

Community views on factors affecting medicines resource allocation

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Australian Health Review

DOI:
[10.1071/AH16209](https://doi.org/10.1071/AH16209)

Published: 01/01/2019

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):
Chim, L., Salkeld, G., Kelly, P., Lipworth, W., Hughes, D., & Stockler, M. (2019). Community views on factors affecting medicines resource allocation: Cross-sectional survey of 3080 adults in Australia. *Australian Health Review*, 43(3), 254-260. <https://doi.org/10.1071/AH16209>

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1 ***Community views on factors influencing medicines resource allocation: A cross sectional***
2 ***survey of 3080 adults in Australia***

3 **Abstract**

4 **Objectives:** To determine Australian community views on factors that influence distribution of
5 health spending in relation to medicines.

6 **Methods:** Cross-sectional web-based survey of 3080 adults aged 18 years or older. Participants
7 were asked to rank, in order of importance, 12 criteria according to which medicines funding
8 decisions might be made.

9 **Results:** 1213 (39.4%) of respondents considered disease severity to be the most important
10 prioritisation criterion for funding a new medicine. This was followed by medicines treating a disease
11 affecting children (13.2%), and medicines for cancer patients (9.1%). Medicines targeting a disease
12 for which there is no alternative treatment available received highest priority from 8.6 % of
13 respondents. The remaining 8 prioritisation criteria were each assigned a top ranking by respondents
14 ranging from 6.6% to 1.7%. Medicines targeting a disease for which there is no alternative treatment
15 available were ranked least important by 7.7% of respondents compared to 2.4%, 1.9% and 1.0% for
16 medicines treating severe diseases, diseases affecting children and cancer, respectively. 'End-of-life
17 treatments' and 'rare disease therapies' received the least number of highest priority rankings (2.0%
18 and 1.7% respectively).

19 **Conclusions:**

20 These results provide useful information about public preferences for government spending on
21 prescribed medicines. Understanding of public preferences on funding of new medicines will help
22 the PBAC/government determine circumstances where greater emphasis on equity is required and
23 help inform medicines funding policy that best meets the needs of the Australian population.

24 **What is known about this topic?** There is increased recognition of the importance of taking into
25 account public preferences in the health technology assessment (HTA) decision-making process.

26 **What does this paper add?** The Australian public view the severity of disease to be the most
27 important funding prioritisation criterion for medicines, followed by medicines used to treat children
28 or to treat cancer.

29 **What are the implications for practitioners?** The general public are capable of giving opinions on
30 distributional preferences. This information can help inform medicines funding policy and ensure
31 that it is consistent with the values of the Australian population.

32 **Introduction**

33 In Australia, the Pharmaceutical Benefits Advisory Committee (PBAC) is responsible for advising the
34 government as to which medicines should be subsidised on the Pharmaceutical Benefits Scheme
35 (PBS). In fulfilling this role, the PBAC is the steward of a large sum of public money: for the 12
36 months ending 30 June 2015, for example, total PBS spending amounted to \$9.07 billion ¹.

37 The PBAC makes its recommendations primarily on the basis of evidence of clinical effectiveness,
38 safety and cost effectiveness derived from clinical trials and population-based observational studies.

39 The PBAC also takes into account other factors, such as equity, in its consideration of what does, or
40 does not, constitute “value for money”. In this context, the term “equity” refers to access to PBS
41 listed drugs in a manner that takes into account the distribution of benefits and potential harms
42 based on factors such as prognosis, disease severity, age, distributional effect, context (eg.
43 emergency or prevention), socioeconomic and geographical status and other issues not typically
44 considered as part of quality of life measurements².

45 Previous analyses of PBAC recommendations demonstrated that the PBAC has been broadly
46 consistent in its use of economic efficiency as a key criterion for decision making ^{3,4}. The probability
47 of a positive recommendation does increase with lower incremental cost effectiveness ratios but

48 there is no evidence of a fixed threshold for the value of a life year or a quality adjusted life year
49 (QALY)⁴. Importantly, the PBAC has been found to actualise equity considerations by accepting a
50 higher incremental cost effectiveness ratio (ICER) for medicines addressing a high unmet clinical
51 need⁵⁻⁷ and/or greater uncertainty in the available clinical evidence for rare diseases⁸.

