Executive Summary

December 2014
Acknowledgements

- This research was supported by an Australian Research Council's Linkage Project grant with funding from partner organisations Queensland Health and Adelaide Health Services (project number LP100200446).
- Dr Jennifer Whitty is supported by a research fellowship funded by the Queensland Government Department of Employment, Economic Development and Innovation, Queensland Health and Griffith University.
- The planning and implementation of this jury was informed by the work of The Jefferson Center for New Democratic Processes. A report on a Citizens' Jury held in Western Australia as part of a cooperative agreement between The Jefferson Center and the Department for Planning and Infrastructure, Government of Western Australia provided a template for the structure of this report.
- Thanks are due to the witnesses and the members of the Citizens’ Jury who gave their time to contribute to this research.

Project Personnel

Chief investigators
- Professor Paul Scuffham, Griffith University
- Professor Elizabeth Kendall, Griffith University
- Professor Paul Burton, Griffith University
- Dr Jennifer Whitty, Griffith University
- Professor Andrew Wilson, Queensland University of Technology
- Professor Julie Ratcliffe, Flinders University

Partner investigators
- Ken Meldrum, Queensland Health
- Christopher Seiboth, Southern Adelaide Local Health Network Inc.
- Dr Kalipso Chalkidou, National Institute for Health and Clinical Excellence, UK
- Professor Littlejohns, Kings’ College London
- Michael Cleary, Queensland Health

PhD candidates
- Paul Harris, PhD candidate, Griffith University
- Rachael Krinks, PhD candidate, Griffith University

Support staff
- Kylie Rixon, Senior Research Assistant, Griffith University
- Anne Bucetti, Project Officer, Griffith University

For further information contact:
Professor Paul Scuffham
School of Medicine
Griffith University
University Drive
Meadowbrook Qld 4300

Ph: +61 7 3382 1511
cjproject@griffith.edu.au
EXECUTIVE SUMMARY

Citizens’ Juries (CJ) offer a way of seeking informed public views using a democratic, deliberative process. This report describes the methods, processes, and verdicts of a CJ held in Queensland in May 2013, focussing on public preferences around the surgical management of obesity. This CJ was undertaken as part of larger research study led by Griffith University and funded by an Australian Research Council Linkage Grant, along with partner investigators Queensland Health, Southern Adelaide Local Health Network Inc., the National Institute for Health and Clinical Excellence, Flinders University, and Queensland University of Technology. The larger project aims to facilitate the identification and application of optimal methods for engaging the public in healthcare decision-making, provide guidance on the appropriate population groups to consider when eliciting preferences, and provide direct public input to guide health policy. The project is using two methods to engage the public and address a range of methodological questions: the deliberative CJ and the Discrete Choice Experiment (DCE). The DCE is a quantitative method that can elicit the relative strength of preference of the public around a priority-setting topic, and the trade-offs the public are prepared to make.

Two juries were held: one in Brisbane and one in Adelaide. The Brisbane jury was held from Friday 17th May to Sunday 19th May 2013. It was led by facilitators with experience in running citizens’ juries and other deliberative democratic forums. Over three consecutive days, 17 jurors listened to six expert witnesses and three consumer witnesses, engaged in deliberations, and reached a verdict on the questions put to them.

The second jury was held in Adelaide on 28 June 2013. It was a single day event with 12 jurors. The questions, facilitators, and topics were the same as for the Brisbane jury, but Adelaide had different expert witnesses.

Dissemination is an integral design component of this research and will occur continuously as part of the study. Queensland Health (QH) and South Australia Health (through Central Adelaide and Hills Medicare Local Limited) will receive reports on the deliberation and outcomes of the juries and the results of the associated DCEs. In addition, the results will be presented in PhD theses, published in leading peer-reviewed journals in the area, and presented at scientific conferences.

This is a report on the second Citizens’ Jury, which was about the surgical management of obesity. The purpose of this report is to describe the method and process of developing and conducting the Citizens’ Jury and to outline the verdicts reached by the juries. When detailed analyses of the qualitative and quantitative data are finalised, result will be reported.

This report draws on observer field notes, and the evaluations of jurors, facilitators, and staff. Witnesses and jurors were promised confidentiality, therefore initials or codes will be used throughout this report rather than names.

Figure 1 presents the four questions put to the juries. Table 1 to Table 4 summarise the verdicts reached by the juries. The details of, and rationales behind, the verdicts are presented starting on page Error! Bookmark not defined..
1. What should be the criteria for patient access to publicly funded obesity surgery? (ie, who can get the surgery?) In answering the above question, consider whether obesity surgery should be restricted to:

- People under 45 years of age?
- People with a BMI greater than 45?
- People diagnosed with Type 2 Diabetes within the last two years?
- What, if any, other criteria might be appropriate for patient access to publicly funded obesity surgery.

2. What should be the criteria for prioritising people for treatment (ie, how should we decide who gets the surgery first?)

