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

Louise Freebairn

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APPENDICES

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Harnessing new technologies to inform health decision making: Dynamic simulation modelling as a decision support tool for diabetes in pregnancy

Louise Freebairn, Epidemiology Section and Dr Paul Kelly, Chief Health Officer & Deputy Director General, Population Health Protection & Prevention Division, ACT Health

There is mainstream acceptance that decision making for health programs and policies should be evidence-based; however this can be difficult to achieve. The concept of “evidence informed decisions” is particularly challenging in population health policy and practice, where many of the current “big questions” are complex and not easy to address. These problems have multiple interacting causal factors with competing possible courses of action for decision makers to choose between, each course of action potentially resulting in complex and unintended consequences.1,2 Many factors, including availability and diversity of information, opinion and experience, timing, the political cycle, local norms, the influence of external players, and the availability of funds all influence decision-making.3,4

Research methods in prevention science have traditionally taken a reductionist approach focusing in detail on components of a system.5,6 For example, many studies have looked at the effectiveness of specific interventions on specific target groups. These studies have contributed, and will continue to contribute significantly to our knowledge, however, these methods have difficulty accounting for the complexity of population health where there are delays between cause and effect and unanticipated consequences of interventions.7 New approaches, such as dynamic simulation modelling, provide insights into broader system behaviour in population health and enhance the evidence available for decision making.

Dynamic simulation modelling

Dynamic simulation modelling is a systems science method that recreates complex systems and human behaviours as a computer, or mathematical, model. These models can answer “what if” questions about the likely impacts over time of different policy and intervention options and combinations so that they can then be considered more broadly before implementation in the real world.1,8 Dynamic simulation modelling has been used to map health system components and their interactions, bring together evidence, examine and compare the potential outcomes of interventions, and guide more efficient investment and conscientious disinvestment of resources.8 This is important for preventive health policy and practice where decision support tools must have the capacity to steer a course through the complexity of interactions that give rise to real-world public health problems such as the global epidemic of chronic disease.1,8,9

Advances in technology have made modelling methods more user-friendly and allow for greater participation in model development. Participatory model development engages multidisciplinary stakeholders in a group model building process where participants share their knowledge about the causal pathways for the focus issue and where and how interventions have an impact on outcomes. Through a series of participatory workshops, the model building group, informed by evidence and data, collaboratively identify and map the key risk factors and likely causal pathways leading to outcomes of interest. The map is then used to construct, quantify and test a computer modelled representation of the causal pathways and intervention effects for the focus issue.1,8,10-12

The Population Health Protection & Prevention, ACT Health, in partnership with The Australian Prevention Partnership Centre, has brought together local, national and international researchers, clinicians and policy makers (see modelling participant group description below) to collaboratively develop a dynamic simulation model for Diabetes in Pregnancy in the ACT.13 More information about this process is available here: http://preventioncentre.org.au/our-work/research-projects/gestational-diabetes-through-a-systems-science-lens/.

Diabetes in Pregnancy in the ACT

Diabetes in pregnancy (DIP) is increasing both in the ACT and Australia,14,15 and this is challenging the capacity of diabetes services. The increase in DIP is associated with an increasing prevalence of risk factors such as overweight and obesity, older maternal age and increasing numbers of women from high-risk ethnic groups.14 Diagnostic screening guidelines were modified in 2015 to address the changing characteristics of women becoming pregnant and the increasing prevalence of type 2 diabetes mellitus.16 The new guidelines recommend that women who are high risk for developing diabetes in pregnancy should be screened in the first trimester of pregnancy.16 Consequently, these women are diagnosed with DIP earlier in their pregnancy and require services for a longer period of time. With increasing prevalence of risk factors, service providers report that women are more frequently presenting with a combination of risk factors resulting in more complex diabetes care needs.
Harnessing new technologies to inform health decision making: Dynamic simulation modelling as a decision support tool for diabetes in pregnancy

The rising prevalence of DIP is having a significant impact on health service demand and resources, and the need to “do things differently” was identified by participants. The model can inform investments for intervention in DIP, spanning the spectrum from clinical to population health interventions. Workload and resource use have been incorporated into the model to enable it to act as a resource allocation decision support tool. Prevention of risk factors was also prioritised in the model as small delays in the development of diabetes will have large implications for the longer-term burden of disease and costs to the health system. The model considers the short, intermediate, and long term implications of the increasing prevalence of risk factors for DIP. At the time of publication, this model was being finalised.

