

The Use of Incentives to Stop Smoking in Pregnancy among Aboriginal and Torres Strait Islander Women

Discussion Paper

Marita Hefler and David Thomas



Incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health





Discussion Paper

Marita Hefler and David Thomas



© The Lowitja Institute, 2013

ISBN 978-1-921889-24-0

First published in August 2013

This work is published and disseminated as part of the activities of The Lowitja Institute — Australia's National Institute for Aboriginal and Torres Strait Islander Health Research, incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH). CRCATSIH is a collaborative partnership partly funded by the Cooperative Research Centre Program of the Australian Government Department of Industry, Innovation, Climate Change, Science, Research and Tertiary Education.

This work is copyright. It may be reproduced in whole or in part for study or training purposes, or by Aboriginal and Torres Strait Islander community organisations subject to an acknowledgment of the source and no commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holder.

Additional copies of this publication can be obtained from:

The Lowitja Institute

PO Box 650 Carlton South VIC 3053 Australia

T: +61 3 8341 5555 F: +61 3 8341 5599 E: admin@lowitja.org.au W: www.lowitja.org.au

Authors: Marita Hefler and David Thomas

Managing Editor: Cristina Lochert Design and print: Inprint Design (6944)

For citation: Hefler, M. & Thomas, D. 2013, *The Use of Incentives to Stop Smoking in Pregnancy among Aboriginal and Torres Strait Islander Women*, The Lowitja Institute, Melbourne.





Table of Contents

Abbreviations	iv	
Preface	1	
Executive Summary	2	
Background	3	
The Roundtable	3	
Presentations	4	
Incentives to support women to stop smoking in pregnancy: International evidence and experience – Ms Catherine Chamberlain	4	
The AWHI-Incentives Trial – Dr Marewa Glover	6	
Project ENtiCe: Encouragement for nicotine cessation – Dr Marita Lynagh	6	
Stop smoking in its tracks: Formative research, developments and pilot study – Dr Megan Passey	7	
lssues	10	
Low consent rate for trials	10	
Ethics	10	
A broader approach?	11	
Individual, family or community targeting?	12	
Research and service partnerships	12	
Client-service provider relationships	13	
Empowerment and 'shame/stigma'	13	
Unintended consequences	14	
Practicalities	14	
Measuring success	15	
What are the gaps?	15	
Concluding Remarks	16	
Appendix 1: Agenda	17	
Appendix 2: List of Participants		

Abbreviations

AMIHS Aboriginal Maternal and Infant Health Service

CI Confidence interval

RCT Randomised controlled trial

RR Relative risk or risk ratio. In this paper, RR is used to show the impact of

interventions on quitting. For example, an RR of 2 means an intervention doubles

the probability of quitting.



Preface

The Lowitja Institute¹ has a long history of providing a place for Aboriginal and Torres Strait Islander and non-Indigenous people, researchers and the users of research (policy-makers and practitioners), government and Aboriginal community controlled health services to come together and talk about sensitive issues of concern for research.

There is international interest in incentives as a potential strategy to reduce smoking in pregnancy. In Australia, there is interest among researchers in testing their efficacy, with a particular focus on population groups with high smoking prevalence including Aboriginal and Torres Strait Islander women. However, there are also real concerns about the potential unintended consequences of this approach and about the practical and ethical difficulties of any trial or potential new policy involving such incentives.

This discussion paper describes a Roundtable which brought together invited participants from the Aboriginal community controlled health service sector, government, research organisations, antenatal care services and tobacco control. The Roundtable provided an opportunity to raise issues and canvass different perspectives on the use of incentives to reduce smoking in pregnancy among Aboriginal and Torres Strait Islander women.

This paper provides an overview of presentations and discussions. It summarises findings from international research, formative research and proof-of-concept trials in Australia and New Zealand, and highlights challenges and lessons learned to date. Participants at the Roundtable were offered the opportunity to provide feedback on a draft of this report.

The comments reported in this discussion paper should not be read to imply endorsement of these views by the organisations of the participants, including the Lowitja Institute, nor should they be taken to represent consensus views as there was a diversity of perspectives among participants. This report attempts to capture that diversity. We have chosen not to identify who said what in the discussions.

Bringing together key stakeholders at this early stage in the exploration of the potential use of incentives for stopping smoking in pregnancy is crucial. We hope that this paper encourages and informs future discussions about the approaches to reducing smoking during pregnancy and consideration of the use of incentives.

David Thomas

Associate Director Research and innovation The Lowitja Institute

¹ The Lowitja Institute incorporates the Cooperative Research Centre (CRC) for Aboriginal and Torres Strait Islander Health. Its predecessor organisations are the CRC for Aboriginal and Tropical Health and the CRC for Aboriginal Health.

Executive Summary

Key findings from the current international evidence presented to the Roundtable show that contingent incentives² have the strongest effect of any intervention tested to assist smoking cessation during pregnancy. However, this is based on a small number of trials that have been conducted in the United Kingdom and the United States which have also used intensive support. Nonetheless, the effect has translated into a significant reduction in pre-term and low birth weight.

Initial findings from small research studies in Australia and New Zealand show that incentives are feasible and acceptable to Indigenous and other women. However, an important caveat is that two of the trials to date have only achieved low consent and participation rates. The only trial with Australian Aboriginal women achieved good participation rates, with recruitment and implementation by antenatal service providers.

