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

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Chapter 1: Introduction

This thesis explored the novel use of participatory DSM as an integrated decision support and knowledge mobilisation tool in Australian health policy settings. A participatory action research framework [1, 2] was utilised to study and evaluate the implementation of a participatory approach to DSM in a case study focused on prevention and management of diabetes in pregnancy in the Australian Capital Territory (ACT). Diabetes in pregnancy (DIP) was identified as a priority focus topic as incidence is increasing significantly in the ACT, nationally and internationally, resulting in increasing pressure on services to meet demand [3]. DIP impacted on 16% of pregnancies in the ACT in 2016 (increasing from 5% in 2006) and decision makers require tools to support effective decision making. DSM provided an opportunity to explore and compare the implications of health intervention options for diabetes in pregnancy services in the ACT and inform policy and program decision making (Chapter 3). Key findings related to the participatory modelling approach from the DIP case study were triangulated with supplementary data drawn from two additional case studies based in the neighbouring state of New South Wales (NSW). One applied participatory DSM to explore strategies to reduce alcohol related harm, and the other to examine the type and scale of interventions necessary to achieve the NSW Premier’s target to reduce childhood overweight and obesity by 5% by 2025. The three case studies are described in detail in Chapters 4 and 6.

1.1. Origin of the thesis

My interest in decision support methods and knowledge mobilisation stemmed from over 20 years working in the health sector in a range of roles including clinical psychology and health service planning, but predominantly in maternal and child epidemiology working
with clinicians and policy makers to facilitate the use of evidence to inform policy and program decisions. Over this time, I observed that, despite an abundance of information and data being available for many priority topics, it was not available in a form that addressed the most frequent question in policy advice “What should we do about this?”

The reliance in health services research on traditional statistical analytic techniques, such as regression analysis and aetiological fractions, has provided substantial knowledge about diseases and their aetiology, however these methods can provide only limited understanding of the complex adaptive systems within which public health policy decisions are made [4, 5]. Complex adaptive systems are characterised by feedbacks, interrelations among components, self-organisation and adaptation, and time delays between cause and effects [4]. I was interested in exploring the potential value of more sophisticated analytical tools that could accommodate the dynamics of complex systems e.g. temporal dynamics, and the interrelationships between elements of the system such as feedback, and system responses to interventions for health policy settings. Tools, such as DSM, used in other sectors such as environmental sciences, manufacturing and business to synthesise, integrate information and forecast likely outcomes of policy and guide decisions [6-8] were not often considered as a method to support health policy decision making [9, 10]. I was interested to explore and assess the feasibility and value of using a participatory approach with this method for a priority public health issue, in this case gestational diabetes mellitus, in our local health service, ACT Health, in the Australian Capital Territory.

I focused on the participatory approach because I valued the expertise of my clinical and policy colleagues and wanted to collaborate closely with them to integrate their significant knowledge and other forms of evidence to develop a DSM for this priority health issue. My initial reviews of the literature indicated that the research on stakeholder participation in model development had primarily occurred in the environmental modelling field, with a
rich history of community-based model development, for example the work of Peter Hovmand, Peter Senge and Alexey Voinov [7, 11, 12]. There had been limited exploration of participatory modelling in the health sector and when DSM projects had been undertaken for health topics, they rarely involved end-user decision makers in the model development [13]. However, end-user involvement is a key factor in increasing trust in model outputs and facilitating their use to support decision making [10]. There were no studies of end-user experiences and perceptions of the participatory process and DSM as a health policy decision support tool.

My research interests aligned well with the principles of The Australian Prevention Partnership Centre (TAPPC), who funded my PhD research. TAPPC is a partnership centre in which research is co-produced by academic researchers, systems practitioners and policy makers across Australia. TAPPC aims to identify systems, strategies and structures to inform better decisions for improving the prevention of lifestyle-related chronic disease in Australia [14]. My employer, ACT Health, was a founding funding partner of TAPPC along with the National Health and Medical Research Council, NSW Health, the Australian Department of Health and a private health insurance funder. The study setting is described further in Chapter 3.

1.2. Rationale for the thesis

Achieving evidence-based policy for complex public health issues is challenging [15-17]. The challenges include misalignment of research activities and policy questions in terms of focus topic, timing and knowledge dissemination methods [18-20]. The knowledge mobilisation field has evolved in response to these challenges and encompasses a diverse range of activities and frameworks which aim to address the evidence policy gap [21]. Systems thinking and systems science approaches are increasingly being utilised to
understand and mobilise knowledge for complex issues such as those encountered in public health [22]. Dynamic simulation modelling is a systems science approach that can be used to develop understanding about complex problems using computer simulation [23, 24]. By involving end-user stakeholders in the model development, participatory DSM can facilitate the adoption and use of the models to inform decision making [10, 25]. The detailed literature analysis underlying this rationale is described in Chapter 2.