What if?
Dynamic simulation modelling is a decision support tool allowing for policy and practice scenarios to be simulated and explored. This “what if” capacity can be used to compare interventions alone or in combination before they are implemented. Examples of “what if” questions that can be explored in the ACT Diabetes in Pregnancy model include: What if we implemented population health interventions to reduce modifiable risk factors for diabetes in pregnancy? What if we targeted particular sub-groups with these interventions? How should the intervention be delivered? What if we modified the model of care for diabetes in pregnancy services? What is the likely impact on resource use?

Diabetes in Pregnancy ACT Modelling Group Participants
The Diabetes in Pregnancy Modelling group participants included policy and program officers, endocrinologists, a neonatologist, a general practitioner, diabetes educator, public health professionals, medical and population health researchers and dynamic simulation modelling experts. Participants included local, national and international experts in the field travelling from South Australia, Northern Territory, New South Wales and Saskatchewan, Canada to participate in the workshops.

Conclusion
Participatory dynamic simulation modelling provides opportunity for diverse health stakeholders to collaborate and explore policy and health service scenarios for priority public health topics and support decision making. Technological advances in modelling software combined with participatory modelling methods place the decision maker at the centre of the process in the development of dynamic decision support tools. Research into the impact of these methods on decision making is ongoing.

References
Appendix 2: Ethics approval letters

Ethics approval letters from:

- ACT Health Human Research Ethics Committee; and
- University of Notre Dame Australia Human Research Ethics Committee.
Ms Louise Freebairn  
Manager  
Health Outcomes and Knowledge Translation  
Epidemiology Section  
Health Improvement Branch  
PO Box 825  
Canberra City ACT 2601  

Dear Ms Freebairn

ETHLR.15.160

The ACT Health Human Research Ethics Committee’s Low Risk Sub-Committee received notification of the proposed study:

Simulation modelling: A systems approach to supporting the use of evidence to inform decision making for gestational diabetes at its meeting of 11 August 2015.

I am pleased to inform you that, following further correspondence, your application has been approved.

The Sub-Committee agreed that the application is for low risk research and determined that the research meets the requirements of the National Statement on Ethical Conduct in Human Research and is ethically acceptable.

I attach for your records an Outcome of Consideration of Protocol form.

I confirm that the ACT Health Human Research Ethics Committee is constituted according to the National Statement on Ethical Conduct in Human Research 2007 and is certified for single review of multi-centre clinical trials. ACT Health HREC operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

Yours sincerely

[Signature]

Louise Marauta PSM PhD  
Chair  
ACT Health Human Research Ethics Committee  
Low Risk Sub-Committee  
9 September 2015
ACT HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Outcome of Consideration of Protocol

Submission No: ETHLR.15.160 Date of Approval: 8 September 2015

Project Title: Simulation modelling: A systems approach to supporting the use of evidence to inform decision making for gestational diabetes

Submitted by: Ms Louise Freebairn

Your project was considered by the ACT Health Human Research Ethics Committee and Approved for a period of 3 years.

First Annual Review due: 1 September 2016

The Ethics Committee require as part of the review process that:

- At regular periods, and not less frequently than annually, Principal Investigators are to provide reports on matters including:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with other approved procedures.
  - as a condition of approval of the protocol, that Investigators report immediately:
    - adverse affects on subjects
    - proposed changes in the protocol
    - unforeseen events that might affect continued ethical acceptability of the project.
- All published reports to carry an acknowledgement stating:
  - Approved on 9 September 2015 by the ACT Health Human Research Ethics Committee's Low Risk Sub-Committee.