Among participants in the Roundtable, key concerns were:

- · Whether the existing evidence was sufficiently strong to warrant further research on use of incentives among pregnant Aboriginal and Torres Strait Islander women, rather than on other less controversial smoking cessation interventions in pregnancy
- The low consent and recruitment rates achieved in the two Australasian proof-of-concept trials
- The ethics of incentives, in particular, exploiting economic desperation and desire for financial reward when women are experiencing financial hardship. Also, the ethics of excluding nonpregnant women (and men) through targeting smoking in pregnancy versus the imperative to offer effective intervention(s) to tackle the most important preventable risk factor for adverse pregnancy and perinatal outcomes.

These were seen by many participants as critical to resolve before considering interventions which include incentives.

Other contentious issues raised by several participants as important to be addressed included:

- Focusing too much on individual pregnant women with the potential for shame and stigma
- The potential impact on the relationship between pregnant women and their service providers.

The discussion pointed to a number of possible ways forward in considering appropriate interventions for smoking cessation in pregnancy and the potential use of incentives:

- The need for interventions to take a broad approach both in terms of how smoking itself is addressed and in the context of the range of issues facing families
- Reducing the focus on the individual pregnant woman
- The need to consider a range of partnership models
- The importance of using empowering language
- The need to ensure that other current evidence-based approaches to smoking cessation are being fully implemented before the effectiveness of incentives are evaluated.

A contingent incentive is one that is only paid on achievement of an agreed task or outcome. It differs from a non-contingent incentive, which is paid for participation, regardless of outcome. An additional component of contingent incentives can be increasing the size of the incentive over time for cumulative achievement.

Background

Maternal smoking during pregnancy is the most important preventable cause of adverse pregnancy and perinatal outcomes, including low birth weight and infant mortality. Despite falling smoking prevalence, smoking in pregnancy among some disadvantaged groups remains a significant health problem, with smoking during pregnancy being three times more common among Aboriginal and Torres Strait Islander women than non-Indigenous Australian women (52% compared to 16%).3

The 2009 Cochrane review of interventions for smoking cessation during pregnancy found that incentive-based programs produce higher smoking cessation rates among pregnant women in late pregnancy than any other tested intervention. 4 Studies to date have been conducted in the United States among a predominantly white, lower socioeconomic population of pregnant smokers. This Roundtable provided the opportunity to discuss early findings and lessons learned from Australia and New Zealand.

The Roundtable

The Roundtable was held on 28 May 2013 in Sydney. Donna Ingram of the Metropolitan Local Aboriginal Land Council gave the Welcome to Country.

The Roundtable process ensures the early involvement of all potential users in the research process and facilitates a collaborative approach. The process is designed to be structured and participative, using a mixture of formats, both presentations and discussions. Respect for the different views and perspectives and acknowledging that different sectors can legitimately have different views is an underpinning principle.

The purpose of the Roundtable and this discussion paper is not to endorse or not any potential new research or policies, rather to identify key issues and how these issues might be addressed.

The Roundtable was hosted by David Thomas from the Lowitja Institute and the Menzies School of Health Research and discussions were facilitated by Marita Hefler from the University of Sydney and the Tobacco Control journal. The agenda and list of attendees are included as Appendices 1 and 2.

Sullivan, E. A., Laws, P. & Grayson, N. 2006, Smoking and Pregnancy, AIHW cat. No. PER 33, Australian Institute of Health and Welfare, Canberra

Lumley, J., Chamberlain, C., Dowswell, T., Oliver, S., Oakley, L. & Watson, L. 2009, Interventions to Promote Smoking Cessation in Pregnancy, Cochrane Database of Systematic Reviews, July 8(3): CD001055, doi: 10.1002/14651858.CD001055.pub3

Presentations

Four speakers presented findings from international and Australian research evidence about the use of incentives to reduce smoking in pregnancy, the lessons and challenges from two proofof-concept trials currently underway in Australia and New Zealand, and from a completed pilot program with Aboriginal women. The presentations are summarised below, in the order in which they were presented on the day. The order of presentations is different from the Agenda (Appendix 1) due to late arrivals caused by fog interrupting air travel to the meeting.

Incentives to support women to stop smoking in pregnancy: International evidence and experience

Ms Catherine Chamberlain

Catherine Chamberlain set the scene, presenting international evidence and experience on incentives to support women to stop smoking in pregnancy. She is one of the lead authors of the 2009 Cochrane Review on Interventions to Promote Smoking Cessation in Pregnancy⁵ and is currently working on the update, which has been split into two separate reviews. The first review on pharmacological interventions was published in 2012.6 The second review of psychological interventions is currently being completed, and is due for submission at the beginning of June 2013.

She briefly outlined the key reasons for addressing smoking in pregnancy, noting that it is the most significant 'potentially preventable' cause of pre-term birth and low birth weight. It is also a marker of social disadvantage and a cause of health inequality that has complex associations with poverty, marginalisation and mental health. Ms Chamberlain noted that while smoking rates are declining, the rates among Indigenous women in Australia and New Zealand remain high.