52 Further, the PBAC in its deliberation may consider the 'Rule of Rescue' (RoR). The consideration and
53 application of RoR allows the PBAC to potentially reverse a decision not to recommend listing on the
54 because of its consideration of comparative cost-effectiveness (and any other relevant factors).

55 However, evidence (based on the published Public Summary Documents (PSDs) for past PBAC
56 recommendations) indicates that the RoR has been applied infrequently by the PBAC and that there
57 were few documented examples where application of the RoR has led to a positive PBAC
58 recommendation⁹. PBAC consideration of the RoR requires the following four factors to be met: (1)
59 no alternatives exist in Australia (2) the medical condition is severe, progressive and expected to
60 lead to premature death (3) the medical condition applies to only a very small number of patients
61 and (4) the proposed medicine provides a worthwhile clinical improvement sufficient to qualify as a
62 rescue from the medical condition². However, the relative influence/weight of the RoR factors is not
63 quantitatively pre-defined. Importantly, the RoR as with other relevant factors supplements, rather
64 than substitutes for evidence based consideration of cost-effectiveness².

65 The PBAC also provides advice on the inclusion of medicines on the Life Savings Drugs program
66 (LSDP)⁹. The LSDP sits outside the PBS to provide an alternate funding arrangement for access to
67 medicines that are not eligible for funding under the PBS due to unacceptable cost effectiveness.
68 While those making submissions to the PBAC occasionally include population survey data on
69 community preferences, assessments of equity are most commonly based on assumptions about
70 community priorities. Given the central role that the general public has in funding publicly
71 subsidised health technologies through taxes, and as beneficiaries of these technologies, it is
72 increasingly recognised that this is inadequate, and that more information is needed about public
73 preferences when making decisions about the funding of new medicines¹⁰⁻¹².

74 Around the world, government agencies responsible for the selection and reimbursement of
75 prescribed medicines and other health technologies are increasingly concerned with how best to
76 incorporate community preferences into their decision making^{13, 14}. In Australia, the PBAC currently
77 considers patients and the public views through consumer representation on the Committee, via an
78 online consumer input process, as well as through consumer hearings convened by the PBAC for
79 selected submissions. Recent examples of such hearings include those for lymphoma (brentuximab
80 vedotin, bendamustine, idelalisib and obinutuzumab), which were considered at the March 2015
81 PBAC meeting¹⁵, and for ovarian cancer and Morquio A syndrome (olarparib and elosulfase alfa
82 respectively) which were considered at the March 2016 PBAC meeting¹⁶.

83 Another important approach to eliciting consumer preferences, which supplements more direct
84 forms of consumer engagement, is to conduct surveys of representative samples of the community.
85 These have been used previously to support policy concerning the funding of cancer drugs in the
86 UK¹⁷, to assess the preferences for the funding of orphan drugs¹⁸ and to understand public
87 agreement with policies aimed to facilitate access to life-extending drugs used at the end of
88 patients' lives¹⁹. To date, however, no representative community survey has explored how members
89 of the Australian community rank various criteria according to their importance to funding decisions
90 for prescribed medicines. We therefore conducted an on-line survey of 3080 Australians aged 18
91 years or older in order to measure community preferences for the distribution of the benefits and
92 costs of PBS listed drugs.