Important gaps in knowledge remain regarding: the feasibility of using participatory approaches in DSM to facilitate evidence informed decision making in Australian public health settings; how the involvement of stakeholders as participants in DSM projects impacts on the quality, trustworthiness and ultimately the use of model outputs for decision making; and the perceived value of participatory simulation modelling as an evidence synthesis and decision support method. These gaps in knowledge are explored in detail in the research protocol presented in Chapter 3.

This thesis contributes new knowledge by exploring the novel use of participatory simulation modelling as an integrated decision support and knowledge mobilisation tool in Australian health policy settings. The thesis explores the processes involved in, and the feasibility and value of, the participatory modelling approach. It describes the experiences of end-user decision makers engaged in the case study processes, and their perceptions of the value and utility of DSM and the likely impacts on policy and program decision making.

1.3. Overarching theoretical framework and research approach

A Participatory Action Research (PAR) methodology was chosen as it encapsulates the theoretical framework for this research to address the identified gaps in knowledge described above. The PAR framework was chosen as it closely aligns with the active, collaborative, iterative process of participatory DSM development and the involvement of
researchers as participants in the process. The framework also aligns well with the principles of partnership and co-production underpinning TAPPC and their remit to develop the information, tools and actions needed for effective systems-level prevention of chronic disease [14]. I completed the research for this thesis as the project lead for the primary DIP modelling case-study, and as an embedded researcher with TAPPC and ACT Health responsible for facilitating and studying the participatory modelling process.

There are many definitions of PAR that reflect wide ranging views, however most definitions agree that PAR is inquiry that is done by or with insiders to an organisation or community [26]. It is a reflective process that is deliberately and systematically undertaken, and requires that conclusions and recommendations be supported by evidence produced from the research [1, 26]. PAR is oriented to actions or cycles of actions that address a particular problematic situation [1, 26]. PAR embeds the research in the context. The research is planned and implemented, the effects observed and reflected on to determine next steps all within the context of the organisation or community of focus [1, 27].

The key features of action research include its collaborative nature and its emphasis on taking unified action on an issue [28]. It involves genuine partnership between researchers and decision makers, who work directly with the identified issue, across each stage of the research project, from identifying the problem to disseminating the results [2, 28]. This partnership involves shared control of the research agenda and commitment to mutual learning in the research process to improve researchers’ and research partners’ understanding of one another’s positions and contributions [28]. The case studies in this thesis were highly collaborative. The modelling teams and key policy partners worked collaboratively to negotiate the focus topics for the case studies, co-produced the DSMs and prioritised interventions to be tested.
An important qualitative element of PAR is how people are drawn into the processes of inquiry and action and how they participate and collaborate [27]. The goal of PAR is to make action more effective while simultaneously building up a body of scientific knowledge [2, 27, 28]. The goal of PAR in the context of this thesis was the co-production of knowledge that was useful, valid, descriptive, and informative of how practice and policy interventions may have a positive impact on public health issues.

PAR comprises iterative cycles of gathering data, analysing the data, planning action, taking action and evaluating, leading to further data gathering and so on. The PAR spiral [2] is presented in Figure 1 and shows the main steps of planning, acting, observing and reflecting.

Figure 1: Participatory Action Research Spiral

1.4. Application of the participatory action research framework to the research objectives

In participatory action research projects, there are two action research cycles operating in parallel [27, 29]. One is the action research spiral of plan, act, observe and reflect, described above, in relation to the applied research project. This is referred to as the core action research cycle [29]. In this research the development of three DSMs using a participatory process is the core action research cycle. This cycle relates to Research objective 1 (below).

The second is a reflection cycle which is an action research cycle that is undertaken alongside the core action research cycle. At the same time as the researcher is engaging in the project or core action research cycles, they are diagnosing, planning, taking action and evaluating about how the action research project itself is working and what is being learned [27, 29]. This secondary process of reflection has also been referred to as the ‘thesis’ action research cycle [29]. However, I haven’t adopted this term here to avoid confusion with my PhD thesis; which comprises of both the ‘core action research’ and ‘reflection action research’ cycles (Figure 2).

In this research, the reflection cycle involves the examination of the participatory process itself, investigating what worked well, what could be improved, how the participatory process contributed to the development of the models and what the experience was like for participants. This cycle relates to Research objective 2.
The action research cycles and their relationship to the research objectives are represented diagrammatically in Figure 2. The overall research objectives for this thesis were:

1. To pilot DSM to optimise the use of evidence to inform policy and program decision-making by synthesising and integrating diverse evidence sources into a decision support tool for diabetes in pregnancy using a participatory modelling approach. (Core action research cycle)

2. Investigate the perceived value and efficacy of participatory simulation modelling methods as an evidence synthesis and decision support method in an applied health sector context. (Reflection action research cycle)

These research objectives were investigated using a case study approach with three applied health policy and program examples. The primary focus and core case study for this research was the modelling project to inform prevention and management of diabetes in pregnancy in the ACT (Case Study 1). Two other case study modelling projects were used as sources of supplementary data to triangulate the findings for Research Objective 2, and
as comparison to see whether and how the findings from Case Study 1 are reflected in other settings. The research objectives and research questions are described further in the published research protocol included in Chapter 3.