Ms Chamberlain's review of the qualitative literature found that smoking is an embedded and unquestioned part of the lives and identities of many women. While smoking in pregnancy triggers anxiety and guilt, quitting is considered to have downsides because of the potential to disrupt relationships and the fact that it is a habit that is perceived as helping to cope. The role of partners in influencing smoking was noted. While stopping smoking in pregnancy is a desirable health goal, there are nonetheless a number of contentious health issues to be aware of, including inadvertently undermining women's rights, increasing marginalisation and stigma, victim-blaming and focusing on the individual, thus failing to address the root causes of smoking such as inequalities.

Ms Chamberlain then outlined the findings of the Cochrane review, which included 86 randomised control trials (RCTs) of smoking. Importantly, these findings help identify the impact of specific interventions on smoking cessation. Counselling demonstrated a significant effect when compared to usual care (31 studies; risk ratio [RR] 1.44, 95% confidence interval [CI] 1.19 to 1.75), a borderline

⁵ Lumley, J., Chamberlain, C., Dowswell, T., Oliver, S., Oakley, L. & Watson, L. 2009, Interventions to Promote Smoking Cessation in Pregnancy, Cochrane Database of Systematic Reviews, July 8(3): CD001055, doi: 10.1002/14651858.CD001055.pub3

⁶ Coleman, T., Chamberlain, C., Davey, M. A., Cooper, S. E., Leonardi-Bee, J. 2012, Pharmacological Interventions for Promoting Smoking Cessation During Pregnanc, Cochrane Database of Systematic Reviews, Issue 9, art. no. CD010078, doi: 10.1002/14651858 CD010078

effect when compared to less intensive interventions (16 studies; RR 1.30, 95% CI 1.00 to 1.82) and there was no significant effect in the single study comparing cognitive behaviour therapy with an alternative counselling intervention (RR 1.15, 95% CI 0.86 to 1.53).

Incentives did not demonstrate a significant effect when compared to usual care (two studies; RR 3.39, 95% CI 0.10 to 130.49), but did when compared with a less intensive intervention (one study; RR 3.64, 95% CI 1.84 to 7.23) and an alternative intervention (one study; RR 4.05, 95% CI 1.48 to 11.11). Feedback demonstrated a significant effect only when compared to usual care and provided in conjunction with other strategies, such as counselling (two studies; RR 4.35, 95% CI 1.89 to 10.21), but not when compared to a less intensive intervention (two studies; RR 1.19, 95% CI 0.45 to 3.12). There were no significant differences where health education was compared with usual care (three studies; RR 1.51, 95% CI 0.64 to 3.59) or less intensive interventions (two studies; RR 1.50, 95% CI 0.97 to 2.31).

Comparisons of social support and less intensive interventions did not demonstrate a significant effect (six studies; RR 1.29, 95% CI 0.94 to 1.78), but did when the single trial of partner support was removed and only peer support interventions were included (five studies; 95% CI 1.49, 95% CI 1.01 to 2.10). However, studies where peer support was provided as part of a broader intervention to improve maternal health did not show a significant effect when compared to usual care (two studies; RR 1.35, 95% CI 0.05 to 34.13) or a less intensive intervention (two studies; RR 0.80, 95% CI 0.46 to 1.39).

Based on these figures, contingent incentives show the strongest effect. It was noted that these findings are consistent with other reviews of financial incentives in pregnancy and incentives for reducing substance abuse more generally. Despite this, the result should be treated with caution due to the fact that it is based on only four trials, with a total of less than 500 women, all were undertaken in the United States and incentives were paired with intensive support. However, the interventions had a significant impact on health outcomes, with an 18 per cent reduction in preterm births and low birth weight infants.

Ms Chamberlain then provided an overview of a program undertaken by the National Health Service Tayside in Dundee, Scotland, and showed a short video interview with the project leader. The intervention was based on qualitative research to identify what was most important to the target women. 'Putting food on the table' was seen as a priority, so an incentive of £12.50 per week of grocery vouchers was paid. The intervention resulted in a doubling of the number of mothers quitting. It was based on the principle of making it as easy as possible, therefore pharmacies, which are accessed by the women for a range of services, were used as the key service provider because they were both accessible and familiar. In the geographical target area there is one pharmacy within 500 metres of every house.

Mistakes identified and lessons learned from the trial were: not involving politicians from the beginning (because the project did come to the attention of the media), and the need to establish contracts with pharmacies and provide training. Success was measured as 'turning up' for intervention, not only quitting. It was noted that being paid was helpful for women to deal with social pressure to smoke, as it provided an acceptable justification to peers. Unintended consequences included a 'sense of failure' if unable to quit, which led to women not re-engaging with services. Because the incentive was very important financially to some women termed 'breadline survivors', this group sometimes had arguments over results when they returned a positive result and were

⁷ Interview can be viewed at http://www.youtube.com/watch?v=SIm9BAU9YMs

ineligible for payment. Apparently, there were no false negative results. In terms of success, quit rates were 54 per cent at four weeks post-partum, 32 per cent at 12 weeks, and 17 per cent at 3 months.

The AWHI-Incentives Trial

Dr Marewa Glover

Dr Glover presented experience from a proof-of-concept trial she is currently running in New Zealand. The project started recruiting in January, with the plan to have 80 participants recruited by April. Currently, 19 participants are enrolled, randomised into three groups. Due to recruitment difficulties, this phase of the project has been extended to six months. Dr Glover noted that this is the first time she has had difficulty recruiting, despite experience of several other trials involving Māori women. Recruitment methods included newspaper advertisements for two days per week in eight papers (six recruited); presentations to local providers and community groups; notices distributed through local providers; partnerships with local providers (12 recruits); radio interviews, media articles and a Facebook page (one recruit). A total of 51 women were referred, of whom 49 were eligible to participate. Of these, 19 proceeded to randomisation and 10 have completed the trial.