93 **Methods**

94 We undertook a cross sectional web based survey of 3080 adult Australians aged 18 years or older.
95 This paper focuses on the findings from the ranking exercise conducted as part of the present study.
96 SSI, a market research company with a large online panel (~ 409,000 registered members) was used
97 to recruit survey participants. Recruitment was controlled by gender, age and geographical area

98 (state of residence) in order to ensure that the sample was representative of the general adult
99 Australian population. Participants were compensated for their time and received 'reward points'
100 averaging \$1.40 from the panel provider. Selection of the 12 prioritisation criteria was informed by
101 both the published literature and criteria currently used by the PBAC when assessing new medicines
102 for public subsidy.^{5,6,7,8,9,10} The 12 prioritisation criteria, were: (1) severity of disease (2) availability
103 of alternative medicine (3) significant innovation (4) carer burden (5) disadvantaged populations (6)
104 children (7) end-of-life treatments (8) cancer treatments (9) rare disease therapies (10) cost to the
105 PBS and savings to patient (11) medicines that help patients return to work (12) Life-style related
106 diseases and individual responsibility.

107 The survey asked respondents which criteria they believed were the most important in healthcare
108 spending and resource allocation. Respondents were asked to rank the 12 prioritisation criteria from
109 one to 12, with one being the most important criterion. The survey was pilot tested with 111
110 participants in August 2015. An additional question regarding the state of residence was added after
111 pilot testing. The full survey was administered during October 2015 and closed when our target of
112 3000 complete responses was achieved. Socio-demographic data were collected to test associations
113 between respondents' views on the prioritisation criteria and demographic characteristics.

114 **Ethics approval**

115 This study was approved by Human Ethics Research Committee at Sydney University (protocol
116 number: 2014/906).

117 **Statistical analysis**

118 Descriptive statistics were used to summarize demographic variables. Empirical studies have found
119 that willingness to pay and funding preferences are influenced by respondents' personal
120 circumstances such as age, income, health status, household composition^{17,20}. Multinomial logistic
121 regression modelling was used to assess whether gender, age, marital status, education, health
122 status, cancer history, country of birth, private health insurance, employment status, household

123 income, and dependent children were associated with the top ranking of the 12 prioritisation
124 criteria. The model included all explanatory variables listed.

125 **Results**

126 A total of 3080 adult members of the general public in Australia completed the on-line survey. The
127 3080 respondents broadly reflected the Australian population in terms of age, gender and
128 geographical area (**Table 1**). 39.4% of respondents considered disease severity to be the most
129 important prioritisation criterion (**Table 2**). This was followed by medicines for diseases affecting
130 children (13.2%). Cancer medicines came third and were ranked most important by 9.1% of
131 respondents, while medicines targeting a disease for which there is no alternative treatment
132 available received highest priority from 8.6 % of respondents. The remaining 8 prioritisation criteria
133 were each assigned a top ranking by respondents ranging from 6.6% to 1.7%.

134 The four prioritisation criteria that were assigned the highest priority, also received the largest
135 number of top 3 rankings: disease severity (n= 1966, 21.3%), medicines for children (n= 1260,
136 13.6%), cancer medicines (n= 1112, 12.0%), and medicines targeting a disease for which no other
137 medicine is available (n= 957, 10.4%).

138 Medicines targeting a disease for which there is no alternative treatment available were ranked least
139 important (i.e. with a respondent's assigned rank order of 12) by 7.7% of respondents compared to
140 2.4%, 1.9% and 1.0% for medicines treating severe/life threatening diseases, treating a disease
141 affecting children and medicines for cancer patients, respectively.

142 'End-of-life treatments' and 'rare disease therapies' received the least number of highest priority
143 rankings (2.0% and 1.7% respectively).

144 **Relationship between respondent characteristics and prioritisation** 145 **preferences**

