Using citizens’ juries in health policy decision-making: a systematic review and personal reflection

Annette Braunack-Mayer
Head, School of Population Health

adelaide.edu.au
Systematic Review

Research questions

Methodology

Findings
- where, when, how, with what outcomes
Systematic Review

Research questions

Methodology

Findings
• where, when, how, with what outcomes

Personal reflection:
Our jury experiences
- Topics
- Ethical analysis
- Outcomes
- Challenges
The Rabbit Problem
by Emily Gravett
(and a lot of rabbits)

(and a lot of research participants)
Systematic review

Our jury experiences

**FluViews (ARC Linkage Grant)**
Annette Braunack-Mayer, Wendy Rogers, John Moss, Janet Hiller, Peng Bi, Amy Salter, Rod Givney, Helen van Eyk, Jackie Street

**VALiD (ARC Linkage Grant)**
Mike Gold, Annette Braunack-Mayer, Phil Ryan, Kathryn Duszynski, Jesia Berry, Vicki Xafis

**Health Bridges (ARC Linkage Grant)**
Annette Braunack-Mayer, Helen Marshall, Maree O'Keefe, Teresa Burgess, Rebecca Tooher, Jo Collins, Claudia Proeve, Maureen Watson, Heather Ashmeade, Rachel Skinner, Kirsten McCaffery

**HealthyLaws (ANPHA Research Grants Program)**
Annette Braunack-Mayer, Jackie Street, Vivienne Moore, Megan Warin, Drew Carter, John Moss, Tracy Merlin, Chris Reynolds, Danny Broderick
Our jury experiences

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Industry partners

South Australian Department of Health
New South Wales Department of Health
Surveillance of Adverse Events Following Vaccination in Victoria (SAEFVic)
Australian Paediatric Surveillance Unit (APSU)
South Australian Department of Education and Children's Services
CSL Ltd
GlaxoSmithKline
Variety of deliberative approaches

BIG BUNNIES, LITTLE BUNNIES, BLUE, BROWN, ORANGE &

BUNNIES, BUNNIES with SMUGGLERS, BUTTERFLIES &

DROOPY EARS & EARS & SOME HALF WAY INBETWEEN

FRIENDLY, GRUMPY, LAID BACK &

YOUNG BUNS, TEENAGERS, & DISTINGUISHED OLD CHAPS!
Range of ways to define deliberative approaches...

- **Inclusivity**
  - Open-mindedness
  - Diversity amongst participants
  - ‘Ordinary people’

- **Deliberation**
  - Reaching for consensus through discussion

- **Active citizenship**
  - Justifying each view and the group’s view

*(try to) capture these principles in both systematic review and our own research juries*
Systematic review

• How have health researchers adapted and applied the citizens’ jury model?

• What is the fit between these methodological adaptations and principles – inclusivity, deliberation and active citizenship?
Methodology for systematic review

- ENTRQ guidelines for reporting systematic reviews of qualitative research
- Published documents 1995-2010
- Search terms: based on deliberative inclusive methods used in health research
- Inclusion if contained all/most elements of citizens’ jury model
Elements of citizen jury model used:

- Generally 12 - 25 participants selected to reflect community, acting as independent experts
- ‘Charge’ or research question provided by organisers
- Deliberation informed by evidence provided by expert witnesses
- Verdict
Systematic review questions

- Topic areas
- Geographic location
- Recruitment strategies and impact
- Duration, timelines and impact
- Conduct:
  - Role of steering groups, moderation and structured deliberation
- Expert witnesses and testimony
- Formulation, report and dissemination of recommendations
Findings

Study search and selection

Approx 15000 abstracts retrieved
- duplicates, book reviews, magazine articles and editorials removed

13,176 abstracts scanned for relevance
- excluded: involved experts only, not directly health related, no deliberative inclusive method

1069 articles selected for full text reading
- articles did not meet inclusion criteria

75 articles entered into database
- other deliberative methods

37 papers describing 66 citizens’ juries
37 papers describing 66 juries:

• in 2 studies

• 22 used term citizens’ jury

• of juries
  – with multiple sites and juries, same question
  – 1 with single site and jury and question
  – 11 with multiple sites and juries, multiple questions
  – with single site, multiple juries, same question
Findings

• How have health researchers adapted and applied the citizens’ jury model?

• What is the fit between these methodological adaptations and principles – inclusivity, deliberation and active citizenship?