Dr Glover noted the challenge of recruitment methods not working well and that there is high loss to follow up.8 She speculated that possible reasons may be that pregnant smokers may be feeling 'bombarded' because of 'smoke-free pummeling', pathologising of smoking, and the fact that primary health care providers are paid when they provide smoking cessation services and so may choose to protect these payments by not referring clients to a trial. In addition, she questioned if racism within health services and the public, as demonstrated by public remarks in the media, was compounding barriers to participation in the trial.

Because of the recruitment challenges and uncertainty around the reasons, Dr Glover has recently undertaken a short survey to canvass the views of potential participants. Eighty-six women were recruited over three weeks through direct approach on the street. Among those who participated in the survey, it was found that 74 per cent would consider taking part in research asking about smoking while pregnant. Likely reasons for low consent rates might be shame (whakamaa), not prioritising quitting, laziness, culture, stress, addiction, stubbornness and lack of knowledge of the harms of smoking while pregnant. From the survey, it was concluded that Māori and Pacific women are willing to take part, but they needed to be recruited via direct approaches rather than through health services.

Project ENtiCe: Encouragement for nicotine cessation

Dr Marita Lynagh

Dr Lynagh presented interim findings from a proof-of-concept trial currently being undertaken by the University of Newcastle in the Hunter New England Area Health Service. The reasons for undertaking the trial included—in addition to other reasons—the fact that contingent reinforcement has a strong theoretical grounding, as do financial incentives, and there is evidence

Loss to follow up occurs when participants are not able to be retained in the trial following enrolment. This may occur due to researchers being unable to contact participants, failure to present for appointments, or discontinuing participation for other reasons.

of effectiveness of financial incentives in other health behaviours such as immunisation. The intention of the trial is to test the feasibility of a personal financial incentive for women attending public hospital antenatal care. The feasibility will be measured by consent and loss to follow up, potential barriers and facilitators, cost effectiveness and actual quit rates. Practical aspects such as use of touchscreen laptops, implementation in a public hospital setting and acceptability and compliance with use of saliva and hair cotinine⁹ analysis are also being assessed.

The study design used the standard antenatal care schedule as the basis for intervention and randomised participants into three groups: group A (control, no incentive payment), group B (\$20 incentive), and group C (\$40 incentive). For each incentive group, the base amount was paid at the first follow-up visit with smoke-free status verified and increased by the same amount at each subsequent visit (i.e. group B were paid \$20 at first follow-up visit, \$40 at second follow-up visit, \$60 at third visit, etc.; group C were paid \$40 at first follow-up visit, \$80 at second, \$120 at third and so on). Payment was made in cash. The maximum number of visits with incentives payable was eight—a maximum total payment of \$720 payable for group B and \$1440 for group C.

As with the New Zealand trial, there were challenges with recruitment. The number of women who completed an initial screening for eligibility was 1318; of those, 171 (13%) were eligible to participate, of which 23 (14%) consented to participate. Reasons for non-consent are unclear, as the ethics committee would not allow researchers to follow up with non-consenters to determine reasons for refusing to participate.

Overall, the findings to date show that use of rewards has encouraged 20 per cent of women to quit successfully and use of rewards appears to be feasible. The loss to follow up is low (9%), however, this is from a low consent rate (14%). Saliva cotinine is acceptable for validation of smoking status, but hair cotinine is not (only one woman agreed to provide a hair sample). Touchscreen laptops are highly acceptable, but space is problematic in a busy public hospital clinic.

Stop smoking in its tracks: Formative research, developments and pilot study

Dr Megan Passey

Dr Passey provided an overview of a collaborative project undertaken between the University of Sydney and the Aboriginal Maternal and Infant Health Service (AMIHS) program in the North Coast region of New South Wales. The project was initiated in 2007 following a request from the local AMIHS team. Consultation with Bundjalung Elders and a community reference group guided and supported the work.

In the initial stages, the team found little evidence on what would work for pregnant Aboriginal women, but plenty of available evidence for non-Indigenous women—including incentives—which the team were able to draw on. To determine the best approach, the team undertook a qualitative study with women and survey providers, as well as surveys with pregnant Aboriginal women and with antenatal care providers in New South Wales and the Northern Territory. The research did not

⁹ Cotinine is a metabolite of nicotine. Its presence in saliva is a biomarker for tobacco smoke exposure. The level of cotinine present is proportional to the amount of exposure, and therefore provides an indicator of both active and passive tobacco smoking.

focus on incentives, but did include questions on the use of incentives. Only the findings related to incentives were presented at the Roundtable. The research found that incentives were strongly endorsed provided smoking could be properly monitored, care was needed in managing failure to avoid shame, and there should be an empowering approach. The surveys found that incentives were fairly evenly supported by women (63%) and staff (56%). However, women and staff expressed significantly different views on the perceived helpfulness of other strategies. Incentives were rated as the second most helpful by women, after support for family (64%), whereas they were rated by staff as the second least helpful.

