# Patients' involvement in decisions about medicines:

## GPs' perceptions of their preferences

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#### **ABSTRACT**

#### **Background**

Patients vary in their desire to be involved in decisions about their care.

#### Aim

To assess the accuracy and impact of GPs' perceptions of their patients' desire for involvement.

#### **Design of study**

Consultation-based study.

#### Setting

Five primary care centres in south London.

#### Method

Consecutive patients completed decision-making preference questionnaires before and after consultation. Eighteen GPs completed a questionnaire at the beginning of the study and reported their perceptions of patients' preferences after each consultation. Patients' satisfaction was assessed using the Medical Interview Satisfaction Scale. Analyses were conducted in 190 patient–GP pairs that identified the same medicine decision about the same main health problem.

#### Results

A total of 479 patients participated (75.7% of those approached). Thirty-nine per cent of these patients wanted their GPs to share the decision, 45% wanted the GP to be the main (28%) or only (17%) decision maker regarding their care, and 16% wanted to be the main (14%) or only (2%) decision maker themselves. GPs accurately assessed patients' preferences in 32% of the consultations studied, overestimated patients' preferences for involvement in 45%, and underestimated them in 23% of consultations studied. Factors protective against GPs underestimating patients' preferences were: patients preferring the GP to make the decision (odds ratio [OR] 0.2 per point on the five-point scale; 95% confidence interval [CI] = 0.1 to 0.4), and the patient having discussed their main health problem before (OR 0.3; 95% CI = 0.1 to 0.9). Patients' educational attainment was independently associated with GPs underestimation of preferences.

#### Conclusion

GPs' perceptions of their patients' desire to be involved in decisions about medicines are inaccurate in most cases. Doctors are more likely to underestimate patients' preferred level of involvement when patients have not consulted about their condition before.

#### Keywords

family practice; patient participation; prescriptions; primary health care.

#### INTRODUCTION

In recent years there has been an increased emphasis on patients playing an active role in decision making about their care. Greater patient participation is associated with better health outcomes and with improved satisfaction.1-4 A systematic review of research on communication between patients and professionals concerning medicines, carried out in a range of healthcare settings, found little evidence of shared decision making.5 However, patients vary in their desire to be involved in decisions about their care, and a significant minority of patients may not want to make shared decisions. 6-9 Desire for a more active role has been more common among patients who are younger, female, more highly educated, and healthier.10-13

Over a third of patients may not achieve their desired role in decision making when consulting with doctors. <sup>14-15</sup> In a UK primary care study, 60% of patients achieved the decision-making role they wanted with their GPs. <sup>14</sup> However, 25% of patients had a less active role, while 15% of patients had a more active role than they preferred. A hospital-based study in the US found that patients whose

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participation in decision making was greater or less than they preferred were less satisfied with their treatment than patients whose participation matched their desired role.<sup>16</sup>

US research has shown that doctors' perceptions of their patients' decision-making preferences are often inaccurate.17-18 Strull et al often found that doctors overestimated hypertensive outpatients' desire to make decisions, although they underestimated patients' desire for information and discussion about their care.18 O'Connor et al, in a telephone survey of the general population in Canada, found that the most common preference was for shared decision making, with only 6% of participants wanting the doctor to make the decision with or without consideration of the patients' view.12 Bruera et al found that patients at a US tertiary palliative care outpatient clinic wanted a less shared approach to decision making than their doctors thought.17 Doctors tended to be more accurate in detecting their female than their male patients' decisionmaking preferences, although there was no relationship between doctors' accuracy and patients' income, education, or age.17,19 In a simulation study of life threatening illness in the UK, junior hospital doctors were found to be good at making technical medical assessments and not quite as good at including patients' wishes.20

In the current study, doctors' perceptions of their patients' preferences for involvement in decision making about their treatment in a primary care setting were examined. The main aim was to the extent to which underestimated their patients' desire involvement in decisions about prescription medicines. The research focused on GPs' underestimation of their patients' preferences for involvement because underestimation has been