146 Country of birth ($p= 0.04$), employment status ($p= 0.04$) and having dependent children ($p= 0.0001$)
147 were associated with funding preferences (see Supplementary file). Respondents who were born
148 overseas were significantly more likely to assign a top priority to medicines that help patients return
149 to work (OR= 1.57, 95% CI= 1.06 to 2.32, $p= 0.02$), and to medicines targeting life style unrelated
150 diseases (OR= 1.57, 95% CI= 1.01 to 2.42, $p= 0.04$) than to prioritise disease severity, compared to
151 those born in Australia. Respondents with dependent children were significantly more likely to
152 assign a top ranking to medicines targeting diseases affecting children (OR= 2.04, 95% CI= 1.52 to
153 2.78, $p<0.0001$), and to cancer medicines (OR= 1.45, 95% CI= 1.01 to 2.04, $p= 0.04$). Respondents
154 who are in part time employment were significantly less likely to assign a top finding priority to
155 medicines targeting rare diseases than those working full time (OR= 0.19, 95% CI= 0.05 to 0.66, $p=$
156 0.01). Compared to respondents who were in full time employment, respondents who were neither
157 in employment nor unemployed (i.e. 'other' category, for example those who were looking after a
158 home or studying full time) were significantly more likely to assign a top ranking to medicines
159 targeting diseases that affect patients who are not financially well off (OR= 1.72, 95% CI= 1.02 to
160 2.87, $p= 0.04$). Further, these respondents were significantly less likely to allocate the highest
161 funding priority to medicines targeting life style unrelated diseases (OR= 0.15, 95% CI= 0.03 to 0.63,
162 $p= 0.01$) compared with those in full time employment.

163 There was also some evidence that health status ($P= 0.06$) and private health insurance ($P= 0.06$)
164 were associated with funding preferences. Compared with respondents rating themselves as in very
165 good health, respondents who rated themselves as in good, average, or poor/very poor health were
166 significantly more likely to assign a top ranking to medicines targeting diseases that affect patients
167 who are not financially well off (OR= 1.90, 95% CI= 1.13 to 3.20, $p= 0.02$; OR= 2.33, 95% CI= 1.35 to
168 4.01, $p= 0.002$; OR= 2.40, 95% CI= 1.20 to 4.79, $p= 0.01$ respectively), and to medicines that cost the
169 government more and thereby save patients more in out-of-pocket costs (OR= 2.25, 95% CI= 1.19 to

170 4.26, p= 0.01; OR= 2.18, 95% CI= 1.11 to 4.28, p= 0.02; OR= 3.12, 95% CI= 1.39 to 7.02, p= 0.006
171 respectively). Respondents who do not have private health insurance were significantly more likely
172 to allocate the highest funding priority to medicines that cost the government more, thereby saving
173 patients more in out-of-pocket costs compared to those with private health insurance (OR= 1.58,
174 95% CI= 1.07 to 2.31, p= 0.02). ,

175 Discussion

176 The results of our study give a clear picture of public preferences regarding resource allocation for
177 medicines. The targeting of severe or life threatening diseases is clearly and by far the most
178 important prioritisation criterion , followed by medicines targeting diseases affecting children,
179 cancer medicines and medicines targeting diseases for which no treatment alternative is available.
180 Whilst the first three top ranking prioritisation criteria were assigned a least important ranking by a
181 small proportion of respondents (1 to 2.4%). Medicines targeting a disease for which no alternative
182 treatment exists were ranked most and least important by a similar proportion of respondents (8.6%
183 and 7.7%, respectively). One possible explanation for this variation is that societal opinion on the use
184 of this as a prioritisation criterion for new medicines funding may be divided and ‘polarised’.

185 Further, findings from this study resonate with previous studies^{11, 17, 19, 21, 22}, which have shown that
186 members of the general public give higher priority to medicines used for the treatment of severe
187 illness and for those with no available alternatives. The finding of support for prioritising anti-cancer
188 medicines is also generally consistent with existing evidence^{23, 24}, and could explain the current focus
189 both in Australia and internationally on achieving timely access to such treatments²⁵. However, as
190 cancer medicines are the only disease specific medicines explored in this study, this finding should
191 be interpreted with caution. We found no compelling evidence for prioritising end-of-life
192 treatments. This is consistent with a study by Linley et al¹⁷, which examined the views of the UK
193 general public about the current and proposed medicines prioritisation criteria used by the UK
194 National Institute of Health and Care Excellence (NICE) and government.