In addition to incentives—paid as vouchers for use at local stores—the design of the project included assessment and intensive counselling using a motivational approach for all women, free nicotine replacement therapy, educational resources, social support groups, interventions for other drug use, and support from household members. Recognising that role modelling is important, assistance was also provided to assist members of the AMIHS team to quit. The visit schedule was twice weekly for three weeks, weekly for the next four weeks, then fortnightly until birth, weekly for six weeks post-partum, then fortnightly until six months post-partum. The value of the incentive started at \$10, increased by \$2 for each visit and could be reset if there was a lapse then return to smoke-free. The maximum available per participant was \$970.

The key principles used to determine the schedule and value of rewards were based on research in the United States which indicated that rewards should be provided as soon as possible after confirmation of cessation, should progressively increase in value, be of sufficiently high value to be attractive, be frequent in the early phases with gradual tapering off, and continue to post-partum. The community reference group helped determine the value and structure of the rewards.

During the set up phase, similar concerns were raised as in other trials of the possibility of women delaying quitting or taking up smoking for rewards, and potential resentment from non-smokers. There were also concerns that the voucher would be seen as a welfare voucher and cause shame. The program was therefore designed to address and monitor these issues by including recent quitters in the program and specially designing the reward voucher as a 'reward', with training for businesses in the importance of congratulating the women. The validity of the smokerlyser reading was also raised as a concern.

The participation rate for the trial was 58 per cent of eligible participants. Of those that participated, the completion rate was 86 per cent: 19 women completed the study. Eighty-four per cent of the participants made a quit attempt; 42 per cent were quit at 36 weeks. The reward amounts ranged between \$56 and \$820; the median amount was \$294.

In terms of feasibility, the key challenges were around team capacity to implement all elements of the program, including frequency of visits, running groups, and the distances covered for outreach. No major issues were identified related to the incentives. Feedback provided by the women were that they loved the frequency of support, found the rewards very motivating, constant reinforcement from the AMIHS team was important, and ongoing support with strategies was valued. Feedback from the AMIHS team was that being able to offer quit support was much more powerful than usual care and combining rewards with other support was very effective. Being able to earn rewards was reported by the AMIHS team to have generated significant pride among participants. However,

one of the teams thought that women who had not succeeded may have been embarrassed and the experience may have been disempowering. None of the women reported this.

Dr Passey identified a number of questions which she considered remain unanswered including how effective rewards are with Aboriginal women, both during pregnancy and post-partum: their cost-effectiveness; whether they undermine intrinsic motivation, the accuracy of smokerlysers for people exposed to secondhand smoke, unintended consequences, whether they would promote uptake or delayed quitting. These questions should be addressed in any future research.



Issues

The issues discussed are summarised below. They have been grouped under broad headings, which should be treated as a guide rather than definitive categorisation; many of the issues can and do overlap the categories listed. The order in which the issues are listed does not reflect priority or importance, but the key overall themes. The discussion on the day moved between different issues that were explored from a range of angles and several were raised at multiple points through the day. Additional feedback was provided through evaluation and feedback forms on the day and an online survey following the event. Participants were also given the opportunity to comment on the draft report to ensure that it accurately reflected discussions.

Low consent rate for trials

The low consent rate given to participate in trials was raised as a major issue of concern by several Roundtable participants. Some participants felt that this was indicative of a broader problem and that this reluctance to engage raised questions about the likely cost-effectiveness and viability of any future initiatives involving incentives. For comparative purposes, it should be noted that consent rates are typically low in smoking cessation research trials, generally around 20–30 per cent. Nonetheless, this issue raises broader questions about cost-effectiveness. Even if the intervention itself proves to be effective for those who choose to participate, if the overall numbers are too small it undermines the population-based cost-effectiveness.

Dr Glover's street-based survey provided some insights about the views of potential participants. However, for many participants of the Roundtable this is a fundamental issue that would need to be resolved for cessation programs with incentives to be rolled out, or even for larger scale research. The proof-of-concept trials presented by Dr Glover and Dr Lynagh are in the early stages and may yield further insights about this issue as they progress. In the absence of further research about participation rates, it may be incorrect to presume that there is lack of interest in participating in incentive-based programs – there may be multiple explanations, including the possibility that women are simply not interested in quitting smoking regardless of the type of intervention offered. The consent rate in the trial presented later in the day by Dr Passey was considerably higher than the two proof-of-concept trials – it may be that the more comprehensive approach and guidance from the community reference group helped with improving interest.

Ethics

There was considerable concern about the issues of 'breadline survivors' (from the Scottish research in Ms Chamberlain's presentation) and potentially exploiting economic desperation. Given that smoking is itself a marker for socioeconomic disadvantage and inequality is a root cause of smoking, the tension between addressing smoking itself rather than the underlying inequality may be problematic when using incentives as a lever for behaviour change. Concerns were also expressed about the issue of excluding some by targeting incentives at pregnant women. There was a diversity of views expressed on this issue. Some felt that the very specific targeting was appropriate and that incentives offered an additional motivator for pregnant women who are

uncomfortable using NRT; others felt that it was unfair to exclude women who may be in equally difficult circumstances but are ineligible due to not being pregnant.

Others felt that singling out pregnant women could add to stigma and adds to surveillance of the female/Indigenous body. It also places a disproportionate burden of responsibility on pregnant women — this is discussed further in other sections. It was noted that experiences from the formative research indicated incentives are perceived as less problematic for women themselves and that in the pilot project presented by Dr Passey the women reported valuing the incentives. There has been some concern about the use of incentives among governments in New Zealand.

