Prescription medicines: decision-making preferences of patients who receive different levels of public subsidy

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Abstract

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Objective To compare the relative importance of medicine attributes and decision-making preferences of patients with higher or lower levels of insurance coverage in a publicly funded health care system.

Design and setting Cross-sectional telephone survey of randomly selected regular medicine users aged ≥ 18 years in the Hunter Valley, NSW, Australia.

Main variables studied Questions about 27 medicine attributes and active involvement in decisions to start a new medicine.

Results After adjustment, there were few differences between the 408 concession card holders (high insurance) and 410 general beneficiaries (low insurance) in their assessment of the importance of medicine attributes. For both groups, the explanation of treatment options, establishing the need for the medicine, and medicine efficacy and safety were the most important considerations. Medicine costs, the treatment burden and medicine familiarity were less important; the views of family and friends ranked lowest. There was a statistically significantly greater influence of the regular doctor for the concession card holders than general beneficiaries (93.6 vs. 84%, adjusted OR 2.80, 95% CI 1.31, 5.99). Concession card holders were more likely to favour doctors having more say in the decision-making process (crude OR 1.69, 95% CI 1.28, 2.24), and more likely to report the most recent treatment decision being made by the doctor alone, compared with general beneficiaries (61.2 vs. 40.3%).

Conclusion Medicine need, efficacy and safety are viewed as paramount for most patients, irrespective of insurance status. While patients report the importance of participation in treatment decisions, delegation of decision making to the doctor was common in practice.

Background

Most high-income countries and a growing number of low- and middle-income countries provide drug benefits programmes that protect patients from prohibitive medicine costs.¹ Often that protection comes in the form of a publicly funded price subsidy to the patient. These programmes have been under increasing financial pressures in recent years because of the high costs of new drugs. Governments have a limited range of responses to this budgetary pressure. They can achieve lower prices through tendering and generic substitution, can use pharmacoeconomic analyses to demonstrate value and sometimes argue for lower prices, or they can share some of the costs with patients by requiring co-payments.¹

There is considerable variation in how governments share the costs of medicines with consumers. Some cover a proportion of the total medicine costs; others use a fixed co-payment, possibly linked to a measure of ability to pay.¹ In Australia, where this study was conducted, patients pay a fixed amount, but the amount depends on their welfare status. There is a 'safety net' that reduces medicine costs beyond a certain annual level of consumption; despite this, co-payment costs can still cause hardship and impact adversely on the individual's capacity to afford medications.²⁻⁴ In Australia, there is evidence that costs impact differently on prescription medicine use by general beneficiaries and concession card holders.^{2,5}

Most research in this field has addressed the affordability of medicines covered by insurance programmes. But at its core, the policy of charging patients is not simply about sharing costs. There is a common but largely unstated view that strong price signals to patients may influence attitudes and behaviours and reduce 'wasteful' practices. The concern is that overly generous benefits carry risks – a moral hazard. So, investigation of the behaviours of patients and their responses to cost sharing requires an analysis of beliefs and attitudes towards the provision of medicines and an investigation of whether these differ between individuals with

higher or lower levels of insurance coverage. These beliefs and attitudes are likely to be influenced by how patients view their relationships with their doctors, who are important agents in the chain of events that result in the writing of a subsidised prescription.

The work described here is part of a larger study exploring the impact of cost sharing by patients in Australia on medicine choices and utilisation. This study asked respondents to quantify the relative importance of a number of medicine attributes and the extent to which they delegate responsibility for decision making to their doctor. We contrasted responses from general beneficiaries and concession card holders to assess the influence of the different levels of insurance coverage. We compared patients' preferred (stated) decision-making role with their self-reported role (revealed decision making) in a recent decision to start a new medicine. Finally, we determined patients' satisfaction with the information communicated to them on the efficacy, safety and cost of the new medicine. The results of this study will be used in a discrete choice experiment,⁶ to measure their preparedness to trade-off the clinical benefits, side effects and cost of alternative medicines.

Methods

This cross-sectional survey of regular medicine users was conducted between April and June 2008 in the Hunter Valley region of New South Wales, Australia. The study was approved by the University of Newcastle Human Research Ethics Committee.