How this fits in

Patients vary in their preferences for involvement in decision making concerning their health care. Research has shown that patients do not usually achieve their preferred level of involvement. GPs make accurate assessments of patients' preferences in only a third of cases and they are more likely to underestimate patients' preferences if the patient is consulting with a new problem. GPs' underestimation of patients' preferences for involvement does not have an adverse effect on the patient–GP relationship.

associated with lower patient participation, and has been found to have a negative impact on patient outcomes. Also investigated were factors affecting GPs' underestimation of patients' preferences for involvement, and the impact that GPs' estimates of their preferences have on patients' and their own satisfaction with the consultation, as well as their perceptions of their relationship with each other.

#### **METHOD**

A questionnaire study was conducted to examine patients' preferences for involvement in decision making about prescription medicines and their GPs' perceptions of these preferences. Patients completed a questionnaire before and after consultation with their GP. The GPs completed a questionnaire at the beginning of the study and after each consultation with the participating patients. Before consultation, patients were asked about preferences for involvement in decision making about medicines for their main health problem. GPs were asked to estimate the patients' preferred level of involvement in decision making after their consultation with the patient. Each patient's preference was then compared with the GP's estimate of the patient's preference.

#### Participants and procedure

An opportunistic sample of seven general practices (list size >6000 patients) in inner south London was invited to participate in the study. All practices served a population of mixed socioeconomic and ethnic groups. Eighteen fully-qualified GPs from five different practices volunteered. Consecutive patients over 18 years of age consulting these GPs were invited to participate between June and November 2003. These patients were approached in the waiting room, and given an information sheet explaining the study. No change was made in the usual frequency or length of consultation times during the research. The pre-consultation interview did not delay patients' readiness to see the GP in any instance.

#### **Questionnaires**

The pre-consultation questionnaire asked patients about the main health problem they wanted to discuss with the doctor and their preferred level of involvement in decisions about medicines for this problem. Patients' decision-making preferences were assessed using the measure developed by Degner and Sloan.<sup>8</sup> Patients were asked to choose one of the following five statements:

I would prefer that I make the decision about medicines I take for this problem.

I would prefer that I make the final decision about medicines I take for this problem after seriously considering my doctor's opinion.

I would prefer that my doctor and I share responsibility for deciding about medicines I take for this problem.

I would prefer that my doctor makes the final decision about medicines I take for this problem, but seriously considers my opinion.

I would prefer that my doctor makes all decisions about medicines I take for this problem.

The pre-consultation questionnaire also assessed the duration of each patient's main problem, prescribed medicines taken for this problem, whether the patient had discussed this problem with a doctor before, if the patient had other problems he or she wanted to discuss, how many times the patient consulted with the GP previously, and the patient's sex, ethnic group, and educational qualifications.

The post-consultation questionnaire asked patients about decisions that had been made about medicines for their main problem during the consultation, the most important medicine decision made, satisfaction with the decision and with their level of involvement, intention to take any medicines as prescribed, satisfaction with the consultation and with their GPs' communication, and perception of the quality of their relationship with the doctor. Satisfaction regarding communication with their GPs was assessed using the eight-item 'rapport' subscale of the Medical Interview Satisfaction Scale.<sup>21</sup>

At the beginning of the study GPs were asked to complete a one-page questionnaire about their ethnic group, sex, and preferred role in decision making about medicines with their patients using an adapted version of the five statements of Degner and Sloan.8 After each consultation, GPs completed a questionnaire about what they perceived was the main problem the patient wanted to discuss; medicines decisions made about this problem, and which of these was the most important; their perception of the patient's preferred role in this decision (again using an adapted version of the five statements of Degner and Sloan); the quality of their relationship with the patient; and their own satisfaction with the consultation.

Questionnaires for patients and doctors and the recruitment process were piloted with two GPs and 20 patients in a local surgery.

#### **Analysis**

The analysis was limited to those patient–GP pairs in which the patient and GP identified the same main health problem discussed and reported on the same most important medicine decision made about this problem during the consultation. These statements were adjudicated by two of the authors where there was any uncertainty.