One participant observed that it is value-laden to oppose the use of incentives on the grounds that women should quit for the sake of their health, given that there is some evidence incentives work. Prioritising health over other things may not reflect everyone's values, in which case incentives may be appropriate to achieve abstinence in pregnancy. Another questioned the need to do research if incentives are likely to be effective – why not just go ahead and roll it out? It was noted that policy-makers need evidence in order to be able to implement such an initiative.

The question was raised whether it would be acceptable to target Aboriginal women only, rather than targeting women by socioeconomic disadvantage, or a universal approach. Given that smoking is a marker of disadvantage, and that to target certain groups would risk being perceived as tokenistic, it was considered by several participants that a universal approach would be preferable. This has been the approach within the trial area in Scotland (although the geographic area is identified as an area of deprivation, so this is an example of targeting by identified community rather than individuals). Programs should be adapted to suit the local context and community.

While there are significant ethical concerns about using incentives, it was also pointed out it is an ethical obligation for antenatal care providers to offer women best practice. Offering incentives to individuals may be part of that, within a full suite of options at the community level. Many antenatal services may not be able to offer the full suite of community level options, but, rather, could only contribute by offering individual support to their clients.

A broader approach?

Several participants canvassed the need for any attempts to tackle smoking in pregnancy to be part of a broader approach, both in terms of smoking and general wellbeing.

Prior to the Roundtable some participants had flagged the issue of smoking and alcohol consumption going together and suggested that both should be addressed concurrently to maximise effectiveness. This was seen as being of particular relevance in communities with high rates of foetal alcohol spectrum disorder. Others noted that there is a range of other issues of concern that are tied-in with child and family wellbeing, including vaccination, the involvement of government welfare authorities, and overall levels of alcohol consumption within families. Smoking is therefore part of a package of issues to be addressed to promote wellbeing.

It was also noted that exposure to secondhand smoke and smoking in the home is an issue that has adverse impacts in pregnancy and beyond. Addressing these issues may be an easier 'way in' which then allows smoking in pregnancy to be targeted. The narrow incentive-based focus may be a reason for low recruitment rates in the trials presented by Dr Glover and Dr Lynagh. As one participant put

it, people have a 'bullshit detector' and may see incentives as being an artificial strategy to do what they should be doing anyway. It was noted that, in the pilot study with pregnant Aboriginal women, the incentives offered were valued as part of a comprehensive support program.

Some participants also suggested that focusing on women only in pregnancy may be counterproductive and that it would be better to target all women (with a particular focus on reaching women before they are pregnant). This would not only have population-wide benefits, but would also avoid 'singling out' pregnant women and inadvertently adding to shame and stigma. There were also concerns that only focussing on women when they were pregnant might be seen as 'anti-women' as it was treating them only of value as incubators for the foetus. However, it was also pointed out that most pregnant women want to do the best they can for their baby; it is important to support them to do this and clinicians have a duty of care to do so.

Individual, family or community targeting?

Several participants expressed concerns about focus on an individual and suggested that familybased interventions would be more appropriate and effective. Other options included a focus on the entire family, community-based approaches or service-level interventions.

There was some discussion about the need to support families to do better – a goal that can be supported by all, and is not just about smoking, but is one of many issues. There were concerns expressed that there is too much focus on pregnant women, when there are many other things — 'small steps are needed'. Shifting to a child focus was also put forward as a better approach.

Experience from a project in Victoria that targeted the whole community was given as an example of a broader approach that has found a high level of acceptance among target groups. Such an approach reduces the responsibility placed on individual pregnant women, may reduce stigma, and is likely to promote a more supportive social context for quitting. One participant later noted that there should be a focus not only on the acceptability of the intervention, but also the effectiveness if it is highly acceptable but does not result in cessation, improvement in pregnancy and perinatal health outcomes will not be achieved.

Research and service partnerships

The partnership models used in the research projects that were presented generated reflection and discussion about the most appropriate models for the variety of contexts in Australia. In response to the description of strategies used in the Scottish study, it was suggested that using Aboriginal community controlled health services (or their pharmacists) instead of private pharmacies would be more appropriate, as they are known to the community and there is already a level of trust.

For future research, it was suggested that health services may need to be co-investigators, not merely recruiters for participants. This strategy has potential to improve recruitment rates and may explain the higher recruitment rates in the pilot project presented by Dr Passey. However, it was noted that this is unlikely to be feasible in research involving large numbers of services. There was also some debate about the appropriateness of whether health services should be delivering incentives, or if they should be provided separately.

Other suggested partnership models included the idea of using community Elders, such as the 'Strong Women Strong Babies' project in the Northern Territory which is based on traditional roles of older women to provide guidance for younger women. This was seen as a way of drawing on the strength of traditional practices, and also utilises an appropriate relationship to be advising women about being smoke-free, avoiding some of the potential issues outlined in the section on client—service provider relationship.

It was noted that the new federally funded Aboriginal Tobacco Action Workers in many Aboriginal Community Controlled Health Services are non-clinical roles, which may make it difficult for them to be involved in an incentives program. However, this was not seen as a problem by participants representing tobacco action workers, and it was noted that they currently already provide a full range of cessation services.