Louise Moreau
PSM PhD
Chair
ACT Health Human Research Ethics Committee
Low Risk Sub-Committee
9 September 2015
Ms Louise Freebairn  
Manager  
Health Outcomes and Knowledge Translation  
Epidemiology Section  
Health Improvement Branch  
PO Box 825  
Canberra City ACT 2601  

Dear Ms Freebairn  

ETHLR.15.150  

Thank you for your letter of 2 August 2016, requesting amendments relating to:  

Simulation modelling: A systems approach to supporting the use of evidence to inform decision making for gestational diabetes  

The following has been approved out of session:  

- Audio recordings to be transcribed by external transcription company Rev  
- Participant Information Sheet, model development group, revised August 2016  

This correspondence has been recorded on the Committee's file and will be reported to the next available meeting.  

Yours sincerely,  

August Marchesi  
Director  
Human Research Ethics  
25 August 2016
Ms Louise Freebairn
Manager
Health Outcomes and Knowledge Translation
Epidemiology Section
Health Improvement Branch
PO Box 825
Canberra City ACT 2601

Dear Ms Freebairn

ETHLR.15.150

Thank you for your letter of June 2017, requesting amendments relating to:

Simulation modelling: A systems approach to supporting the use of evidence to inform decision making for gestational diabetes

At its meeting of 12 July 2017, the Committee approved:

- To include participants from modelling projects that are further advanced and have used the same participatory processes in the post-workshop interviews
- Participant Information Sheet, model application group, version 1.4 dated June 2017
- Consent Form, version 1.3 dated June 2017
- Indicative questions for the semi-structured interviews

This information is now recorded on the Committee’s files.

Yours sincerely,

A/Professor Paul Craft MPH FRACP
Acting Chair
ACT Health Human Research Ethics Committee
Low Risk Sub-Committee
12 July 2017
8 October 2015

Associate Professor Lucie Rychetnik & Ms Louise Freebairn
School of Medicine
The University of Notre Dame Australia
PO Box 944
Broadway NSW 2007

Dear Lucie and Louise,

Reference Number: 0151195
Project Title: “Evaluation of simulation modelling to inform policy and program options for gestational diabetes in the ACT.”

Your response to the conditions imposed by a sub-committee of the university’s Human Research Ethics Committee, has been reviewed and assessed as meeting all the requirements as outlined in the National Statement on Ethical Conduct in Human Research (2014). I am pleased to advise that ethical clearance has been granted for this proposed study.

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.

On behalf of the Human Research Ethics Committee, I wish you well with your study.

Yours sincerely,

Dr Natalie Giles
Research Ethics Officer
Research Office

e: Prof Christine Bennett, Dean, School of Medicine Sydney,
   Prof George Manda, SRC Chair, School of Medicine Sydney.
19 September 2016

A/Prof Lucie Rychetnik & Ms Louise Freebairn
School of Medicine
The University of Notre Dame Australia
P.O Box 944
Broadway NSW 2007

Dear Lucie and Louise,

Reference Number: 015119S

Project Title: “Evaluation of simulation modelling to inform policy and program options for gestational diabetes in the ACT.”

Your response to the conditions imposed by a sub-committee of the university’s Human Research Ethics Committee, has been reviewed and based on the information provided has been assessed as meeting all the requirements as mentioned in National Statement on Ethical Conduct in Human Research (2007). Therefore, I am pleased to advise that your request for an amendment has been granted for this approved study.

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.

On behalf of the Human Research Ethics Committee, I wish you well with your study.

Yours sincerely,

[Signature]

Dr Natalie Giles
Research Ethics Officer
Research Office

Prof George Maris, SRC Chair, School of Medicine Sydney
11 July 2017

Associate Professor Lucie Rychetnik & Ms Louise Freebairn
School of Medicine
The University of Notre Dame Australia
PO Box 944
Broadway NSW 2007

Dear Lucie and Louise,

Reference Number: 0161198
Project Title: “Evaluation of simulation modelling to inform policy and program options for gestational diabetes in the ACT.”

Your response to the conditions imposed by a sub-committee of the university’s Human Research Ethics Committee, has been reviewed and assessed as meeting all the requirements as outlined in the National Statement on Ethical Conduct in Human Research (2007, updated May 2015). I am pleased to advise that ethical clearance has been granted for this proposed amendment to your study.