Participants

Participants had to be current users of prescription medicines who anticipated using them for the next 6 months. Respondents were categorised according to their eligibility for concessional benefits under the Australian Pharmaceutical Benefits Scheme.⁷ In 2011, general beneficiaries (who do not receive welfare payments) pay a maximum of AU\$ 34.20 per prescription item, while concession card holders (elderly and those

in receipt of social security support) pay up to AU\$ 5.60 per prescription item. A safety net scheme protects people with high medication needs. Once an individual or family reaches a safety net threshold (AU\$ 1317.20 for general beneficiaries and AU\$ 336.00 for concession card holders), the medicine will be less expensive (AU\$ 5.60 for general beneficiaries) or free (for concession card holders) for the rest of the calendar year. There is optional private health insurance in Australia but this does not routinely cover the costs of prescription medicines. Information was obtained on participants' age, gender, highest level of education completed, marital and employment status, number of children in the household, and whether or not they had a regular doctor or held private health insurance. In addition, we collected information on self-reported health status using five categories (poor, fair, good, very good and excellent).

Survey development

Medicine attributes

We used the results from qualitative work previously conducted by us² and from themes identified from the literature^{8–11} to identify key attributes of medicines that might influence participants' decisions about starting a new medicine. We developed 26 questions related to the nine attributes as follows: – benefits associated with the medicine (three items), risks of the medicine (three items), the need for the medicine (three items), cost (three items), other treatment options (three items), who recommended the treatment (three items), the burden or inconvenience associated with taking the medicine (four items), previous experience with the medicine (one item) and the importance of the views of others including family and friends (three items). As we wanted to examine roles in decision making, we added a single question asking respondents about the importance of being actively involved in the decision to start a new medicine.

In total, there were 27 items assessing the importance of the medicine attributes. These

were scored using a five-item Likert response scale (not at all important, of little importance, moderately important, important and very important). Question sets were grouped (e.g. those relating to benefits or side effects) and presented to respondents in randomised order, and symmetrical scales were randomly presented in proper or inverted order; both of these techniques reduce the bias from order effects.¹²

Decision making-role

In addition to the single item in the medicines attributes part of the survey, we explored the preferred (stated) decision-making role for participants using the validated Degner Control Preferences Scale.¹³ Respondents were asked to imagine they had to make an important choice about treatment for themselves (an example might be deciding whether to take a cholesterol-lowering medicine or a blood pressure medicine). Each participant was asked a series of questions, comparing two options at a time; the options provided are categorised into five preferred decision-making roles with increasing delegation of authority for decision making to the doctor. The categories are as follows: (i) making the decision yourself, (ii) you make the decision yourself after seriously considering the doctor's opinion, (iii) you and the doctor share equally in deciding about your treatment, (iv) doctor makes the final decision after seriously considering your opinion and (v) you would prefer to leave all decisions regarding treatment to your doctor.

To compare respondents' stated preference for decision making with recall of their actual (revealed) decision-making role, we asked who had made the decision the last time a new medicine had been started. Response options were as follows: the doctor decided for you, you and your doctor decided together, you decided by yourself or you can not remember.

Satisfaction with information provided

We asked participants how much information was provided by the doctor on the potential benefits, side effects and costs of the last new medicine started. Response options for each

aspect were as follows: you received no information, you wanted more information, you received as much information as you wanted and you received more information than you wanted.

Procedure

A three-phase pilot test of the survey consisted of 50 completed interviews, with participants drawn from Hunter Valley households not included in the study. At the end of each phase of testing, minor modifications were made to further refine the wording and flow of the questionnaire. A copy of the survey is available on request. The final survey instrument was administered using a computer-assisted telephone interview (CATI) system by trained staff at the not-for-profit Hunter Valley Research Foundation (<http://www.hvrf.com.au/>). The procedures standardised the introduction scripts, wording of all questions and response options and directed the interview using skips, branching questions and prompts as appropriate. Randomisation was applied to both household selection (random digit dialling of households from the NSW Electronic White Pages) and participant selection to minimise bias and reduce volunteer effects. Up to 10 attempts were made to contact the household. The person answering the telephone was asked the number of people in the household aged ≥ 18 years and his/her age position in the household. The CATI system selected one person at random e.g. Nth oldest, with no substitutions permitted. This sequence prevented the person answering the telephone misrepresenting themselves as the selected respondent. Eligible participants were regular medicine users. The purpose of the study was explained, and verbal consent to continue with the interview was obtained. The interview could be rescheduled to a more convenient time and, where requested, additional written information sent to the selected respondent before the interview proceeded. Quota sampling was used to ensure that there were equal numbers of general beneficiaries and concession card holders included in the survey. Interviewers for the study under-

went training in the background to the study, detailed CATI collection procedures and methods and up to 2 h practical experience in the conduct of the survey and addressing potential respondent questions. Data were recorded in two separate databases: one with the results of every completed interview in the study and the second recording every call attempt.

