Asthma patients can have considerable input into the management of their condition, often engaging in some degree of independent decision making for example, adjustment of treatment by following a personalised written asthma action plan.

There is increasing emphasis on providing services responsive to patients' needs and preferences. Equally, there is recognition that those with long term illnesses may be able to contribute to the conduct of a treatment regimen and participate in treatment decisions. There is good evidence in asthma that actively involving patients in care and treatment decision making improves outcomes.

While the desired level of participation in treatment decisions has been widely explored in some conditions, notably cancer, it is less well explored in other long term health problems—a notable omission since the satisfaction of these patients and their engagement with their treatment regimen are crucial to their long term maintenance. In asthma, other than our own prior exploratory work, only two studies have specifically addressed patients' preferred level of involvement in treatment decisions. At present we therefore have only a poor understanding of the decision making role preferences of patients with asthma and, importantly, of the reasons why they prefer particular roles in treatment decisions, whether these preferences can be predicted by, for example, demographic variables and the extent to which patients' preferences are met. The present study therefore sought to build on our earlier exploratory work with a more in-depth exploration of asthma patients' role preferences and the contributors to these.

**METHODS**

**Study design and aims**

The study was a cross sectional survey. Its aims were:

- to identify patients' preferred level of involvement in treatment decision making—that is, their decisional role preferences—and their rationales for these preferences;
- to identify patients' perceived level of involvement in treatment decision making;
- to assess congruence between patients' preferred and perceived roles in treatment decision making;
- to seek patients' views on facilitators of and barriers to their participation in treatment decisions; and
- to explore the relationship between decisional role preferences and demographic variables.

**Study sites and sample**

Patients were identified from asthma registers in 10 primary care sites and one specialist respiratory centre (2:1 ratio of primary care: specialist centre). Asthma affects adults of all ages and socioeconomic groups, occurring in both ethnic majority and minority populations and, in adults, is more prevalent in women than in men. These considerations were borne in mind within our recruitment strategy. Our exploratory work had indicated that recruitment from socially deprived areas was likely to be difficult. In order to ensure that the sample recruited represented views of respondents across the social spectrum, we over-represented general practices from socially deprived areas (five of the 10 sites). Individuals from minority ethnic groups were included (provision having been made for use of bilingual workers if necessary). However, as the study localities had only small ethnic minority populations, we anticipated that patients from such groups would make up only a small percentage of the sample. Patients were stratified within each site by age, sex, and disease severity.
If an individual declined to participate, a replacement from within the same stratum was identified in an endeavour to maintain balance across the strata. Inclusion criteria were age 18+; able to converse in English; clinician diagnosed asthma; prescription for at least bronchodilators in the last 12 months; non-smoker if aged 45 or over (to exclude possible COPD); no respiratory disease other than asthma.

Comparable studies in other conditions found that approximately 20% of respondents preferred an active decisional role. The nQuery Advisor software package for sample size calculation showed that estimation of the percentage of individuals selecting an active role to be 20% with a 95% confidence interval with half width of ±5% would require a sample of at least 226 patients.

Data collection methods and instrument
Data were collected face to face using a previously piloted structured interview schedule whose main component was the well-validated Control Preferences Scale (CPS). Its structured interview schedule whose main component was the well-validated Control Preferences Scale (CPS). Its transferability to asthma was assessed in our earlier exploratory work.

The CPS comprises five vignettes, each presented on a sort card (box 1). The scale is underpinned by a theoretical model of participation as a continuum from active through collaborative to passive—hence the sort cards can be considered individually or in terms of one of these three role types. Respondents choose the most preferred from randomly presented pairs of cards until all possible pairings of the five sort cards have been seen and an hierarchical preference order (from most to least preferred role) has emerged. Data were collected regarding perceived role in decisions using a second set of sort cards from which the words “I prefer” were omitted. Respondents selected the one card which most closely reflected their perceived role. Additional data were collected by means of open ended questions regarding rationale for role preference, barriers to and facilitators of participation, and circumstances which might alter role preference; responses were recorded verbatim. These procedures have been applied successfully in previous studies.

Demographic data collected were age, sex, socioeconomic status, highest educational level, ethnicity (as stated by respondent), asthma severity, and duration of condition.

Data analysis
Data were coded and entered into the SPSS statistical package (version 10.1). Data from open ended questions were thematically analysed and reduced prior to data entry. Decision making role preferences were reported as distributions based on whether an individual’s choice conformed with an active, collaborative, or passive role in decision making (box 1).