Other researchers identified as working on this project are:

<table>
<thead>
<tr>
<th>Name</th>
<th>School/Centre</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Paul Kelly</td>
<td>ACT Health</td>
<td>Co-Supervisor</td>
</tr>
<tr>
<td>Dr Jo-An Atkinson</td>
<td>Sax Institute</td>
<td>Co-Supervisor</td>
</tr>
</tbody>
</table>

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.

On behalf of the Human Research Ethics Committee, I wish you well with your study.

Yours sincerely,

Dr Natalie Giles
Research Ethics Officer
Research Office

cc: Prof George Mantz, S12 Chair, School of Medicine Sydney
Appendix 3: Participant information and consent forms

Participant information form and consent forms are included for: firstly, the model development group who participated in the diabetes in pregnancy case study and secondly, the end-user participants from the additional case studies who were interviewed.
Evaluation of simulation modelling to inform policy and program options for gestational diabetes in the ACT

Project Overview:

This project is an evaluation of the use of simulation modelling as a systems science tool to support decision making for gestational diabetes programs and policies in the ACT.

Simulation modelling provides policy makers with a unique tool for synthesizing and leveraging existing data, evidence and expert and local knowledge to examine in a robust, risk-free and low cost way, the likely impact of different policy scenarios prior to implementation. Recent advances in modelling software capability and more user-friendly interfaces have meant that simulation modelling is now more broadly accessible, enabling a transparent and participatory approach to be used for the development of more complex models.

The outputs of such models can be used to inform broader policy dialogues to determine which policy and program options can and should be pursued.

As you have agreed to participate in the gestational diabetes model development workshops, you are now eligible to participate in this evaluation.

Investigators:

The Principal Investigator for this project is Louise Freebairn from the Epidemiology Section, ACT Health, and PhD student at University of Notre Dame. The investigator team includes Dr Paul Kelly, ACT Chief Health Officer; Associate Professor Lucie Rychetnik, Dr Jo-An Atkinson and Eloise O’Donnell from The Australian Prevention Partnership Centre; and Professor Alison Kent and Professor Chris Nolan from the Canberra Hospital and Health Services.

Participant Information:

You are invited to take part in this evaluation based on your participation in the gestational diabetes simulation modelling project. Before you decide to take part in this evaluation it is important for you to understand why the evaluation is being done and what it will involve. Please take time to read the evaluation of simulation modelling policy and program options to manage gestational diabetes in the ACT, April 2016
following information carefully. Please ask the study team any questions you have and request any further information you need.

**Why is this study being done?**
The purpose of this study is to evaluate a systems modelling approach to understand the factors associated with gestational diabetes and its treatment and to optimise the use of evidence to inform policy and program decisions.

**What is involved in the study?**
Participants of this evaluation will participate in model development workshops. Evaluation of the modelling process will involve audio recording of workshops. The focus of the audio recording is on group interactions rather than the contribution of any one individual. In addition, you will be asked to complete surveys before and after the workshops and may be invited to participate in recorded interviews with the researcher before and after the workshops.

Participants will:

- Attend model building workshops which involve group discussion and will be audio recorded for the evaluation
- Be invited to participate in semi-structured interviews - this will be interviews with yourself and a member of the research team before and after the model development process. They are expected to take less than one hour and will be scheduled for a mutually convenient time and place

**Why have I been chosen?**
You have been chosen to participate in this evaluation because you have been identified as a clinical, policy or research expert in the field of systems modelling or gestational diabetes who has agreed to attend the model development workshops.

**Do I have to take part?**
Participation in this evaluation is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not impact on your employment or your relationship with the researchers or other participants in the research.

You can refuse to take part in this evaluation or withdraw from it at any time without giving a reason and without consequence. If you choose to withdraw, the information you have provided prior to the point of withdrawal will be included in the study analysis unless you request removal of the information where feasible. From the point of withdrawal no further information will be collected from you or included in the study.
Are there any risks?
There are no anticipated risks from participating in the evaluation. Your involvement will not impact on your employment or your relationship with the researchers or other participants in the research.

Are there any benefits?
The evaluation may provide benefits to decision making for gestational diabetes diagnosis and treatment, however it may or may not directly benefit you. Your participation may help others in the future.

What are the costs?
There will be no cost to you for participating in this evaluation. Travel costs associated with your participation will be covered by The Australian Prevention Partnership Centre. Please contact the Louise Freebairn on louise.freebairn@act.gov.au if this applies to you.