Principal component analysis

To check that the attributes of medicines proposed by us identified the key components that might influence decision making, responses to the 27 Likert scale items were subjected to a principal component analysis (PCA). PCA is a variable reduction procedure resulting in a small number of components that account for most of the variance in a set of observed variables (survey items). The principal axis method was used to extract the components. The mathematical method looks for a linear combination of variables that extracts the maximum variance.¹⁴ It then removes this variance and seeks a second linear combination that explains the maximum proportion of the remaining variance. This is repeated, resulting in a series of orthogonal (uncorrelated) factors or components. Both the eigenvalue greater than one criterion (Kaiser criterion) and the scree test were used to determine the number of components extracted.¹⁴ Factors with low eigenvalues (< 1) contribute little to the explanation of variances and are ignored in favour of more important factors. The scree test is a graphical representation of eigenvalues; the elbow of the curve indicating a possible solution for the number of components. The components were then subjected to a Varimax rotation, an orthogonal rotation of the factor axes that facilitates identification of each variable with a single component. In interpreting the rotated component pattern, an item was said to load on a given component if the factor loading was 0.4 or greater for that component and was < 0.4 for other components.

To check the validity of the PCA approach we applied, we re-examined the component solution by randomly dividing the responses from the

participants into two groups, using one half of the responses to develop the components (factors) and the remaining responses to confirm that the components identified adequately represented the data collected.

Statistical analysis

Descriptive statistics were used to summarise the data. Likert scale responses for the 27 items assessing the importance of medicine attributes were divided into two categories – *important* ('important' and 'very important') and *not so important* ('moderately important', 'of little importance' and 'not at all important'). Logistic regression analyses were conducted to examine differences between the concession card holder and general beneficiary groups in demographic characteristics and responses to the 27 questions, with patient category as the outcome variable. We derived crude and adjusted odds ratios and 95% confidence intervals, adjusting for age, sex, education, employment status, marital status, private health insurance status, regular GP, self-reported health and number of children in the household. Ordinal linear regression analysis was used to examine the differences between concession card holders and general beneficiaries in responses on the Degner Control Preferences Scale, self-reported participation in the most recent decision to start a medicine and satisfaction with the information provided on benefits, side effects and costs of that medicine. We derived crude and adjusted odds ratios and 95% confidence intervals, adjusting for the demographic characteristics listed earlier. All analyses were performed with sas 9.2 (SAS Institute, Cary, NC, USA).

Results

Overall, the CATI interviews took an average of 21 min to complete. Of 1222 eligible household contacts, there were 388 household and personal refusals, 16 incomplete and 818 completed interviews (408 concession card holders, 410 general beneficiaries), giving a response rate of 67%.

As expected, there were statistically significant differences between concession card holders and general beneficiaries on all variables measured except gender (Table 1). Concession card holders were older, had lower levels of education, a lower proportion were employed, fewer were married, they had lower rates of private health insurance and reported slightly worse overall health. Concession card holders had fewer children aged less than 18 years in the household and more had a regular GP than did respondents in the general beneficiary category.

While our sample contained fewer men than the Australian population (37 vs. 49.4%, respectively), reported rates of private health insurance coverage were similar to the Australian population at that time.¹⁵

Principal component analysis

The principal component analysis was conducted on usable responses from 709 participants. Only the first eight components displayed eigenvalues > 1, and the results of the scree test also suggested that only the first eight components were meaningful, and these were retained for rotation. Combined, these eight components accounted for 57% of the total variance in participants' responses. The eight components identified were labelled *decision making*, the *need* for the medicine, *benefits*, *risks*, *trust* (the doctor involved), *cost*, the *burden* associated with treatment, *familiarity* with the medicine. Testing of the PCA procedure using two random samples of responses confirmed the eight-component solution.

Importance of attributes

The importance of each of the 27 aspects on the decision to start a new medicine is summarised in Table 2, with the responses grouped according to the categorisation determined by the principal components analysis. Responses to the survey questions were not normally distributed; 15 attributes were identified as important or very important by more than 80% of respondents.