RESULTS
Two hundred and thirty adults with asthma (152 from primary care) were interviewed. Their demographic characteristics and asthma severity are shown in table 1. Deliberate inclusion of “difficult to reach” groups impacted on recruitment, with rates ranging from 25% in the most socially deprived site to over 60% in the most affluent site. The overall recruitment rate was 232/769 (30.2%); data from two patients were excluded as incomplete.

Preferred decisional role
The collaborative role (C) was the single most popular, selected by just over one third of respondents (table 2). More respondents preferred one of the passive roles (card D or E, 40.4%) than one of the active roles (card A or B, 23.9%). Card A was least preferred by 126 (54.8%), E by 98 (42.6%), compared with B (n = 3 respondents), C (n = 1), and D (n = 2). Box 2 presents common rationales for role preference and box 3 lists typical circumstances under which role preference would change.

Perceived decisional role
Most respondents (n = 166, 72.2%) considered that their role was either semi-passive or passive, so that they had little active involvement in treatment decisions (table 2).

Facilitators of and barriers to participation
Patient related, professional related, and organisational barriers to and facilitators of participation were identified, with patient-professional relationships and lack of time being most commonly commented upon (box 4).
Relationship between most preferred role and demographic variables/asthma severity

Decisional role preferences were compared by demographic group and severity of asthma (Table 3). Preferences were similar for patients from primary care and secondary care ($\chi^2$ test for trend = 0.26, df = 1, p = 0.61) and there was no significant association with sex ($\chi^2$ test for trend = 1.94, df = 1, p = 0.16), duration of condition (Kendall’s $\tau_b$ = 0.03, p = 0.54), or severity of asthma (Kendall’s $\tau_b$ = 0.07, p = 0.22). There were significant associations between role preferences and age (Kendall’s $\tau_b$ = 0.18, p < 0.001), highest level of education ($\chi^2 = 30.27$, df = 12, p = 0.003), and socioeconomic group (for the 139 in current employment, Kendall’s $\tau_b$ = 0.24, p<0.001). Older individuals typically (but not exclusively) preferred a more passive role, as did those with fewer educational qualifications and those from less skilled occupational groups. The result for educational qualifications should be interpreted with caution since most individuals with no qualifications were also above the mean age. Likewise, the smaller group sizes should be considered when interpreting findings for socioeconomic group.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Primary care (n = 152, 66.1%)</th>
<th>Specialist respiratory centre (n = 78, 33.9%)</th>
<th>Total sample (n = 230)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>51.2</td>
<td>53.3</td>
<td>51.9</td>
</tr>
<tr>
<td>Median</td>
<td>50.5</td>
<td>54.0</td>
<td>51.5</td>
</tr>
<tr>
<td>SD</td>
<td>16.7</td>
<td>13.4</td>
<td>15.6</td>
</tr>
<tr>
<td>Range</td>
<td>19–94</td>
<td>22–79</td>
<td>19–94</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>62 (40.8)</td>
<td>35 (44.9)</td>
<td>97 (42.2)</td>
</tr>
<tr>
<td>Women</td>
<td>90 (59.2)</td>
<td>43 (55.1)</td>
<td>133 (57.8)</td>
</tr>
<tr>
<td>Duration of condition (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>23.4</td>
<td>18.9</td>
<td>21.9</td>
</tr>
<tr>
<td>Median</td>
<td>18.5</td>
<td>15.0</td>
<td>17.3</td>
</tr>
<tr>
<td>SD</td>
<td>17.6</td>
<td>15.9</td>
<td>17.2</td>
</tr>
<tr>
<td>Range</td>
<td>0.5–77</td>
<td>1–62</td>
<td>0.5–77</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal qualifications</td>
<td>32 (21.1%)</td>
<td>17 (21.8%)</td>
<td>49 (21.3%)</td>
</tr>
<tr>
<td>Sub-degree</td>
<td>44 (28.9%)</td>
<td>22 (28.2%)</td>
<td>66 (28.7%)</td>
</tr>
<tr>
<td>Degree and above</td>
<td>33 (21.8%)</td>
<td>12 (15.4%)</td>
<td>45 (19.6%)</td>
</tr>
<tr>
<td>Professional/work related qualifications</td>
<td>43 (28.3%)</td>
<td>27 (34.6%)</td>
<td>70 (30.4%)</td>
</tr>
<tr>
<td>Socioeconomic group (after NS-SEC&lt;sup&gt;2&lt;/sup&gt;)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (higher managerial and professional)</td>
<td>29 (19.1%)</td>
<td>14 (17.9%)</td>
<td>43 (18.7%)</td>
</tr>
<tr>
<td>2 (lower managerial and professional)</td>
<td>22 (14.5%)</td>
<td>8 (10.3%)</td>
<td>30 (13.0%)</td>
</tr>
<tr>
<td>3 (intermediate)</td>
<td>10 (6.6%)</td>
<td>5 (6.4%)</td>
<td>15 (6.5%)</td>
</tr>
<tr>
<td>4 (small employers and own account workers)</td>
<td>1 (0.7%)</td>
<td>0</td>
<td>1 (0.4%)</td>
</tr>
<tr>
<td>5 (lower supervisory and technical)</td>
<td>4 (2.6%)</td>
<td>1 (1.3%)</td>
<td>5 (2.2%)</td>
</tr>
<tr>
<td>6 (semi-routine)</td>
<td>20 (13.2%)</td>
<td>7 (9.0%)</td>
<td>27 (11.7%)</td>
</tr>
<tr>
<td>7 (routine)</td>
<td>10 (6.6%)</td>
<td>8 (10.3%)</td>
<td>18 (7.8%)</td>
</tr>
<tr>
<td>8 (never worked and long term unemployed&lt;sup&gt;4&lt;/sup&gt;)</td>
<td>8 (5.3%)</td>
<td>8 (10.3%)</td>
<td>16 (7.0%)</td>
</tr>
<tr>
<td>Student</td>
<td>3 (2.0%)</td>
<td>2 (2.6%)</td>
<td>5 (2.2%)</td>
</tr>
<tr>
<td>Retired</td>
<td>45 (29.6%)</td>
<td>25 (32.1%)</td>
<td>70 (30.5%)</td>
</tr>
<tr>
<td>Asthma severity (after BTS/SIGN&lt;sup&gt;6&lt;/sup&gt;)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1 (mild intermittent asthma)</td>
<td>20 (13.2%)</td>
<td>3 (3.8%)</td>
<td>23 (10.0%)</td>
</tr>
<tr>
<td>Step 2 (introduction of regular preventer therapy)</td>
<td>68 (44.7%)</td>
<td>24 (30.8%)</td>
<td>92 (40.0%)</td>
</tr>
<tr>
<td>Step 3 (add-on therapy)</td>
<td>37 (24.3%)</td>
<td>18 (23.1%)</td>
<td>55 (23.9%)</td>
</tr>
<tr>
<td>Step 4 (poor control on moderate dose of inhaled steroid + add-on therapy: addition of fourth drug)</td>
<td>25 (16.4%)</td>
<td>25 (32.1%)</td>
<td>50 (21.7%)</td>
</tr>
<tr>
<td>Step 5 (continuous or frequent use of oral steroids)</td>
<td>2 (1.3%)</td>
<td>8 (10.3%)</td>
<td>10 (4.4%)</td>
</tr>
</tbody>
</table>