Access to the results of the study
Results will be used in a Doctor of Philosophy research thesis by the principal investigator listed above. They will also be published in journal articles and conference papers.

In any publication, information will be provided in such a way that you cannot be identified. Results will be provided to you, if you wish.

What about confidentiality?
Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at ACT Health.

If you have any questions please contact the research team

Louise Freebairn, Epidemiology Section, ACT Health,

Phone: 02 6205 2608 or email: louise.freebairn@act.gov.au

Should you have any problems or queries about the way in which the study is conducted, and do not feel comfortable communicating with the staff conducting this survey, please contact: ACT Health Human Research Ethics Committee (ACTH-HREC), Level 6, Building 10, Canberra Hospital, Telephone: (02) 6174 7968 or acthealth-hrec@act.gov.au

Evaluation of simulation modelling policy and program options to manage gestational diabetes in the ACT, April 2016
Consent Form for Participation in a Research Project

I, _______________________________ (name of participant)
of _______________________________ (address)

have been asked to consent to participation in a research project entitled:

Modelling policy and program options to manage gestational diabetes in the ACT

In relation to this study I have read the Participant Information Sheet and have been informed of the following points:

1. Approval has been given by the ACT Health Human Research Ethics Committee (ETHLR.15.150) and the University of Notre Dame Human Research Ethics Committee (015119S).

2. The aim of the study is to apply and evaluate a systems modelling approach to understand the factors associated with gestational diabetes and its treatment and to optimise the use of evidence to influence policy and program decision making.

3. The results obtained from the study may or may not be of direct benefit to me.

4. The study procedure will involve completion of surveys, audio-recorded model development and engagement workshops and audio-recorded evaluation interviews.

5. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the ACT Health Human Research Ethics Committee Secretariat, Canberra Hospital, Yamba Drive, Garran ACT 2605 (ph: 6174 7968).

6. I can refuse to take part in this project or withdraw from it at any time without giving a reason and without consequence. If I choose to withdraw, the information I have provided prior to the point of withdrawal will be included in the study analysis unless I request removal of the information where feasible. From the point of withdrawal no further information will be collected from me or included in the study.

7. I understand that while the results of the research will be made accessible my involvement and my identity will not be revealed.

After considering all these points, I accept the invitation to participate in this study.

Name: (please print) ______________________ Date: ________________

Signature (Participant) ______________________

Investigator: (please print) ______________________ Date: ________________

Signature (Investigator) ______________________

Modelling policy and program options to manage gestational diabetes in the ACT, version 1.2, July 2015
Evaluation of participatory simulation modelling to inform policy and program decision making for complex health issues

Project Overview:

This project aims to investigate the use of participatory dynamic simulation modelling as a tool to support decision making for health sector programs and policies.

Simulation modelling provides policy makers with a unique tool for synthesizing and leveraging existing data, evidence and expert and local knowledge to examine in a robust, risk-free and low cost way, the likely impact of different policy scenarios prior to implementation. Recent advances in modelling software capability and more user-friendly interfaces have meant that simulation modelling is now more broadly accessible, enabling a transparent and participatory approach to be used for the development of more complex models.

The outputs of such models can be used to inform broader policy dialogues to determine which policy and program options can and should be pursued.

Investigators:

The Principal Investigator for this project is Louise Freebairn from the Epidemiology Section, ACT Health, and PhD student at University of Notre Dame. The investigator team includes Dr Paul Kelly, ACT Chief Health Officer; Associate Professor Lucie Rychetnik from the University of Notre Dame and Dr Jo-An Atkinson from The Australian Prevention Partnership Centre.

Participant Information:

You are invited to take part in this study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask the study team any questions you have and request any further information you need.

Why is this study being done?

The purpose of this study is to apply and evaluate a systems modelling approach to understand the factors associated with complex health issues and to optimise the use of evidence to inform policy and program decisions.

Evaluation of simulation modelling for policy and program decision making, version 1.4, June 2017
What is involved in the study?

Participants will be invited to participate a recorded interview with the researcher. The interview is expected to take approximately one hour.

Why have I been chosen?