	Concession card holders <i>N</i> = 408	General beneficiaries <i>N</i> = 410	Crude odds ratio (95% CI)
Mean age in years (SE)	65.4 (0.72)	49.3 (0.65)	1.09 (1.07, 1.10)
Gender (%)			
Male	38.2	36.3	1.00
Female	61.8	63.7	0.92 (0.69, 1.22)
Highest level of education (%)			
Primary	4.7	1.2	16.3 (5.5, 47.7)
Lower secondary	53.2	28.0	8.1 (4.9, 13.2)
Technical college	26.7	32.4	3.5 (2.1, 5.8)
Higher School	9.3	12.2	3.3 (1.7, 6.0)
Certificate/College University	6.1	26.1	1.00
Employment status (%)			
Employed	10.8	75.3	1.00
Not employed	89.2	24.7	25.2 (17.1, 37.0)
Marital status (%)			
Married	45.6	66.6	1.00
Not married	54.4	33.4	2.4 (1.8, 3.2)
Private health insurance (%)			
Yes	44.6	71.7	0.32 (0.24, 0.43)
No	54.9	28.0	1.00
Has a regular GP (%)			
Yes	98.3	92.9	4.4 (1.9, 10.1)
No	1.7	7.1	1.00
Self-reported overall health (%)			
Poor	8.1	2.7	1.00
Fair	25.0	13.2	0.63 (0.30, 1.34)
Good	38.7	41.5	0.31 (0.15, 0.63)
Very good	24.0	32.2	0.25 (0.12, 0.51)
Excellent	3.9	10.5	0.12 (0.05, 0.30)
Number of children in household (%)			
None	88.7	65.9	1.00
One	5.4	14.6	0.27 (0.16, 0.46)
Two	3.7	13.2	0.21 (0.11, 0.38)
Three or more	2.2	6.3	0.26 (0.12, 0.56)

Table 1 Sociodemographic characteristics of respondents

Concession card holders versus general beneficiaries

There were small but statistically significant differences between concession card holders and general beneficiaries in the assessment of the importance of eight of the 27 items. However, after adjustment for demographic characteristics, a statistically significant difference remained for only one item, *How important is it that your regular doctor has prescribed it?*, ranked important or very important by more concession card holders than general beneficiaries (93.6 vs. 84%, adjusted odds ratio 2.80, 95% CI 1.31, 5.99, Table 2).

Ranking of items

Highest ranked in importance for the respondents was the explanation of all treatment options available; knowing that there might be non-medicine alternatives, such as diet or exercise, and having time to consider the options presented were ranked lower (ranks 15 and 17, respectively).

After the explanation of all treatment options, information on the need for the medicine was important to participants (ranks 2, 4, 5, 14). The doctor's assessment of need was rated more important than the respondent's own perceived need for treatment (rank 5 vs. 14).