3. What about patients who don't meet the above criteria? (ie, what should happen to them?)

4. Should surgery for obesity be given a lower priority for resourcing/funding than other elective surgeries?

Figure 1  The questions put to the juries
Table 1. Summary of criteria for determining access to publicly funded bariatric funding

<table>
<thead>
<tr>
<th>Criteria suggested</th>
<th>Brisbane verdict *</th>
<th>Adelaide verdict</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 45 years of age</td>
<td>Between 30-50 to be reviewed in 5 years. Some jurors saying between 25 and 60 best, but can be outweighed by other factors.</td>
<td>No age restriction. Under 18 years considered in extreme cases.</td>
</tr>
<tr>
<td>BMI greater than 45</td>
<td>No - BMI over 35</td>
<td>No - BMI over 35</td>
</tr>
<tr>
<td>Type II diabetes diagnosed in last 2 years</td>
<td>No time restriction. Other comorbidities considered.</td>
<td>No - up to 5 years. If BMI &gt; 50, comorbidity not required.</td>
</tr>
<tr>
<td>Other criteria</td>
<td>Commitment shown through lifestyle changes over 6 months</td>
<td>Commitment shown through changing diet and exercise</td>
</tr>
<tr>
<td></td>
<td>Means testing, so privately insured people access private hospitals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Screening for genetic conditions that surgery won't improve</td>
<td></td>
</tr>
</tbody>
</table>

* All criteria to be subject to a review in 5 years

Table 2. Summary of criteria for prioritising eligible patients

<table>
<thead>
<tr>
<th>Brisbane verdict * (in order of importance)</th>
<th>Adelaide verdict (in order of importance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of comorbidities</td>
<td>Shown commitment to lose weight and actively participated in a clinic or similar programs. Consideration should be given to limited access or capacity.</td>
</tr>
<tr>
<td>BMI over 35</td>
<td>People with comorbidities such as type 2 diabetes, and people who can't access other medical procedures (such as transplants) due to obesity.</td>
</tr>
<tr>
<td>Shown commitment by working closely with dieticians and psychologists over 6 months</td>
<td>BMI over 35, with high VAT.</td>
</tr>
<tr>
<td>Aged 30 to 50 years (least important), subject to a review in 5 years</td>
<td></td>
</tr>
</tbody>
</table>

* All criteria to be reviewed in 5 years

* The Queensland jury deliberated long and hard about using age as a rationing tool to restrict access to bariatric surgery. Eventually the Queensland jury decided to restrict public bariatric surgery to people between the ages of 30-50 as a rationing tool. Some jurors were acutely uncomfortable with using rationing tools such as age and denying their fellow citizens access to life saving or life transforming surgery. The Queensland jury was the only jury during our study that linked their verdict to a Five Year Review. During finalisation of their verdict this jury recommended that all of their criteria be reviewed in five years.
Table 3. Helping patients who do not meet the criteria for accessing publically funded bariatric surgery

<table>
<thead>
<tr>
<th>Brisbane verdict</th>
<th>Adelaide verdict</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thorough assessment</td>
<td>Access to programs and clinics that take a holistic, multi-disciplinary approach</td>
</tr>
<tr>
<td>Access to dieticians, psychologists, lifestyle groups, and self-help/wellbeing groups</td>
<td>Provide access to group support</td>
</tr>
<tr>
<td>A one-stop-shop</td>
<td>Provide more access to community activities/sports/facilities</td>
</tr>
<tr>
<td>Home support</td>
<td>Advertise the services available</td>
</tr>
<tr>
<td>Explore alternative access to funds for private treatment, eg, superannuation or low interest loans</td>
<td>Consider public health measures such as taxes for certain foods (such as soft drinks) and subsidies for healthy foods</td>
</tr>
<tr>
<td>Information for GPs about non-surgical options</td>
<td></td>
</tr>
</tbody>
</table>

Table 4. Prioritisation of bariatric surgery as an elective surgery in the public health system

<table>
<thead>
<tr>
<th>Brisbane verdict</th>
<th>Adelaide verdict</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bariatric surgery should be considered as equally important as other forms of elective surgery</td>
<td>Bariatric surgery should be considered as equally important as other forms of elective surgery</td>
</tr>
<tr>
<td>The priority of bariatric surgery should be elevated when it could avoid or postpone other forms of elective surgery</td>
<td>More funding should be allocated to bariatric surgery in the public health system</td>
</tr>
</tbody>
</table>

Discussion:

Although the Adelaide Jury was shorter, there were the same number of witnesses, the same format (a consumer panel and an allied health panel at both juries) and the topics and content covered were very similar at both juries. In addition, the same facilitators were employed to run both juries.

The time for jurors to bond, for small group discussions and for deliberations were substantially less in the Adelaide jury compared with the Brisbane jury. Nevertheless, with guidance, the Adelaide jurors were able to have discussions as a wider group and develop their recommendations within the time allocated. The Brisbane jury used their time to the full.

Two factors may have enabled the Adelaide jury to reach conclusions and recommendations in the shorter time: a small group (n=12), and facilitators who were informed by their previous experience from running the Brisbane jury. The size of the group in Adelaide allowed for greater interaction between jurors and for the discussions to be contained by the facilitators – both in small break-out groups and in the wider group during deliberations. That is, there were fewer divergent different points of view to be heard.

The facilitators, having run the three day jury in Brisbane two weeks earlier were fully informed of the topic. This allowed them to have greater ability to direct the discussions and deliberations, and thus focus the jurors and the outcomes. This was efficient but unintended. That is, to reduce
external factors that may influence the results, the study design required the same facilitators, and thus eliminate on source of confounding. However, rather than eliminating this source of confounding, it introduced a source of contamination. A different facilitator, who had not been involved in the Brisbane jury, may not have gained an outcome or recommendations within the one day limit of the Adelaide jury.

Both obesity juries struggled with the idea of using age as a rationing tool and both juries made it clear they viewed age as a criteria as not as important as other criteria. However, the South Australian jury decided not to ration the surgery based on age.

The Brisbane jury was the only jury to insist on a review of their recommendations and it speaks to the discomfort some of the jurors within that jury felt about the denial of the older consumers being denied access to treatment. The moral responsibility for deciding whether to continue to deny fellow citizens over the age of 50 from accessing bariatric surgery in the public system was, via the five year review, placed in the hands of unknown future hypothetical reviewers.