership Centre and other agencies who aim to expand the usage of these technologies for policy decision support.

Finally, it is important to reflect on my own position as an employee within ACT Health – which I believe was invaluable in enabling and facilitating the implementation of this collaborative project. While undertaking this research I also continued to work part-time as a Manager within the Epidemiology Section in ACT Health. In this capacity I was embedded within the health service, which provided invaluable opportunities to use my established professional relationships to establish the project within ACT Health, and to engage participants in the model development process. My work context also enabled me to subsequently apply the findings of the research to inform ACT Health policy development for diabetes in pregnancy. Fortuitously, the completion of the DIP model coincided with the timing of the ACT Health Minister’s interest in diabetes, and diabetes in pregnancy in particular, as an important health issue. To facilitate communication of the model and engagement with the Minister and her advisers, a suite of knowledge translation products was developed, including a fact sheet, an interactive dashboard and a podcast (Chapter 7). However, just prior to the date scheduled for the model to be presented to the Minister, other priorities subsumed her attention. These included a major organisational restructure in which ACT Health was a split into two agencies, and intense, negative local media interest in
her portfolio (for example https://www.canberratimes.com.au/canberra-news/health-split-not-a-fix-but-good-step-forward-fitzharris-20181002-p5079a.html). These issues resulted in the postponement of the presentation to, and engagement with, the Minister. However, at the time of writing she remains interested in the model as a new analytical method for informing policy and it is intended that the meeting will proceed – although after the submission of this thesis. It is important to note that whilst these matters were specific to the context of the ACT at the time of this thesis, similar fast moving events are the norm in the modern political context. They need to be considered when embarking on complex modelling projects and to guide realistic expectations about the timing and likelihood of successful impact.

Recommendations and next steps:

Recommendation 1: Develop strategies to share knowledge and support interdisciplinary modelling collaborations

One of the most important determinants of the successful policy modelling projects examined in this thesis was the collaboration and communication among those involved: the modellers themselves, the participants and stakeholders and the end-users of the model outputs. This cross-disciplinary collaboration was essential to yield useful policy models that were actually used by decision makers [13, 56]. However, because of the diversity of professional backgrounds among those involved, it was challenging to navigate the differences in terminology, methodological approaches and domain understanding for each discipline [7, 56, 57]. In all of the case studies included in this thesis, “translators” played a pivotal role in working between the disciplines to facilitate communication and understanding [56]. Further development of strategies and methods to support interdisciplinary modelling collaborations, and communication forums to share knowledge across disciplines (e.g. [7]) is recommended to facilitate ongoing advances in cross-disciplinary participatory modelling research.
Recommendation 2: Incorporate strategies derived from this participatory action research in the implementation of future participatory modelling projects

There were also many challenges associated with the practical implementation of the participatory aspects of the modelling. It was time consuming, intellectually demanding and required effective and patient coordination and facilitation skills. However, the benefits outweighed the challenges, providing opportunity to develop useful, policy-relevant models that were truly grounded in rigorous evidence and the significant knowledge base of the participants. Participant interest and engagement remained high across the three case studies and opportunities to utilise the models to inform decision were facilitated through their professional network. Detailed recommendations and procedural guidance for the implementation of participatory DSM were reported in Chapters 4 to 6. The key recommendations are summarised below:

**Emphasise co-production** – co-production of knowledge was reported by all participants as a highly valued outcome. It is recommended that a diverse group of expert participants be engaged as equal partners in all phases of the project from negotiating a focus topic, to engaging in the model development activities, actively contributing expert knowledge, refining the models, reviewing the model results and identifying and facilitating opportunities to communicate policy and program insights. Ensuring that the participant group includes representation of groups who have an important stake in the focus topic is recommended to facilitate the acceptance and use of the model.

**Focus on a current priority topic** – Participatory modelling processes are time consuming and resource intensive. Therefore, it is recommended that future modelling projects include a planning phase in which the focus topic is considered and negotiated with policy partners prior to commencement.

**Recruit key project roles** – It is recommended that the two key project roles that facilitated effective engagement of expert participants in these case studies be utilised in future modelling projects. These are the **Domain expert**, a well-respected authority on the focus issue and who can play a lead role in the project planning and workshop facilitation; and the **Translator**, a person who can translate the characteristics of the policy environment and data...
for the modelling team and the model requirements and development process for the participants.

**Encourage openness and transparency in the process** – The participatory process provides a valuable opportunity to leverage significant knowledge in the development of policy decision support models. A challenging, but rewarding, aspect of the process was openly engaging with participants to iteratively critique, refine and ultimately improve the model. It is recommended that openness and transparency in the process be encouraged in future modelling projects to increase trust with participants and achieve policy relevant and useful DSMs.