You have been chosen to participate in this study because you have been involved in a participatory dynamic simulation modelling project, for example the NSW Premier’s Priorities Project – reducing childhood overweight and obesity by 5% project or the Model behaviour – a systems approach to reducing alcohol related harms project.

Do I have to take part?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not impact on your employment or your relationship with the researchers or other participants in the research.

You can refuse to take part in this project or withdraw from it at any time without giving a reason and without consequence. If you choose to withdraw, the information you have provided prior to the point of withdrawal will be included in the study analysis unless you request removal of the information where feasible. From the point of withdrawal no further information will be collected from you or included in the study.

Are there any risks?

There are no anticipated risks from participating in the study. Your involvement in the project will not impact on your employment or your relationship with the researchers or other participants in the research.

Are there any benefits?

The study may provide benefits to decision making for complex health issues, however it may or may not directly benefit you. Your participation may help others in the future.

What are the costs?

There will be no cost to you for participating in this study.

Access to the results of the study

Results will be used in a Doctor of Philosophy research thesis by the principal investigator listed above. They will also be published in journal articles and conference papers.
In any publication, information will be provided in such a way that you cannot be identified. Results will be provided to you, if you wish.

What about confidentiality?

Any information that identifies you in connection with this study will remain confidential and will be disclosed only with your permission. An external company, Rev, will assist with transcribing the audio-recordings. Files are securely stored and transmitted using 128-bit SSL encryption, will never be shared with anyone outside of Rev and will only be visible to the transcribing professionals who have signed strict confidentiality agreements. The Rev confidentiality statement can be found on the website: https://www.rev.com/.

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at ACT Health.

If you have any questions please contact the research team

Louise Freebairn, Epidemiology Section, ACT Health,

Phone: 02 6205 2608 or email: louise.freebairn@act.gov.au

Should you have any problems or queries about the way in which the study is conducted, and do not feel comfortable communicating with the staff conducting this survey, please contact: ACT Health Human Research Ethics Committee (ACTH-HREC), Level 6, Building 10, Canberra Hospital, Telephone: (02) 6174 7968 or acthealth-hrec@act.gov.au
Consent Form for Participation in a Research Project

I, _____________________________ (name of participant)
of _______________________________ (address)
have been asked to consent to participation in a research project entitled:

Evaluation of participatory simulation modelling to inform policy and program decision making for complex health issues

In relation to this study I have read the Participant Information Sheet and have been informed of the following points:

1. Approval has been given by the ACT Health Human Research Ethics Committee (ETHLR.15.150) and the University of Notre Dame Human Research Ethics Committee (015119S).
2. The aim of the study is to apply and evaluate a system modelling approach to understand the factors associated with complex health issues and to optimise the use of evidence to influence policy and program decision making.
3. The results obtained from the study may or may not be of direct benefit to me.
4. The study procedure will involve audio-recorded evaluation interviews which will be provided to and transcribed by Rov transcribing services.
5. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the ACT Health Human Research Ethics Committee Secretariat, Canberra Hospital, Yamba Drive, Garran ACT 2605 (ph: 6174 7968)
6. I can refuse to take part in this project or withdraw from it at any time without giving a reason and without consequence. If I choose to withdraw, the information I have provided prior to the point of withdrawal will be included in the study analysis unless I request removal of the information where feasible. From the point of withdrawal no further information will be collected from me or included in the study.
7. I understand that while the results of the research will be made accessible my involvement and my identity will not be revealed.

After considering all these points, I accept the invitation to participate in this study.

Name: (please print) ___________________________ Date: __________

Signature (Participant) ___________________________

Investigator: (please print) ___________________________ Date: __________

Signature (Investigator) ___________________________

Evaluation of simulation modelling for policy and program decision making, version 1.3, June 2017
Appendix 4: Summary report – Gestational diabetes modelling workshop one

The following report was provided to participants from the model development group for the diabetes in pregnancy case study following workshop one.
Summary of Gestational Diabetes Modelling Workshop One

5 May 2016

Background

The purpose of The Australian Prevention Partnership Centre (TAPPC) is to develop and use systems thinking and systematic ways of preventing lifestyle related chronic disease. People from a range of disciplines, backgrounds and countries have gathered together to come up with practical ways to support decision making and research translation to address these issues.