Table 2 Importance of attributes of medicines

		Important or very important (%)		
How important are the following aspects in helping you decide whether to take this new medicine?	Rank	Concession card N = 408	General N = 410	Crude odds ratio (95% CI)
Decision making				
That all treatment options have been explained to you	1	97.5	98.8	0.49 (0.17, 1.45)
That you are directly involved in decision about medicine	7	90.6	90.9	0.97 (0.60, 1.55)
That there are non-medicine alternatives (diet/exercise)	15	80.3	86.0	0.66 (0.46, 0.96)
Having time to think about options before commencing	17	78.6	80.4	0.89 (0.63, 1.25)
Need				
That the medicine will protect you from getting worse	2	97.8	97.8	0.99 (0.39, 2.53)
What might happen if you do not treat the condition	4	96.3	96.3	1.00 (0.48, 2.07)
That the doctor says you need the medicine	5	95.3	92.2	1.73 (0.97, 3.11)
That you think you need the medicine	14	85.7	83.0	1.23 (0.84, 1.80)
Benefits				
How effective the medicine is likely to be	3	96.8	97.8	0.68 (0.29, 1.61)
That the medicine will cure rather than symptom relief	9	90.7	88.5	1.27 (0.81, 2.01)
Risks				
The possible long term side effects of the medicine	6	91.1	94.6	0.58 (0.33, 1.00)
The side effects associated with the medicine	8	90.6	89.7	1.11 (0.70, 1.76)
The personal risks of side effects	11	87.2	88.0	0.93 (0.61, 1.41)
Trust				
That your regular doctor has prescribed it*	10	93.6	84.0	2.77 (1.72, 4.47)
That a specialist has recommended the medicine	12	90.4	84.1	1.78 (1.16, 2.72)
Doctor other than your regular doctor has suggested	23	63.9	59.5	1.21 (0.91, 1.60)
Cost				
That you can afford the medicine	13	87.7	83.9	1.37 (0.92, 2.04)
How long you will need to buy the medicine	19	77.6	70.8	1.43 (1.04, 1.96)
How much the medicine will cost	20	74.4	72.4	1.11 (0.81, 1.51)
Burden				
How long it will take before the medicine starts to work	16	83.1	75.3	1.62 (1.15, 2.28)
Whether medicine means extra monitoring/follow-up)	18	82.1	72.8	1.72 (1.23, 2.40)
How long you will need to keep taking the medicine	21	75.1	71.6	1.20 (0.88, 1.64)
How often you will need to take medicine (three times per day)	22	70.3	63.6	1.35 (1.01, 1.81)
Familiarity				
Having taken a similar medicine previously	24	60.2	55.0	1.24 (0.93, 1.64)
What you have heard about the medicine in the media	25	43.2	39.6	1.16 (0.88, 1.53)
What family members say about the medicine	26	37.3	29.7	1.41 (1.05, 1.89)
What friends say about the medicine	27	21.0	17.4	1.26 (0.89, 1.79)

*Remains statistically significant after adjustment for age, sex, education, employment status, marital status, private health insurance and self-reported general health (adjusted OR 2.80, 95% CI 1.31, 5.99).

Aligned with need was whether the medicine will work (rank 3). Whether the medicine would offer a cure or provide symptom relief seemed to be of slightly lower importance (rank 9) as was how long it will take for the medicine to work (rank 16).

After need and benefits of treatment, side effects were important to participants, both the short-term and long-term side effects that might

be associated with the medicine (ranks 6 and 8) rather than the more specific assessment of their personal risk of side effects (rank 11). However, these differences in ranking are minor, with more than 87% of participants rating information on all three questions around side effects as important or very important.

That it was your regular doctor (rank 10) or a specialist (rank 12) who prescribed the drug was

reported as an important influence on the decision to use a medicine; a doctor other than your regular doctor was ranked lower in importance (rank 23).

The importance of medicine costs seemed to be in the context of being able to afford the medicine (rank 13) i.e. relative to their own circumstances rather than about how long they would need to buy the medicine or how much the medicine will cost (ranks 19 and 20, respectively).

The potential burden associated with taking the medicine (need for additional monitoring or follow-up, how long you would need to keep taking the medicine, and how many times a day) appeared to be of less concern to the respondents (ranks 18, 21, 22).

The lowest ranked items in this survey related to familiarity with the medicine through having had previous experience of it, what participants had heard about the medicine in the media and the opinions of family and friends (ranks 24–27). Family views appeared to be a stronger influence than those of friends (rated as important or very important by 33 and 19% of overall respondents, respectively).

Roles in decision making

Active participation in the decision to start a new medicine was reported as important or very important to almost 91% of the respondents (rank 7 in the medicine attributes survey), with no differences between concession card holders (90.6%) and general beneficiaries (90.9%).

Results for the Degner Control Preferences Scale are shown in Table 3. Logistic regression

analysis showed statistically significant differences between the two groups, with concession card holders more likely than general beneficiaries to allow doctors to have more say in the decision-making process (crude OR 1.69, 95% CI 1.28, 2.24). However, after adjustment for demographic variables, the differences were no longer statistically significant (adjusted OR 0.89, 95% CI 0.59, 1.34).

'Leave the decision to the doctor' was the stated decision-making preference for 14.8% of concession card holders and 6.4% of general beneficiaries (Table 3). Yet, when asked to recall the most recent decision to start a new medicine, 61.2% of concession card holders and 40.3% of general beneficiaries reported that the doctor alone had made the decision. While concession card holders were less likely to make their own decisions about starting medication (crude OR 0.44, 95% CI 0.33, 0.57), this effect disappeared after adjustment for demographic variables (adjusted OR 0.98, 95% CI 0.65, 1.46).