*Includes housewives and registered disabled.

Table 2 Most preferred and perceived role, with comparison between the two (n = 230)

<table>
<thead>
<tr>
<th>Most preferred role</th>
<th>A (fully active)</th>
<th>B (semi-active)</th>
<th>C (collaborative)</th>
<th>D (semi-passive)</th>
<th>E (fully passive)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A (fully active)</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>14 (6.1%)</td>
</tr>
<tr>
<td>B (semi-active)</td>
<td>2</td>
<td>7</td>
<td>16</td>
<td>8</td>
<td>8</td>
<td>41 (17.8%)</td>
</tr>
<tr>
<td>C (collaborative)</td>
<td>0</td>
<td>4</td>
<td>21</td>
<td>36</td>
<td>21</td>
<td>82 (35.7%)</td>
</tr>
<tr>
<td>D (semi-passive)</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>29</td>
<td>25</td>
<td>61 (26.5%)</td>
</tr>
<tr>
<td>E (fully passive)</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>12</td>
<td>18</td>
<td>32 (13.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>4 (1.7%)</td>
<td>15 (6.5%)</td>
<td>45 (19.6%)</td>
<td>87 (37.8%)</td>
<td>79 (34.4%)</td>
<td>230</td>
</tr>
</tbody>
</table>

Numbers in bold (on leading diagonal) indicate that perceived role equals most preferred role. Numbers in italics (above leading diagonal) indicate that perceived role is less active than most preferred role. Numbers in normal font (below leading diagonal) indicate that perceived role is more active than most preferred role.
Various ordinal logistic regression models were fitted to explore the prediction of most preferred role from age and highest level of education. The results suggested that the effect for age adjusted for education remained highly significant, while that for education adjusted for age tended to be significant for degree level and above and, to a lesser extent, for professional or work related qualifications compared with no formal qualifications.