195 Our study suggests that rare disease therapies *per se* are not a strong driver for public funding
196 preferences. Although this is consistent with other research^{17, 18}, it is nonetheless a somewhat
197 surprising finding given that rarity of disease is one of the four criteria that form the basis of the ‘rule
198 of rescue’ (RoR) PBAC claim². A RoR applies in exceptional circumstances for drugs that provide a
199 worthwhile benefit for a severe and rare condition for which there is no alternative treatment^{2, 9, 26}.

200 The results of our study suggest that the use of rarity of the disease as an inclusion criterion for LSDP
201 or as a basis for a RoR claim does not appear to be supported by the Australian public. One possible
202 interpretation of this result is that rarity is not a shared prioritisation criterion between the general
203 public and the PBAC. Given that rarity of the disease is linked to the total number of eligible patients
204 and cost for funding a medicine, it is, and may need to remain, an important prioritisation criterion
205 from the PBAC/government perspective, especially for high cost medicines.

206 An important strength of our study is that it included a large, broadly representative sample of 3080
207 adult Australians. However, due to the design of our study, non-completion rates and details of non-
208 responders were unavailable for analysis or assessment for potential non-responder bias. Another
209 potential limitation relates to framing effects. It has been found that the choice of wording in
210 surveys is very important²⁷. The results for the prioritisation criterion relating to life-style unrelated
211 diseases appear to be somewhat surprising, with the largest proportion of respondents ranking this
212 criterion last. It is possible that respondents’ preferences may have been confounded by the
213 labelling choice used in the survey. Despite these limitations, our study has important implications
214 for health policy development with respect to the funding of new medicines in Australia.

215 Further, our research shows that respondents’ funding preferences for access to new medicines are
216 influenced by their personal characteristics and circumstances. Therefore, if the general public’s
217 views and preferences are to be included in the PBAC decision making process, a representative
218 sample is required.

219 In summary, the findings of this study provide assurance that the Australian public support some of
220 the currently used prioritisation criteria. However, quantification of criteria weights and equity
221 issues relative to other factors will require further research in order to provide guidance to the PBAC
222 on the cardinality of equity preferences and quantification of ICER increase to account for the
223 specific equity issues/criteria identified.

224 **Conclusions**

225 The reimbursement of prescribed medicines should reflect both evidence of safety and
226 effectiveness, and social values²⁸. As such, it is important to understand societal views and
227 preferences for the distribution of healthcare spending. Results of this study provide useful
228 information on public preferences related to the equity aspects of government spending on
229 prescribed medicines in Australia. Understanding of public preferences on funding of new medicines
230 could help the PBAC/government determine circumstances in which greater emphasis on equity is
231 required, and how equity might be defined and achieved in a manner that is congruent with the
232 values of the Australian population. To ensure that public preferences are reflected in the PBAC's
233 assessments and recommendations, there is a need for further research to determine the best way
234 to incorporate these preferences into PBAC decision making processes. This will, in turn, improve
235 alignment between government and societal preferences for funding of new medicines^{29, 30}.

236 **Table 1: Characteristics of respondents (N=3080)**

Characteristics	N	%	Australia ² %
Gender			
Male	1502	48.8	48.9
Female	1578	51.2	51.1
Age (years)			
18-24	374	12.1	12.2
25-34	542	17.6	18.0
35-44	596	19.4	18.5
45-54	553	18.0	17.9
55-64	481	15.6	15.2
65+	534	17.3	18.2
Marital status			
Married/de facto	1832	59.5	
Separated/divorced/widowed	406	13.2	
Never married	842	27.3	
Education			
Never attended school/ primary/ some high school/ preferred not to answer	444	14.4	
Completed high school	627	20.4	
University, TAFE etc.	2009	65.2	
Cancer history			
Cancer history with death	1175	38.1	
Cancer history with no death/death unknown	489	15.9	
No cancer history	1376	44.7	
Prefer not to answer	40	1.3	
General health			
Very good	544	17.7	
Good	1481	48.1	
Average	842	27.3	
Poor/ very poor	213	6.9	
Country of birth			
Australia	2285	74.2	
Overseas	795	25.8	
Private health insurance			
Yes	1814	59	
No	1266	41	
Employment status			
Working full time	1082	35.1	
Working part time	622	20.2	
Currently not working, but looking for work	376	12.2	
Retired	669	21.7	
Other	331	10.7	
Household annual income			
\$0 to 20,000	249	8.1	
\$20,001- 40,000	610	19.8	