This project will develop a dynamic simulation model that will look at gestational diabetes mellitus (GDM) from an ACT perspective and will be using ACT data. However, the national context will be considered in the model development and the model will be a proof of concept with the potential to expand much more broadly.

The model will consider the short, middle and long-term implications of the current food culture, overweight and obesity and GDM and Type 2 diabetes mellitus. Small delays in the development of diabetes will have large implications for the longer-term burden of disease and costs to the health system. This long-term vision is important as the model is built collaboratively.

Increasing demand for health services due to the rising prevalence of GDM is having a significant impact on resources and the need to “do things differently” was identified by several workshop participants. Workload and resource use will be incorporated into model to enable it act as a resource allocation decision support tool.

This workshop brings together practitioners, policy makers and researchers and allows for greater accessibility of data and expertise. This partnership also allows for research to be translated into policy and program decisions more readily.
Model purpose

The following purposes for the model were synthesised from the key modelling questions contributed by participants at the workshop. Full responses are included in Appendix A.

- Determine the best investments for intervention in GDM. E.g. “I’m here to see if modelling can help determine the right interventions, at the right times, by the right people, in the most efficient and effective way (to make a difference).” Interventions in the model to include both clinical and population health interventions.

- Examine GDM within a context or system e.g. Food environment, personal environment such as stress and coping.

Determining model structure: interventions and outcomes

Participants were divided into two groups to identify priority interventions and outcomes. Interventions and outcomes will be the focus of workshop 2, however it is important to understand the types of interventions and outcomes that will be incorporated into the model when commencing the model build. Workshop 2 will focus on identifying the causal mechanisms for the interventions and outcomes.

Each group identified interventions and outcomes and then all participants voted on those interventions and outcomes they considered to be most important for inclusion in the model (see images below).

Interventions:

This group discussed interventions based on a life course (from pre-pregnancy right through to college, Image A below). It was discussed that the biggest benefit at the population level is achieved when targeting people going from normal weight to overweight.

Most of the interventions that were mentioned were around education and primary prevention around physical activity and healthy eating.
Top 5 prioritised interventions:

1. Weight and height measurement pre pregnancy - having ongoing education about what is a healthy BMI, for pre pregnancy in particular. This would be a combination of awareness and education and measurement. Include a feedback mechanism.

2. Targeted preconception programs for high risk - women who are considered very high risk for GDM, come to program that works on getting them into the right shape before they conceive. (Subset of the first program)

3. Inter pregnancy - lifestyle change targeted at this stage of a woman's life course. Trying to reduce women who have had GDM gain for overweight and obese

4. Early screening at booking for the pregnancy. (Clinically based intervention). Not just for when they come to the hospital, but also when they come to GP - and what that would involve.

5. Incentives for lifestyle change.
Outcomes:

This group identified outcomes for the mother and outcomes for the baby separately and divided them into short term, medium term and long term outcomes (see Images B and C below).

Top 5 prioritised outcomes:

1. Incidence of GDM
2. Maternal diabetes
3. Childhood obesity
4. Early onset diabetes
5. Diabetes complications

Image B: Outcomes for Mother identified by participants
Image C: Outcomes for baby identified by participants

Mapping causal factors to the model infrastructure

Image D: Participants mapping factors to the agent based modelling infrastructure
A “strawman” model infrastructure for three agent state charts was laid out on a large table.

The three state charts were as follows:

Pregnancy state chart: States = not pregnant, 1st pregnancy, subsequent pregnancy
GDM state chart: States = Low risk for GDM, high risk for GDM, GDM diagnosed (with sub states indicating that the GDM was well controlled or not)
Weight state chart: States = normal/underweight, overweight, obese

Participants were asked to identify factors that contribute to people moving between the states in each state chart.

Refining the priority causal factors for inclusion in the model

A sub-group of participants met subsequent to the workshop to refine and synthesise the factors identified. A process of grouping the factors identified the
following themes (listed in no particular order) which will be represented in the model.