1.5. Overview of thesis structure

This thesis is organised into eight chapters, five of which include peer-reviewed journal articles (four have been published, and one is undergoing review). All papers were prepared during my doctoral candidature with the University of Notre Dame. These papers, as well as each chapter, contain their own reference lists. Supplementary material related to ethics approval, study methods, and accompanying the published papers is included in the relevant chapters and in the Appendices.

Chapter 2: Literature Review

This chapter provides an in-depth analysis of the various literatures that are relevant to this thesis, including the broader challenges of achieving evidence informed decision making in the health sector. It explores the synergies between system science and knowledge mobilisation methods and outlines how these approaches were combined in the thesis. DSM is introduced as a system science approach that can be applied to complex public health issues to facilitate the use of evidence to inform policies and programs. Also included is an explanation of the key DSM concepts, and the main methods, their history and application are described. The motivations for using DSM over traditional statistical techniques is explained and the application of participatory processes in DSM is outlined. Chapter 2 also identifies the gaps in knowledge that are explored in more detail in Chapter 3.
Chapter 3: Study methods

Chapter 3 includes the published protocol for this research. This paper describes and discusses in further detail the current gaps in knowledge, which include the feasibility of using DSM in “real world” health policy settings, and the value and effectiveness of using participatory methods in model development. This paper also presents a detailed rationale and research protocol for the primary case study investigating diabetes in pregnancy in the Australian Capital Territory (ACT). The second part of the chapter outlines how the research methods evolved following the publication, in 2016, of the research protocol and explains my role in the research.

Chapter 4: Results Part 1: Mobilising Knowledge for Policy Development: implementing systems approaches through participatory dynamic simulation modelling

The published paper included in this chapter reviews knowledge mobilisation best practice and describes how the participatory DSM examined in this research built on these elements. It reports on the participatory modelling workshops from three policy settings, including the primary case study in the Australian Capital Territory (ACT), and two additional case studies from New South Wales (NSW), which were used as supplementary data sources to explore and compare the feasibility and value of participatory DSM in different settings. The reported findings from across the three case studies are reviewed and presented with reflections on the lessons learned from the participatory simulation modelling experience across policy settings, together with discussion of the benefits and challenges of this approach.
Chapter 5: Results Part 2: Turning conceptual systems maps into dynamic simulation models: revealing the analytical deliberations and decisions of participatory dynamic simulation modelling

The published paper in this chapter focuses on the processes, decisions, interactions and activities that were required to convert the qualitative, conceptual map developed by participants in the participatory workshops (described in Chapter 4) into a quantitative DSM. This paper presents a qualitative, empirical analysis of the core processes, stakeholder interactions and decisions, and practical strategies to develop a rigorous and policy relevant model, which occurred outside the formal participatory workshops at the interface between end-user participants and modellers. The implications for future participatory modelling research and practice are considered.

Chapter 6: Results Part 3: Decision makers’ experience of participatory dynamic simulation modelling methods for public health policy

The published paper included in this chapter reports on a qualitative analysis of the perspectives of end-user decision makers from the three case studies. It examines their views on the value of participatory simulation modelling to inform health policy and program decision making, and their experiences of engaging in the participatory process. The paper discusses interviewees’ motivations for contributing to the modelling projects, and their perceptions about the key elements of the participatory process. The unique benefits of participatory DSM for policy decision making processes are discussed. Also included are a list of recommended implementation strategies based on reflections from the three case study settings.
Chapter 7: Results Part 4: ‘Turning the tide’ on diabetes in pregnancy: Insights from advanced dynamic simulation modelling

The paper included in this chapter presents the DIP model that was developed in case study 1, presented here in the final draft format that is undergoing wider clinical review prior to journal submission. It describes the current challenges for the prevention and management of diabetes in pregnancy, provides an overview of the DIP model structure, logic, parameter inputs, assumptions and model outputs. The implications for DIP prevention and management are also discussed. Associated communication products prepared to facilitate knowledge dissemination to a non-technical audience and model documentation to accompany the manuscript are included in this chapter.

Chapter 8: Discussion and conclusions

The overall key findings of the research and their implications are presented in Chapter 8. These are discussed as a body of work in the context of participatory action research, knowledge mobilisation and the policy and practice implications of using DSM. The importance of using participatory methods to engage key stakeholders to co-produce models for policy decision support and the benefits and challenges of interdisciplinary research are reviewed and discussed. A framework proposed for reporting participatory DSM projects in the environmental sciences field is applied to the primary case study and extended based on the findings from this thesis. This chapter reflects on the strengths and limitations of this real-world research and makes recommendations for the implementation of future participatory modelling projects and for future research.

Appendices

Additional relevant information is provided in a series of appendices. Each appendix is referenced in the text of the Thesis.
References