\$40,001 to 80,000	863	28.0
\$80,001 and over	1008	32.7
Prefer not to answer	350	11.4

Personal annual income

\$0 to 20,000	754	24.5
\$20,001- 40,000	711	23.1
\$40,001 to 80,000	792	25.7
\$80,001 to 180,000	422	13.7
\$180,001 and over	47	1.5
Prefer not to answer	354	11.5

Household composition

With financially dependent children	927	30.1
Without financially dependent children	2153	69.9

State

Australian Capital Territory	47	1.5	1.7
New South Wales	985	32.0	32.2
Northern Territory	10	0.3	0.9
Queensland	587	19.1	19.9
South Australia	236	7.7	7.6
Tasmania	70	2.3	2.3
Victoria	745	24.2	25.1
Western Australia	289	9.4	10.4
Unknown ¹	111	3.6	-

237 ¹The pilot survey did not include this demographic question (n= 111)

238 ² Australia demographics (gender, age and state of residence) are for persons aged 18 years and over, sourced
 239 from the TableBuilder available from the Australian Bureau of Statistics based on the 2011 Census data.
 240 (<http://www.abs.gov.au/websitedbs/censushome.nsf/home/tablebuilder?opendocument&navpos=240>).

241 Abbreviation: TAFE= Technical and Further Education

Table 2: Number of times a prioritisation criterion was assigned the top priority, lowest priority (i.e. with a ranking order of 1 and 12 respectively), and top 3 rankings by respondents

Prioritisation criteria	Rank 1 (most important) n (%) N= 3080	Rank 12 (least important) n (%) N=3080	Top 3 rankings n (%) N= 9240
Severity of disease Preference for funding should be given to new medicines that treat severe or life threatening conditions	1213 (39.4)	73 (2.4)	1966 (21.3)
Children Preference for funding should be given to new medicines targeting diseases that typically affect children	405 (13.1)	57 (1.9)	1260 (13.6)
Cancer treatments Preference for funding should be given to new medicines targeting cancer patients	280 (9.1)	30 (1.0)	1112 (12.0)
Availability of alternative treatment options Preference for funding should be given to new medicines that target diseases for which no other treatments are available	266 (8.6)	236 (7.7)	957 (10.4)
Disadvantaged populations Preference for funding should be given to new medicines targeting diseases that typically affect disadvantaged patients e.g. low income families	204 (6.6)	161 (5.2)	760 (8.2)
Cost to the PBS and savings to patient Preference for funding should be given to new medicines that cost the government more and thereby save patients more in out-of-pocket costs	139 (4.5)	288 (9.4)	474 (5.1)
Medicines that help patients return to work Preference for funding should be given to new medicines that help patients return to work	133 (4.3)	200 (6.5)	508 (5.5)
Carer burden Preference for funding should be given to new medicines targeting diseases that, if untreated, cause patients to be reliant on carers	110 (3.6)	146 (4.7)	594 (6.4)
Life style related diseases and individual responsibility Preference for funding should be given to new medicines targeting diseases that are not considered to be a life-style related disease i.e. diseases that could not be avoided through individual life style changes	109 (3.5)	1041 (33.8)	296 (3.2)
Significant innovation Preference for funding should be given to new medicines that work in a new and different way to existing treatments	107 (3.5)	221 (7.2)	569 (6.2)
End-of-life treatments Preference for funding should be given to new medicines that prolong life –even for a few months- at the end of life i.e. for patients with a life expectancy of less than 2 years	63 (2.0)	476 (15.5)	363 (3.9)
Rare diseases Preference for funding should be given to new medicines targeting rare diseases i.e. diseases affecting less than 2000 patients in Australia	51 (1.7)	151 (4.9)	381 (4.1)

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