Client-service provider relationships

Concerns about the potential impact on relationships between clients and providers were raised in both presentations and discussions. Shame about failure was a particular concern, as it has the potential to affect engagement with antenatal care and other services. In the Scottish trial, it was noted that some participants were unwilling to re-engage with services following relapse, which may impact on the success of future quit attempts. This contrasts with the pilot project presented by Dr Passey, in which the AMIHS team were pleased that women who had not succeeded did not withdraw from antenatal care.

The role of midwives and the potential impact on women's relationships with them was a particularly contentious issue. Some were concerned about midwives having a philosophical resistance to delivering unambiguous smoking cessation interventions due to fear of not appearing supportive of their clients. In other cases, the strength of that relationship was seen as a potential buffer for managing shame associated with relapse. Some felt that appropriately trained midwives are ideal to deliver cessation assistance, as it is part of a holistic service and there would be a reduced risk of stigma arising out of seeing a separate worker or clinic.

The use of CO₂ monitors and mandatory reporting requirements at antenatal care providers was noted as having a potentially negative impact on relationships with clients, and concern was expressed about the potential for government welfare services involvement. Some parts of the United Kingdom are considering introducing mandatory monitoring of smoking, however, it is not planned that this will be linked with incentives for cessation. Dr Glover noted that in New Zealand they have been able to recruit families who receive income from government welfare agencies.

Empowerment and 'shame/stigma'

How smoking cessation intervention is framed, and the language used, was seen as an important issue for consideration. There is a particular concern about much of the language being negative and the need to ensure that approaches are empowering. It was suggested that advice could be 'you "could" give up rather than you "should" give up'.

Dr Glover reported that, in New Zealand, midwives only use 'smoke-free for life' not 'quit'. Also, stages of change are no longer used in cessation advice: all smokers are considered as wanting to

give up (although use of the term 'not ready' is an ongoing problem). Others felt that dropping 'not ready' from assessment would be inappropriate as it accurately reflects some people's position.

The issue of shame and stigma underpins many concerns and was noted as being a potentially more significant issue when incentives are offered. While feedback from some of the research highlighted a sense of pride, the flip side may be a greater sense of shame for those who do not succeed.

While it is recognised that there is a need for supportive language, it was also noted that negative language can help with increasing awareness, as in the AIDS Grim Reaper campaign of the 1980s. A balanced message is needed.

The language used can be an engagement strategy and can help with making the healthy choice also the easy choice. It was noted there is a need to make smoking a less automatic choice.

Unintended consequences

In the Scottish program, a positive unintended consequence was that being able to use the reason 'I'm getting paid to quit' was a socially acceptable reason to refuse smoking with peers.

There was concern that the pressure to earn incentive payments could have potential for domestic violence for women who are not successful in quitting, however, this was disputed by other participants. It was also noted that having a community approach that does not focus on individual women would avoid this risk.

In New Zealand, reinstituting breastfeeding for Māori has been an important goal, since many women stopped breastfeeding as an unintended negative consequence of smoke-free and second hand smoke prevention campaigns. They got the message that they should not smoke when breastfeeding and stopped breastfeeding rather than stop smoking.

It was also noted that there is potential for incentives to impact on welfare payments (note in the Dundee program in Scotland, women have to be attending antenatal care to receive incentives – this is additional to, and does not affect, benefits). Dr Passey pointed out in their program this was not an issue, as incentives were provided through vouchers.

Practicalities

The payment method was raised as an important issue, particularly when considering potential unintended consequences. It was noted that grocery vouchers could lead to different pressures on women than when 'gift' or 'luxury' incentives are used. While the trials have shown that cash, vouchers and goods are acceptable and feasible, the potential impact of each method beyond quit results should be carefully considered. In the only study that has been undertaken with Aboriginal women and a community reference group, the recommendations were for vouchers to be used at local businesses to give the women choices – itself an empowering strategy. The current limited evidence base also means there is minimal guidance for setting incentive levels. Feedback from women in one of the trials presented was that \$100 per week would be appropriate. However, the Dundee trial is successfully recruiting 1/6 of all pregnant women in the target area, at a lower payment rate. The trials currently running in Australia and New Zealand reimburse people 'out of pocket' but it was noted that people 'like to get' items and this can be a strong motivator.

Sustainability is an important issue for translating any research into practice. The need to ensure links with existing services was highlighted, in particular Aboriginal community controlled health services. However, the potential for research fatigue should also be recognised, both for women and health services. It was also noted that the approach used in any research should be translatable into practice. The method of intervention in Dr Passey's presentation based on home visits was seen by some as ideal, however, would not be possible in many settings without additional resources. Others noted that in addition to being very resource intensive, repeated home visiting to talk about smoking could be considered quite intrusive, particularly if it involves non-Aboriginal health care providers visiting Aboriginal women.

Measuring success

There was a range of measures for success in the trials that were presented, which sparked discussion about the most appropriate approach, in particular whether to reward cutting down as well as complete abstinence. Some participants felt that cutting down should be recognised, others, however, observed that cutting down does not typically result in improved health outcomes.

In the Scottish trial, simply engaging is considered a success by the researchers (although it does not receive a payment). While some trials have used birth weights as a measure of outcomes, it is recognised that biochemically validated abstinence should be sufficient.

What are the gaps?