Cohen's  $\kappa$  was used to assess the agreement between patients' and GPs' perceptions of the patients' decision making preferences. Patient-GP pairs in which the GP underestimated the patient's preferred level of involvement were compared with with patient-GP pairs in which the GP correctly estimated or overestimated the patient's desire to participate. Logistic regression analyses, adjusting for clustering by GP, were used to examine the relationship between the characteristics of the patients and the GPs, and GPs' estimates of patients' preferences. Linear regression analyses, adjusting for clustering by GP, were used to investigate the relationship between GPs' estimates of patient preferences, and patient and GP outcomes. Analyses were carried out using Stata 8 (Stata Corporation, College Station, Texas, US).

#### **RESULTS**

Eighteen GPs at five practices were recruited (10 females, eight males; age range 29-57 years, mean 36 years). Between two and five consulting sessions per GP were required to recruit the patients. A total of 479 patients (75.7%) consented, completed, and returned pre- and post-consultation questionnaires. Table 1 shows the characteristics of all participating patients. A total of 376 patient-GP pairs identified the same main health problem, and 190 pairs reported that a medicine decision had been made and identified the same medicine decision. The analysis reported here is restricted to these 190 pairs. In comparison to the patients excluded from this analysis, these 190 patients were more likely to have consulted with only one health problem ( $\chi^2 = 3.88$ , degrees of freedom [df] = 1, P = 0.049) and to have been taking prescribed medication for their main health problem before their consultation ( $\chi^2 = 4.87$ , df = 1, P = 0.027).

## Patients' and GPs' decision-making preferences

The most popular type of decision making for both doctors and patients was shared decision making. All but two of the doctors said they preferred to make shared decisions or for the patient to make the decision after considering the GP's opinion. Thirty-nine per cent of patients said they preferred

Table 1. Demographics and medicine decisions of patients included and excluded from main analyses, n (%).

	Included patients $n = 190$	Excluded patients n = 289
Sex		
Male	70 (36.8)	105 (36.3)
Female	120 (63.2)	182 (63.0)
Age, years		
18–29	40 (21.1)	47 (16.3)
30–39	41 (21.6)	72 (24.9)
40–49	36 (18.9)	44 (15.2)
50-59	29 (15.3)	36 (12.5)
60–69	18 (9.5)	43 (14.9)
>70	26 (13.7)	46 (15.9)
Ethnic group		
White	118 (62.1)	168 (58.1)
Black/Black British	37 (19.5)	54 (18.7)
Asian/Asian British	5 (2.6)	12 (4.2)
Other	26 (13.7)	48 16.6)
Highest qualification		
None	49 (25.8)	88 (30.4)
GCSEs/A levels	45 (23.7)	65 (22.5)
Degree or higher	61 (32.1)	82 (28.4)
Other/unclear	32 (16.8)	42 (14.5)
Agreed most important medicine dec	cision	
New or repeat prescription	146 (76.8)	n/a
Change to a different medicine	14 (7.4)	n/a
Change of amount/frequency	10 (5.3)	n/a
Medicine discussed, not issued	6 (3.2)	n/a
Medicine stopped	5 (2.6)	n/a
Other decision	9 (4.7)	n/a

<sup>&</sup>lt;sup>a</sup>Patient–GP pairs were included in the analyses if they agreed on the patient's main health problem, reported that a medicine decision had been made, and agreed about what this decision was. n/a = not applicable.

to make shared decisions with their doctors about medicines, 45% wanted the GP to be the main (28%) or only (17%) decision maker, and 16% wanted to be the main (14%) or only (2%) decision maker themselves (Table 2). Patients who had consulted previously were less likely to want to make the decision alone or mostly alone.

# GPs' estimates of patients' decision-making preferences

GPs correctly estimated their patients' decision-making preferences in about a third (32%) of cases (see Table 2). GPs were more likely to overestimate patients' preferences (45.4%) than underestimate them (22.7%). The overall rate of agreement between patients' preferences and GPs' estimation of these preferences was very low ( $\kappa = 0.09$ ).

