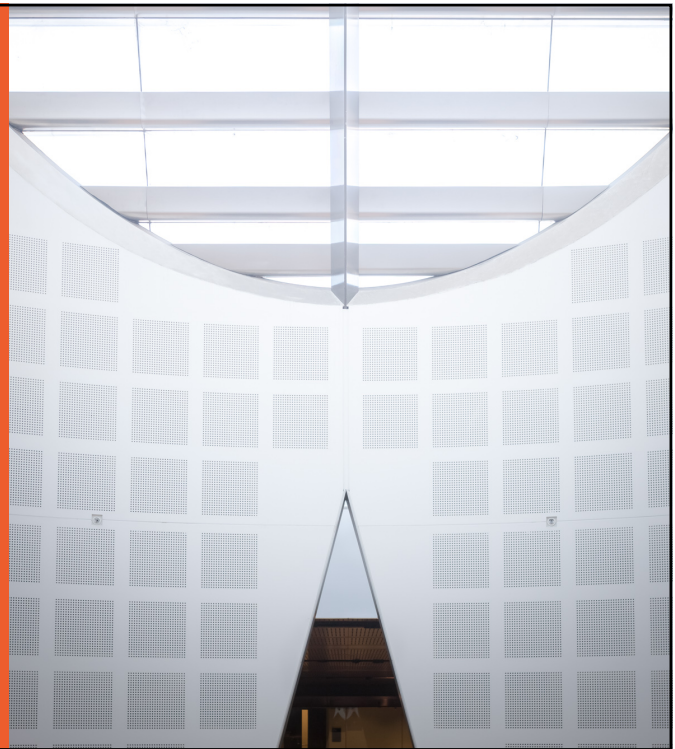


Consumer perspectives of accelerated access to medicines: A mixed methods study

Presented by

Jessica Pace, PhD Candidate
Sydney Health Ethics



Background

- Concerns about ability of current systems to provide timely access to medicines
- Potential policy approaches
 - Special funds for medicines that do not meet cost-effectiveness criteria
 - Personal importation
 - Conditional registration and reimbursement mechanisms
- Unclear risk-benefit balance
 - Wider range of treatment options and earlier access to medicines
 - Increase uncertainty surrounding safety, efficacy and cost-effectiveness
- Stakeholder engagement to determine appropriate risk-benefit balance

Research Questions

- What are the beliefs and values of consumers regarding the approval and funding of new medicines?

Methods: Survey

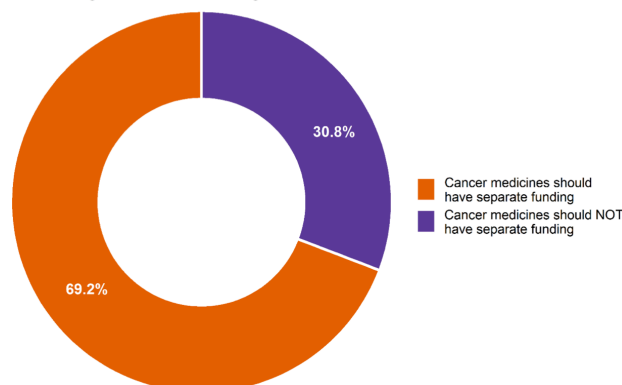
- 59-item telephone survey conducted in August 2018
 - Explore what Australians think about funding cancer medicines
- 1039 participants, largely representative of the broader population
- Fixed choice survey items
- Responses tallied, proportions calculated

Methods: Interviews and Focus Groups

- 13 semi-structured interviews with patients and patient advocates
 - Between 30 and 60 minutes
- 2 focus groups with patients
 - 1.5 hours
- Purposive, convenience and snowball sampling
- Audio recorded, transcribed verbatim and analysed thematically

Findings: Survey

	Item	%		
		Yes	No	Unsure
Government funding of unproven cancer medicines	Would you want the government to fund medicines that are not yet known to be safe if there is a chance that they could help those with cancer?	42.44	29.07	28.49
	Would you want the government to fund cancer medicines that have not yet been proven to be effective?	42.44	29.55	28.01



Findings: Survey Cont'd

		%				
Item		Strongly disagree	Disagree	Agree	Strongly agree	Unsure
Access to unproven cancer medicines	If patients want access to drugs where evidence is unclear, this should only be possible through a clinical trial	2.89	10.59	52.17	22.81	11.55
	If patients want access to drugs where evidence is unclear, they should not have to enter into a clinical trial. Instead, these drugs should be paid for by the government	9.05	37.63	23.68	10.49	19.15
Item		%				
Access to cancer medicines	Do you believe that clinical trials of medicines should be designed to guarantee access to the drug to all research participants?			Yes	No	Unsure
				60.35	18.19	21.46

Findings: Interviews and Focus Groups

- Expressed need for faster access to promising medications for some patients

If you wait for all that process, you've got a whole lot of people dying unnecessarily.

When my dad was diagnosed with prostate cancer, I discovered a drug in America that was in clinical trials, but we couldn't get access to the drug ... It's kind of like why do people in America have access to this, just because we live in Australia we don't?

Findings: Interviews and Focus Groups Cont'd

- Cognisant of potential risks of accelerated access
- Safety and efficacy

So there's a trade-off between time and the cost involved in [drug evaluation], and the safety of making sure that we don't do people damage.

Findings: Interviews and Focus Groups Cont'd

- Budget impact, sustainability of healthcare systems and opportunity costs

It has to be sustainable, financially sustainable. There has to be a budget.

It's like where do you take the money from, is that okay to take it from, you know, education? Not necessarily. They could be the researchers that invent the cure for cancer. It's hard.

Findings: Interviews and Focus Groups Cont'd

- Overall happy with existing systems and didn't see need for wholesale changes

The system we've got is good.... I think the community understands that there's a limit to what can be on PBS.

In general, the community are comfortable with the PBS.

Policy Implications

- Nuanced consumer perspectives
- How the question is asked determines information received
- Need carefully designed tools to elicit consumer perspectives for these to be useful to policy makers

Acknowledgements

- National Health and Medical Research Council (NHMRC grant no: APP1080673)
- Project team
 - Wendy Lipworth
 - Ian Kerridge
 - Glenn Salkeld
 - Ian Olver
 - David Isaacs
 - Sallie Pearson
 - Dr Narcyz Ghinea
 - Bronwen Morrell
 - Miriam Wiersma

Questions