A number of knowledge gaps and unanswered questions were identified that would be important before moving to further research focused on incentives. Some participants felt it was important to have a clearer understanding of the full range of options before focusing exclusively on discussion of incentives. As noted in Ms Chamberlain's presentation, the incentive trials in the Cochrane review are all small, and while incentives appeared to be the most promising intervention, several participants felt that the evidence was not convincing. This meant there was a general question about the feasibility of incentives in real-world settings on a larger scale. It was noted they have been successfully implemented by the AMIHS teams in the small-scale pilot program presented by Dr Passey.

Several participants felt they would like more information about alternatives to incentives, the negatives of incentives, and examples of when they don't work or shouldn't be used. Some participants commented that it may be better to start with a discussion of pregnancy and smoking and use that to determine priorities, rather than focusing only on incentives. A question was raised about whether any incentive studies have been stopped early due to ethical concerns — either because they proved to be so effective it was decided they should become policy or because of unintended consequences.

Some participants were concerned that in light of numerous challenges around implementing incentives, there was a question about the value of expending resources on investigating how well they work. Some participants felt that while it is not clear whether incentives work or not, a better option for limited research funds may be to focus on translational research for less challenging alternatives. Others felt that the systematic reviews and available evidence suggested incentives were worthwhile considering and investigating further.

Concluding Remarks

The final hour of the day was dedicated to start finding a way forward for some of the issues that were raised. Concerns about the ethics were again raised, as was the issue of community ownership, how incentives would work with non-clinical tobacco workers, general concerns about focusing too much on pregnant women, the need to support families, and questions about the value of incentives compared to other approaches.

The day revealed a diversity of views and ideas regarding the potential value of using incentives to promote cessation. An underpinning concern for many was doubt about the strength of the existing evidence base as the rationale for undertaking research specifically focused on incentives. The low recruitment rates for the proof-of-concept trials were a particular concern for some Roundtable participants and warrant further exploration in any future research.

Some participants suggested that committing resources to testing or implementing incentives may divert resources away from other less controversial evidence-based initiatives that may have similar potential but are not currently being implemented fully – if what is currently considered best practice is not being implemented, why move to something new with so many concerns that may mitigate its usefulness?

In addition, it was noted that while there were representatives from a range of sectors participating in the Roundtable, there is a need for further consultation with service providers and community members and organisations before further work on trials or policies about incentives in pregnancy is carried out.

Appendix 1: Agenda

Note: the agenda below is presented as was planned. Due to flight delays, Dr Passey's presentation was rescheduled from the morning to the final presentation of the day and Dr Glover's presentation was moved to just after morning tea.

Time	Activity		
09:00-09:30	WELCOME TO COUNTRY AND INTRODUCTIONS		
09:30-10:30	1. Setting the Scene	Two presentations to give the whole group a broad introduction to the field.	
		 Catherine Chamberlain: The international research evidence and experience with incentives to reduce smoking in pregnancy 	
		 Megan Passey: Formative research and findings from a pilot study using incentives for smoking cessation with pregnant Aboriginal women 	
10:30-10:45	MORNING TEA		
10:45–12:15	2. Discussion: Main concerns	What are the main concerns that would need to be addressed before any rollout of policies to provide incentives to Quit to pregnant Aboriginal and Torres Strait Islander women?	
		How might these concerns be addressed?	
12:15-13:00	LUNCH		
13:00–13:45	3. Current trials	Early learnings from two proof-of-concept trials of incentives to stop smoking in pregnancy	
		Marewa Glover: Auckland trial	
		Marita Lynagh: Newcastle trial	
	4. Discussion: Lessons for future research	How might the concerns raised in the morning be met either before or as part any future research?	
		How might the learnings from the proof- of-concept trials be used to inform future research?	
16:00-16:30	FINAL COMMENTS AND CLOSE		

Appendix 2: List of participants

Jenny Hunt Aboriginal Health and Medical Research Council

Summer Finlay Aboriginal Health and Medical Research Council

Sue Rogers Aboriginal Maternal Infant Health Service

Sharon Wallace Aboriginal Medical Services Alliance Northern Territory

Clare Anderson Anyinginyi Congress

Anke van der Sterren Centre for Excellence in Indigenous Tobacco Control

Helen Eastburn Department of Health and Ageing

David Thomas Lowitja Institute & Menzies School of Health Research

Alan Cass Menzies School of Health Research

Vanessa Johnston Menzies School of Health Research

Catherine Chamberlain Monash University

Jacqui Boyle Monash University

Trisha Williams National Aboriginal Community Controlled Health Organisation

Caron Bowen New South Wales Ministry of Health

New South Wales Ministry of Health Peta Lucas

Katie Panaretto Queensland Aboriginal and Islander Health Council

Pele Bennet Queensland Aboriginal and Islander Health Council

Sue Jacobs Royal Prince Alfred Hospital & Aboriginal Medical Service Redfern

Megan Passey University Centre for Rural Health – North Coast, The University of Sydney

Marewa Glover Centre for Tobacco Control Research, University of Auckland

Lisa Jackson-Pulver The University of New South Wales

Marita Lynagh The University of Newcastle Chelsea Bond The University of Queensland

Marita Hefler The University of Sydney







The Lowitja Institute

PO Box 650, Carlton South Vic. 3053 AUSTRALIA

T: +61 3 8341 5555 **F:** +61 3 8341 5599

E: admin@lowitja.org.au
W: www.lowitja.org.au