## Predictors of GPs' underestimation of patients' decision-making preferences

The associations (logistic regression, unadjusted and adjusted odds ratios allowing for clustering by GP) between patient and GP characteristics, and GPs' underestimation of patients' preferred involvement in decision making are shown in Table 3. There was a greater likelihood of GPs underestimating patients' preferred level of involvement in the decision when the patient had a lower level of educational attainment (although the confidence intervals indicate that the interpretation of this indicator is complex), when the patient had not discussed their main health problem with a GP before, when the patient preferred a higher level of involvement, and when the GP was of Asian or other non-white ethnic origin. These predictors remained significant when controlling for the age and sex of the doctor and the patient, the patient's ethnicity, the duration of the main health problem, the patient taking prescribed medication already, the time of the appointment, the patient's number of previous visits with the GP, the number of problems the patient had to discuss, and the GP's decision-making preferences.

## Impact of GPs underestimating patients' decision-making preferences

There was no significant difference between patients whose GPs underestimated their preferences and those whose GPs correctly

Table 2. Patients' decision-making preferences and GPs' perceptions of these preferences.

_	GPs' perceptions of patients' decision-making preferences					
Patients'						
decision-making	Patient decides	Patient mostly	Shared	Doctor mostly	Doctor decides	
preferences	alone, <i>n</i> (%)	decides, n (%)	decision, n (%)	decides, n (%)	alone, <i>n</i> (%)	Total, <i>n</i> (%)
Patient decides alone	2 (1.1)	0 (0.0)	1 (0.5)	0 (0.0)	1 (0.5)	4 (2.2)
Patient mostly decides	s 4 (2.2)	10 (5.4)	8 (4.3)	1 (0.5)	2 (1.1)	25 (13.5)
Shared decision	6 (3.2)	12 (6.5)	31 (16.8)	20 (10.8)	3 (1.6)	72 (38.9)
Doctor mostly decides	6 (3.2)	13 (7.0)	18 (9.7)	9 (4.9)	6 (3.2)	52 (28.1)
Doctor decides alone	0 (0.0)	4 (2.2)	11 (5.9)	10 (5.4)	7 (3.8)	32 (17.3)
Total	18 (9.7)	39 (21.1)	69 (37.3)	40 (21.6)	19 (10.3)	185 (100.0)

Table 3. Predictors of GPs' underestimation of patients' decision-making preferences.

	Predictor alone		Model including all variables	
Predictor	Unadjusted OR (95% to CI)	P-value	Adjusted OR (95% to CI)	<i>P</i> -value
Time of patients' appointment, pm	1.2 (0.1 to 1.5)	0.738	0.4 (0.4 to 4.1)	0.156
Patient age	1.0 (0.9 to 1.0)	0.168	1.0 (1.0 to 1.0)	0.138
Previous visits with doctor	0.8 (0.6 to 1.0)	0.041	0.9 (0.7 to 1.3)	0.680
If patient had more than one problem to discuss	0.8 (0.4 to 1.8)	0.643	1.8 (0.6 to 5.1)	0.274
Duration of main health problem	0.8 (0.7 to 1.0)	0.063	0.7 (0.4 to 1.2)	0.214
If discussed main health problem with a doctor before	0.4 (0.2 to 0.9)	0.022	0.3 (0.1 to 0.9)	0.040
If taking prescribed medication for main health problem	0.7 (0.4 to 1.2)	1.7	0.250 (0.7 to 3.9)	0.213
Patient sex, female	0.7 (0.4 to 1.3)	0.266	0.8 (0.2 to 2.8)	0.770
Patient ethnicity White Black Other	1.0 0.8 (0.3 to 1.8) 1.6 (0.7 to 3.9)	0.078	1.0 0.4 (0.1 to 1.5) 2.4 (1.0 to 6.1)	0.065
Patient highest qualification None Primary or secondary Tertiary Other	1.0 0.8 (0.3 to 2.1) 0.9 (0.3 to 2.7) 0.9 (0.5 to 2.0)	0.313	1.0 0.3 (0.0 to 1.5) 0.2 (0.0 to 1.1) 2.0 (0.6 to 7.1)	0.042
Doctor sex, female	1.1 (0.4 to 2.6)	1.2	0.893 (0.4 to 4.4)	0.727
Doctor ethnicity, non-white	1.8 (0.7 to 4.6)	4.4	0.222 (1.5 to 12.7)	0.006
Doctor age	1.0 (0.9 to 1.0)	1.0	0.360 (0.9 to 1.1)	0.472
Doctor decision-making preference <sup>a</sup>	1.0 (0.5 to 2.2)	0.5	0.919 (0.1 to 2.0)	0.309
Patient decision-making preference <sup>a</sup>	0.4 (0.3 to 0.5)	0.2	0.000 (0.1 to 0.4)	<0.001