Satisfaction with information provided

Overall, around one-quarter of study participants reported that no information was provided on the potential side effects of the last new medicine prescribed for them; around 13% said they would have liked more information (Table 4). Cost was not discussed in around 63% of cases (60% of concession card holders and almost 70% of general beneficiaries, Table 4), yet few respondents suggested they wanted more information on the cost of the medicine prescribed.

	Number of respondents (%)	
	Concession card holders <i>N</i> = 405 (%)	General beneficiaries <i>N</i> = 408 (%)
Stated decision-making preference		
Make decision yourself	6 (1.5)	15 (3.7)
Yourself after considering doctor's opinion	47 (11.6)	74 (18.1)
You and doctor share decision equally	263 (64.9)	252 (61.8)
Your doctor after considering doctor's opinion	29 (7.2)	41 (10.0)
Leave decision to doctor	60 (14.8)	26 (6.4)

Table 3 Responses on the Degner Control Preferences Scale

Table 4 Satisfaction with information provided on benefits, side effects and cost of the new medicine

Information provided	Concession card holders <i>n</i> (%)	General beneficiaries <i>n</i> (%)	Adjusted OR* (95% CI)
Benefits			
Received none	44 (11.1)	22 (5.4)	0.84 (0.53, 1.32)
Wanted more	44 (11.1)	60 (14.8)	
As much as I wanted	290 (73.2)	298 (73.4)	
More than I wanted	18 (4.5)	26 (6.4)	
Side effects			
Received none	114 (28.4)	85 (21.1)	0.85 (0.57, 1.27)
Wanted more	46 (11.5)	64 (15.9)	
As much as I wanted	225 (56.1)	227 (56.5)	
More than I wanted	16 (4.0)	26 (6.5)	
Cost			
Received none	235 (59.9)	280 (69.3)	1.66 (1.08, 2.56)
Wanted more	5 (1.3)	12 (3.0)	
As much as I wanted	148 (37.8)	105 (26.2)	
More than I wanted	4 (1.0)	6 (1.5)	

*Adjusted for age, gender, education, employment status, marital status, having their own GP and in a health fund.

Discussion

Overall, there were few differences between the concession card holders and general beneficiary respondents in the ratings and rankings of the medicine attributes examined in this study. After adjustment for differences in demographic characteristics, the only statistically significant difference between the two groups was the greater influence of the regular doctor on decision making for concession card holders. Poorer health, more illness and more contact with the medical profession along with lower educational achievement and older age of the concession card holders might explain these observations. Lower education will heighten the information asymmetry between doctor and patient¹⁶, and older age is associated with more traditional, paternalistic doctor–patient relationships.¹⁶ This study underscores the importance of multivariate adjustment when evaluating the impacts of different levels of insurance subsidy. It does not appear from these data that the different levels of subsidy that exist in the Australian Pharmaceutical Benefits Scheme are associated with major differences in attitudes or behaviours in respect of prescription medicines.

There is increasing evidence that patient co-payments, a feature of the Australian Pharmaceutical Benefits Scheme, cause financial concern^{2,17} and may influence prescription acquisition and use for some Australians.^{3–5,18} Given the higher co-payments of the general beneficiary group (AU\$ 31.30 per item at the time of the survey), it might have been expected that cost was of greater importance to this group. However, cost was mostly not discussed during consultations, and for all three cost questions, higher proportions of concession card holders reported it to be an important consideration. Cost appears to be an affordability issue, the co-payment for concession card holders (AU\$ 5.00 at the time of the survey) might be a relatively greater impost on a household budget reliant on a pension or other social security support. However, there is separate evidence that medicine costs are a particular problem for the ‘working poor’,² i.e. those with low household income, with one or more members with chronic disease, who are not eligible to purchase prescriptions at the concessional rate. There were too few participants in this category to examine this further in this study.

Significantly, for both groups, medicine use was studied in the context of an established

need, based on the advice of the general practitioner. The regular doctor or specialist was particularly important as trusted decision maker for the patient. The influence of the doctor was not surprising; 95% of respondents reported having a regular GP, and all respondents were regular prescription medicine users. Most will have established relationships with their doctors that involve a high level of trust and acceptance of the doctor's advice. After need, issues of benefit and risk were rated as the most important considerations. It seems that once the decision has been made that the medicine is needed and that the potential benefits outweigh the perceived risks, other considerations, including copayments, are of lesser importance.