1. Family history/genetic factors
   a. Family history of diabetes
   b. Family history of obesity
   c. Epigenetics
   d. Genes

2. Food
   a. Unhealthy diet
   b. Food security
   c. Food environment

3. Physical Activity
   a. Level of physical activity
   b. Level of sedentary behaviour
   c. Physical environment

4. Health state
   a. Previous pregnancy with GDM
   b. Multiple pregnancy
   c. Previous still birth
   d. Previous macrosomic baby
   e. Previous pregnancy with fetal growth restriction
   f. Personal history of macrosomia

5. Health care system
   a. Type of screening test
   b. Universal or selective screening
   c. Access to health care – rurality/remoteness
   d. Health bureaucracy
   e. Government policy
   f. Infrastructure/environment
   g. Market/trade

6. Metabolic functioning
   a. Weight status
   b. Gestational weight gain

7. Non-modifiable factors
   a. Age
   b. High risk ethnic group
   c. Migration
   d. Polycystic Ovary Syndrome (PCOS)

8. Psychosocial
   a. Education level
b. Social network  
c. Cultural norms  
d. Occupation  
e. Inequality  
f. Psychological factors  
g. Poverty

Next steps:

- Workshop 2 will focus on interventions and outcomes. Participants will identify the causal mechanisms for interventions and pathways for measuring outcomes.
- Participants have been invited to be involved in model development meetings and discussions between workshops.
- Workshop 2 – 19 August 2016.
Appendix A Key questions identified by participants

- I’m interested in the food environment and the impact this has on the problem of GDM. How can we link the acute management of GDM with population level management? How do we measure outcomes that occur at the systems level?
- How do we manage GDM, particularly in the second half of pregnancy?
- How does GDM fit into the broader problem of diabetes and obesity prevention?
- I’m concerned with the continuum of pre-pregnancy, during pregnancy and after pregnancy. Here to see if modelling can help determine the right interventions, at the right times, by the right people, in the most efficient and effective way (to make a difference).
- Consideration of personal and contextual factors that contribute to stress.
- Better ways to assess models of care for managing GDM.
- Interested in looking at different approaches before and after prevention, and how the model can help decide where to invest for intervention.
- Different models of care provision and testing better ways to prevent GDM.
- The risk for the next generation and prevention as early as possible for the next generation.
- What is the best bang for buck for population interventions and clinical management interventions? Also, long term considerations in terms of health services costs and burden of disease.
Appendix 5: News article – Workshop unpicks causes of gestational diabetes as part of simulation modelling project.

Archived: Simulation modelling helps to unpick causes of gestational diabetes

1 June 2016

A multi-disciplinary group of clinicians, policy makers, researchers and modellers have worked together to map the risk factors and causes of gestational diabetes in the ACT.

The team included international guests, Mr Alton McLean, Associate Professor Nate Osgood and Professor Roland Dyck, who are world leaders from Canada in simulation modelling for gestational diabetes.

This was the first of a series of workshops for a PhD project, led by Louise Freebain involving ACT Health, Prevention Centre and the University of Saskatchewan.
Ms Freebairn, Manager of the Knowledge Translation and Health Outcomes Team at ACT Health, said the project aimed to tackle the growing problem of gestational diabetes against the backdrop of increasing interest in systems science methods to examine complex problems.

Simulation modelling is one method under the umbrella of systems science, and can be used as a unique ‘what if’ tool to test the likely impact of a range of possible solutions before implementing them in the real world.

Ms Freebairn said a key outcome of the day was that workshop participants agreed on the importance of a population health approach to address the increasing rates of gestational diabetes.

“One participant used the analogy of current diabetes services rescuing people who have fallen into a river. They don’t have the capacity to run upstream and see why people are falling in because they are too busy pulling people out,” she said. “What they need is somebody to go upstream and stop people falling into the river in the first place. This is where population health approaches can play an important role.”
Ms Freebairn said the project epitomised the collaborative nature of the Prevention Centre, not only because of the multidisciplinary group of participants, but also its policy relevance.

"If the model can inform even small effects in the delay of the onset of diabetes, this will have huge impact in terms of the long-term benefits for health service costs and the burden of disease in individuals and the population," she said.

The next workshop, to be held in August, will explore the likely effect of a range of interventions.

- By Elaine O'Donnell, Research Officer