estimated or overestimated their preferences with respect to patients' satisfaction, intention to take the medicines as decided in consultations, perceptions of their relationship with their GP, GPs' satisfaction, or their GPs' perception of their relationship (Table 4).

#### **DISCUSSION**

#### Summary of main findings

Thirty-nine per cent of patients wanted their GPs

to share the decision about treatment with them. Forty-five per cent wanted the GP to be the main (28%) or only (17%) decision maker. GPs accurately assessed patients' preferences for involvement in approximately a third of cases, overestimated patients' desire for involvement in nearly half, and underestimated them in a quarter. GPs were more likely to underestimate patients' preferred level of involvement when patients had not consulted about their condition before.

Table 4. Differences between outcomes for consultations where GPs underestimated patients' preferences for involvement compared with consultations where GPs overestimated or correctly gauged patients' preferences.<sup>a</sup>

	Mean (SD)		
Outcome	Under- estimated	Overestimated or correct	Difference between means (95% CI)
Patients' satisfaction with their decision-making role	4.56 (0.78)	4.73 (0.59)	0.17 (-0.1 to 0.4)
Patients' satisfaction with treatment decision	4.57 (0.70)	4.74 (0.49)	0.16 (-0.1 to 0.4)
Patients' intention to adhere to treatment decision	4.78 (0.53)	4.87 (0.48)	0.10 (-0.1 to 0.3)
Patients' satisfaction with GPs' communication	36.22 (5.85)	37.67 (3.59)	1.44 (-1.1 to 4.0)
Patients' perceptions of their relationship with GP	4.26 (0.89)	4.63 (0.57)	0.36 (0.0 to 0.8)
Patients' satisfaction with consultation	4.40 (0.91)	4.73 (0.46)	0.33 (0.0 to 0.7)
GPs' perceptions of their relationship with patients	4.05 (0.76)	4.20 (0.68)	0.15 (-0.2 to 0.5)
Doctors' satisfaction with consultation	4.14 (0.72)	4.17 (0.65)	0.03 (-0.3 to 0.4)
Poctors satisfaction with consultation <sup>a</sup> Adjusted for clustering by GP.	4.14 (0.72)	4.17 (0.65)	0.03 (-0.3 to

#### Strengths and limitations of the study

This study examined patients' and GPs' perceptions of involvement in decision making about medicines and not their actual involvement. However, perception is an important element in the dynamic equilibrium between expectation and experience and changes in perception are likely to be reflected in both. Patients' preferences were assessed for involvement in decision making and GPs' preferred role before the consultation, and GPs' perceptions of patients' preferred role were documented after each consultation. These interventions may have had an impact on patients' and GPs' behaviour during their consultations. However, as it was found that agreement between patients' preferences and GPs' perceptions of these preferences was low, the agreement in a normal clinical setting may be even lower without the stimulus of these questions.

In comparison to the patients who were excluded from the analyses because they did not identify the same most important medicine decision made as their GP, the patients included in the analyses were more likely to be consulting about only one health problem and to be taking prescribed medication for their main health problem before their consultation. Therefore, patients included in the analyses may not be representative of all the patients in the participating general practices. Analyses involved a small number of GPs (n = 18), although the number of patients was substantial (n = 190). The generalisability of the results may be further limited by the fact that the study was carried out in an inner city area. Inner city general practices have a high patient turnover; it might expected that GPs in other practices have longer relationships with their patients and, therefore, have more accurate perceptions of their patients' decision-making preferences.