Wide adaptation and broad array of methodological approaches
Topics

- Ethically contentious issues
  - Consent
  - Genetic testing
  - Xenotransplantation
  - Placebo use
  - Bio-banks

- Priority setting for health services and research

- Environmental health
  - Nanotechnology
  - GM foods
  - Road traffic volume
Topics

• Health policy
  – Mammography screening
  – Pandemic communication
  – Food retailing
  – Use of medicines
  – Telemedicine
  – Health system reform

• Community wellbeing
  – Antisocial behaviour
  – Community health
  – Community mental health services
Recent jury questions

• How do we allocate scarce resources in a pandemic?
• Under what circumstances is it acceptable to link data for the purposes of vaccine safety surveillance?
Recent jury questions

• Under what circumstances should adolescent immunisation programs be delivered in schools?
• How can we best enhance the School Based Immunisation Program?
• (What regulation and laws, if any, should we implement in Australia to address childhood obesity?)
Location

38/66 in Canada; 7 Aus & NZ; 6 UK; 3 USA; 1 Brazil; 1 Italy
Recruitment

Intent to recruit a jury descriptively representative of the community

Range of strategies and sources (around 20):
- stratified random sampling;
- random sampling;
- market research company;
- organisations;
- media advertising

Criteria (stated in 15 studies):
- age, gender, race,
- ethnicity, education,
- employment, housing
- tenure, religion,
- occupation, location,
- income, children,
- language spoken at home
Recruitment

• Honoraria:
  – Offered in 12 studies/28 juries
  – Not offered in 3/7
  – Unknown in 13/31

• Representativeness:
  – Could be evaluated in 15 studies/33 juries
  – 6 studies/9 juries unbiased
Representative recruitment used

- stratified sampling with mix of criteria
- recruitment through market research company or directly
- honorarium
‘Unrepresentative' recruitment...
lacked at least one of these components

Leading to:
- More women than men
- Higher education/income
Why does recruitment matter?

Inclusivity

partly determined by jury composition
Inclusivity also influenced by...

- Diversity in expert witnesses
- Jurors' narratives
- Jurors challenging evidence

Some studies attempted to do this but not well reported
Duration and timing

- 66% over 1-2 days
- mostly over weekend
- no relationship between recruitment bias and length of jury
- Longer juries gave more opportunity for engagement and control over final outcome
Moderation and conduct

• Most juries facilitated, but difficult to establish nature and role of facilitation

• Structure provided with workbooks, small group activities, scenarios, voting, court room format
**Expert testimony**

Experts/researchers’ expertise (all but 3)

**Written material** (14 studies)

**Ethical analysis** (7)
Including ethical analysis in our juries

Expert presentation of key ethical concepts

Workshop activities to ‘do’ ethics

Question and answer sessions, integrated with law
Why do moderation, conduct and expert testimony matter?

- Deliberation - reasoned debate amongst equals -

Appears effective when supported by independent facilitation, jury size (≤ 20) and focus on consensus decision-making
Jury outcomes

- Consensus
- Consensus plus minority opinion
- Voting
Outcomes in our juries

• How do we allocate scarce resources in a pandemic?
  Health care workers, researchers, military/essential services

• Under what circumstances is it acceptable to link data for the purposes of vaccine safety surveillance?
  Majority view: no consent
  Minority view: opt-out consent
Outcomes in our juries

• Under what circumstances should adolescent immunisation programs be delivered in schools?
• How can we best enhance the School Based Immunisation Program?

• Consent:
  – No consent (youth jury)
  – Opt out (majority view, adult jury)

• More information, devised with help of students and parents

• Focus on students’ physical and emotional comfort
Data collection and analysis

• Data collection
  – Audio recording (0%)
  – Note taking
  – Workbooks
  – Video-recording
  – Whiteboards and charts
  – Votes
  – Questionnaires, interviews

• Data analysis
  – Qualitative analysis (6 studies)
Jury reporting

- Peer reviewed literature
- Reports
- Presentations to decision-makers
- Community feedback

- 3 studies with decision-maker commitment to consider recommendations
**Decision-maker commitment**

Citizens’ juries reassert the importance of a more active form of citizenship. Smith Wales 2000

Only a small number of studies met this citizenship criterion.
Citizens’ juries and citizenship

But...

- Other vehicles for reporting
- Juries build capacity independent of reporting outcomes
  - Juror engagement and commitment
Challenges for the conduct of juries

- Inclusivity: Losing the ‘individualist perspective’
- Citizenship: Incorporation into policy and practice
- Methodology
Challenges for the conduct of juries: Losing the ‘individualist perspective’

- Potential loss of minority views
- Utilitarian and/or communitarian orientation
Challenges for the conduct of juries: Incorporation into policy and practice

- Early engagement of stakeholders is key, but may not be sufficient
- Political industry involvement
  - hanging personnel
  - confidentiality
  - Risk management and hidden agendas
Challenges for the conduct of juries: Methodology

pistemological tensions

— Are citizens’ juries ‘research’ or ‘community empowerment’
Systematic review


Outcomes in our juries

Acknowledgements

Early Guarnieri, The Rabbit Problem

Recent jury questions

Challenges for the conduct of juries

Personal reflection

Our jury experiences
Thank you!