There were no differences between the two groups on the single question exploring decision-making preference, with 91% of each group reporting participation in decision making as important or very important. However, responses on the validated Control Preferences Scale suggest that concession card holders were more likely to describe themselves as leaving the decision to the doctor (15 vs. 6%), although the difference was not statistically significant after adjustment for demographic variables. The stated preferences for decision making were substantially different to recall for the most recent decision to start a medicine where 61% of concession card holders and 40% of general beneficiaries reported that the doctor alone made the decision. We did not assess satisfaction with the decision-making process.

This apparent dissonance between stated and revealed preferences might be explained in part by personal perception and descriptions of decision making. While both groups agreed that involvement in decision making was important, what may differ is how this plays out and is interpreted in the clinical context. The desire for information is not the same as desire to participate in decision making;¹⁹ patients may want to be informed and actively discuss treatment options but prefer decisions to be made principally by the physician.^{20,21} Others have made the distinction between the process of involvement (option portrayal, exchange of information and

exploring preferences for who makes the decision and when) and the actual decisional responsibility (who makes the decision).²² In an interview study, Smith *et al.*²³ found that those with higher levels of education tended to see themselves as sharing responsibility with the doctor throughout the decision-making process. Those with lower education tended to view their role as consenting to an option recommended by the doctor, accepting responsibility for decision making by agreeing or disagreeing with the recommendation.

The factors or components we identified as influencing decision making for prescription medicines are similar to those included with other descriptions and scales assessing satisfaction with medicines.^{9–11,24} Shikiar and Rentz⁸ have suggested that under some circumstances patients might be willing to trade-off medicine features, for example favouring a medicine that is quicker acting but with a less favourable side effect profile, or a more convenient dosage schedule when benefits and risks are similar. The results of our study do not allow us to comment on this directly. We have identified and ranked medicine attributes according to their reported importance to patients. Willingness or ability to trade on these dimensions is likely to be influenced by many things. If the illness is severe or life threatening, a high risk of side effects alongside a small chance of benefit might be entirely reasonable and at whatever cost. For less severe, chronic conditions, persistent side effects may be intolerable and may make the patient stop therapy altogether. In other cases, it may be an issue of cost, where the patient may not be able to afford the more effective, more convenient medicine regardless of the established need and the recommendation of the doctor. It is possible that while patients report the importance of medicine attributes to their decisions, in practice, they rely on their doctors to interpret differences in these attributes and delegate authority to the doctor to make the decision for them. This interpretation is most consistent with the reports of the most recent prescribing decision in this study.

This study has a number of limitations. It was conducted in a single region – the Hunter region of New South Wales. However, while there are some demographic differences between the Hunter and other Australian regions, there is no reason to expect responses to be substantially different elsewhere in Australia. We focused predominantly on pharmacological approaches to disease management, asking patients to imagine a clinical condition and a new medicine for its treatment. While differences in the severity of a clinical condition envisaged and the consequences of not treating it may have influenced the importance ratings assigned by participants, the domains identified as important are consistent with other studies exploring satisfaction with medicines. For 15 of the 27 items, more than 80% of respondents considered it important or very important to have information on that aspect of the medicine making it difficult to identify meaningful differences on some components. However, the ratings for the attributes of cost, burden and familiarity were substantially lower than the ratings for need, benefits and risks.

Conclusion

This study showed that concession card holders and general beneficiary respondents generally agreed on the importance of the attributes of medicines that influence their decisions about taking a new medicine. The main difference was the greater influence of the regular doctor on decision making for concession card holders. The dominant issue is establishing the need for the medicine, followed by a consideration of the benefits and risks associated with it. Issues of cost, burden and experience or familiarity with the medicine were ranked as less important. More than 90% of respondents thought it important to be directly involved in the decision about a new medicine, yet around 50% reported that the most recent decision to start a new medicine was made by the doctor alone. Delegation of decision-making authority to the doctor may be the logical response to the complexity of evaluating different medicine attributes. In

the Australian health insurance system, the level of subsidy appears to play no important role in determining views about medicines or decision-making preferences.

Conflicts of interest

The authors have no conflicts of interest to declare.

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Authors' contribution

All authors were involved in design of the study, development of the survey and interview questions and interpretation of the study results. JR drafted the manuscript; all authors contributed to revisions of the manuscript. All authors read and approved the final manuscript.

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