Asking patients about their preferred level of involvement assumes that patients have an understanding about shared decision making and about the level of involvement they could have in decisions about medicines. GPs' views of the meaning of patient participation in medicine decision making may differ significantly from those of patients, so interpretation of the agreement between patients and GPs about patients' preferences for involvement should be guarded. Nonetheless, GPs appear to have expectations of greater patient involvement in decisions about their medications. They seem ready to engage with patients who want more input, whether or not their consulting skills and style lead to greater participation in those decisions.

The analysis focused on underestimation of patients' preferences by GPs because it was assumed that underestimation has greater potential for conflict with the interests of patients. Overestimation may also be important if the GP appears to imply that patients should take more responsibility in the decision than they want, or feel able to take.

#### Comparison with existing literature

The finding that GPs overestimated patients' preferences for involvement in over 45% of cases contrasts with previous research in which patients reported taking a more active role than they wanted in only 15% of consultations. There is evidence from a number of sources that patients do want to be involved in decisions about their health. CPs. GPs' overestimation of patients' preferences for involvement in decision making about medicines does not imply that patients achieved more involvement than they wanted. However, it may suggest that GPs are ready to offer

more involvement than patients want. GPs may not know how to encourage patients to become more involved in decision making and patients may not participate because they do not know how to have a more active role.

GPs were unlikely to underestimate patients' decision-making preferences if the patient had a preference for low involvement. While this appears self-evident, its importance in this analysis is that the association between the underestimation by GPs and the other variables remains significant even when controlling for patients' decision-making preferences (for example, when the patient had a preference for low involvement). An explanation cannot be supplied for the observation that GPs of Asian or other non-white ethnic origin (six of the 18 GPs) were more than four times as likely to underestimate the decision-making preferences of patients than white GPs. This may represent a Type 1 statistical error.

GPs were more likely to underestimate a patient's preference for involvement when the patient had not discussed his or her main health problem with a doctor before. However, having discussed the main health problem before was not a significant predictor of patients wanting to make medicine decisions alone or mostly alone. This might suggest that patients who have discussed their main health problem with a doctor previously feel they have already contributed enough and do not want to be more involved in decision making, although their GPs may think that they do.

The final factor associated with underestimation of patients' decision-making preferences was educational attainment. Patients with no formal educational attainment seemed to have been more likely to have their decision-making preferences underestimated compared with those with primary, secondary, or tertiary education. This finding contrasts with O'Connor et al's observation in Canada that responders were more likely to adopt a dependent role in decision making if they had less formal education.12 While this may reflect a tendency for doctors not to involve patients in whom they detect less experience of formal education, the confidence intervals indicate that this relationship is not easy to interpret. Yet, patients' level of education was not a significant predictor of their preferences for involvement in decision making.

Previous research has shown that patients whose participation in decision making matched their preferred level of involvement were more satisfied with their treatment choice and had greater reductions in their anxiety after their visit than patients whose preferred and actual roles did

not match.<sup>15–16</sup> However, it was found that GPs' underestimation of patients' preferences did not have a negative impact on patient or GP perceptions of the consultation or of their relationship. This may be because GPs' underestimation of their patients' preferences was not portrayed during the consultation or, at least, it was not detected by the patient.

### Implications for future research and clinical practice

Only a small minority of patients want the main say in decisions about medicines. However, GPs are not likely to predict accurately the degree to which patients want to be involved in decisions about medicines and are more likely to overestimate their preference for involvement. Therefore, GPs should consider checking patients' preferences with them. If it is accepted that patients should be enabled to share these decisions if they want to, GPs should particularly address the needs of patients who have not previously consulted about the clinical problem.

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#### **Ethics committee**

Ethical approval was given by the Guy's and St Thomas' Foundation NHS Trust Research Ethics Committee (03/02/11)

#### **Competing interests**

The authors have stated that there are none

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