**Communicate** – Communication was critical in all phases of the modelling project. It is recommended that background briefing material about the participatory process is developed prior to the commencement of the participatory process to enable participants to prepare. It is recommended that frequent concise and targeted communication and project updates be provided to participants to facilitate their ongoing engagement without overburdening them. Simple, clear and concise key messages about insights from the model should be derived and tools developed to facilitate communication to a variety of audiences.

**Recommendation 3: Build dynamic simulation modelling capacity among public health professionals and expand research into the application and comparison of modelling methods for health policy questions**

Many of the participants who engaged in the modelling projects had limited experience with DSM methods at the outset [56]. They were therefore unable, for example, to contribute to decisions about the methods used to represent causal pathways, or strategies to overcome gaps in the evidence base. As participant experience with and knowledge of DSM methods increases, further research into end-user or policy makers’ views about different systems science methods will be possible and is highly recommended. For example, the perceived value of agent-based modelling compared with system dynamics modelling in terms of conceptual design, model structure and usefulness for decision making would be of value to explore, along with the preferences for one modelling method over another for different policy questions. These insights would help inform future modelling projects and target areas requiring development. Incorporating DSM concepts and their application to public health
issues into public health professional, biostatistics and epidemiologist training programs is also recommended to increase awareness and adoption of these methods in the health sector.

**Recommendation 4: Develop and test methods to facilitate interdisciplinary communication**

A key challenge identified in this thesis was the design of communication methods that were effective across disciplines. Methods were required, firstly, to communicate model structure and logic in a way that was transparent and understandable for participants, and secondly, to communicate the model results to a broader policy audience. The lack of effective, transdisciplinary communication methods is a barrier to the uptake of modelling for public health [4] and the challenge will increase as more complex and sophisticated policy models are developed. Storytelling was one strategy utilised in this research to both communicate the model structure (Chapter 5) and the model findings (Chapter 7), however further research will be required to explore the effectiveness of this communication approach in other settings and whether other strategies are equally or more effective. Observational and experimental study designs could be utilised to investigate this issue drawing on participatory action research, communications, psychology and organisational behaviour research.

**Recommendation 5: Test the novel participatory methods utilised in these case studies in other settings**

The case studies investigated in this thesis were based in Australian jurisdictional health departments. Further exploration is necessary to determine if the novel collaborative methods used in these case studies would be as effective in other international settings. However, the in-depth analysis identified themes that were generalisable across the three case studies and can be utilised by multiple disciplines, including researchers, modellers, health service planners and policy makers, to inform future participatory modelling projects.
Next steps for the diabetes in pregnancy model

Dynamic simulation models mature over time. Further model development and modification can occur post-commissioning as new knowledge and evidence becomes available or new policy questions arise (Chapter 6) [9]. Further development work is planned for the DIP model developed in the primary case study to leverage its ability to explore intergenerational effects of diabetes in pregnancy on health outcomes. The use of agent-based modelling methods allows for individual agents to “inherit” a maternal history of diabetes in pregnancy. The effect of this on the individual agent’s risk of developing childhood overweight or obesity, diabetes in pregnancy, or early onset type 2 diabetes mellitus will be incorporated into the next version of the model.

Conclusion

This thesis explored the use of participatory DSM to inform health policy discourses, and it is the first empirical research specifically focused on understanding and elaborating the participatory method in applied health policy settings. This aim was achieved through the application and study of a novel participatory modelling approach in one primary and two secondary case studies. The in-depth analysis demonstrated that participatory DSM is feasible, useful and valuable to apply to priority public health issues with global significance [58]. The novel participatory activities utilised in these case studies successfully elicited and mobilised detailed and comprehensive knowledge and evidence about the focus issues which was synthesised and incorporated into the models. The process utilised in the primary case study was examined in detail to uncover the core analytic processes, activities and decisions involved in developing a DSM for diabetes in pregnancy using participatory methods. The analysis identified the common motivators for participation, the highly valued co-production elements and the unique benefits of DSM from the perspective of senior end-user policy makers who engaged in the case studies. The DSMs developed in these case studies are being used to provide policy insights and to inform decision making in Australian health services. The systematic data collection and analysis in this thesis identified key elements required for successful implementation of participatory DSM projects and provided valuable insights and practical guidance for implementing future projects in applied health settings.
References


58. Ten threats to global health in 2019 [https://www.who.int/emergencies/ten-threats-to-global-health-in-2019]