DISCUSSION

The findings of this study confirm the results of previous work,²⁰⁻²² in showing that respondents had identifiable preferences, from active through to passive, regarding their level of participation in treatment decision making. The study adds new knowledge regarding contributors to these preferences, the role of demographic variables in determining role preferences, and the extent to which patients’ preferences were met. While the focus of this study was asthma, the findings address aspects of provider-patient consultations which may have relevance in other long term health problems.

The substantial mismatch between respondents’ most preferred and perceived decisional roles is the most notable finding in this study. This was especially marked in those preferring an active role. Most respondents felt they had little expertise, or depth of knowledge to make a decision on their own. And if they lost ‘faith’ or ‘confidence’ in the doctor – I go in and tell him what’s wrong and what I want!” (laughs). (PC125, preference order BCDEA)

‘I suppose because you’ve got more control over your own destiny. I like to be able to question why and feel that I’ve had a say, I suppose, I wouldn’t like to feel that I’ve had something imposed on me.” (SC055, preference order BDCEA)

‘Past experience – we [self and spouse] have been in contact with lots of doctors and sometimes doctors make the wrong decision. You come to a point where you feel you’ve tried everything and you’ve got to make your own decisions. I do respect doctors’ opinions, but they have got to respect yours. You’re just paying them to do a job like anyone else – I think a lot of people forget that.” (SC041, preference order CBDEA)

Box 2 Common rationales for role preference: illustrative data extracts

**Active role (cards A and B)**

‘Rightly or wrongly, I am inclined to like to make decisions for myself. I’m not saying I’m right – I just like to make the choice myself, to be honest.” (PC098, preference order ABCDE)

‘Because I think it’s about personal choice. I’ve been an asthmatic since I was a baby. And I was basically addicted to my Ventolin – I was getting through four a month! And nobody picked it up. So I changed GP and it was picked up. I went to the GP and said: ‘I think I’m addicted and I want to change it’ and they said ‘Fine’ .... And I think it’s too easy to fall into the trap of letting the doctor make all the decisions for you, whereas I tend to have a more equal relationship with my doctor – I go in and tell him what’s wrong and what I want!” (laughs). (PC125, preference order ABCDE)

‘I suppose because you’ve got more control over your own destiny. I like to be able to question why and feel that I’ve had a say, I suppose, I wouldn’t like to feel that I’ve had something imposed on me.” (SC055, preference order BCDEA)

‘Past experience – we [self and spouse] have been in contact with lots of doctors and sometimes doctors make the wrong decision. You come to a point where you feel you’ve tried everything and you’ve got to make your own decisions. I do respect doctors’ opinions, but they have got to respect yours. You’re just paying them to do a job like anyone else – I think a lot of people forget that.” (SC041, preference order CBDEA)

**Collaborative role (card C)**

‘I want to be involved – to be involved in knowing what’s happening to my body and in what medications I am using. Especially with medicines – I like to be able to feedback on how they are affecting me. It’s a two-way thing.” (PC021, preference order CDEBA)

‘Because obviously I haven’t got the knowledge, the range or depth of knowledge to make a decision on my own. And if it’s yourself, you’re not completely objective either. But it’s my body, so I should have a very big say in what happens. So a balance is probably best. There’s no point in me taking the final decision, as I haven’t got the correct knowledge for that.” (PC033, preference order CBDEA)

**Passive role (cards D and E)**

‘Well, I mean, that’s what they’re there for, that’s what they’re trained for. I’d like to have a little say, but at the end of the day, it’s his decision. It’s no use going to a specialist or consultant if you’re not going to take his advice.” (PC138, preference order DCBEA)

‘Well, two reasons – from his point of view, he has got the expertise, but I could bring my own individual symptoms and suggest occasionally could I try things. But obviously, the final decision is down to him, after my input.” (SC030, preference order DCBEA)

‘Because I haven’t got a clue about medications. And obviously, my doctor’s been in the field for years and knows what he’s talking about, so obviously you’re going to trust him.” (SC014, preference order ECDBA)

‘I don’t believe I’m competent to influence the decision too much. So I trust someone who’s been to medical school for seven years, unlike me, who hasn’t! … I have touching faith in professionals. I accord them the respect in their field that I hope and expect they’d accord me in mine. So it’s a matter of professional courtesy.” (PC033, preference order EDCBA)

Box 3 Common themes regarding circumstances under which respondents’ role preferences would change

**Role preference would be more active than usual if:**
- The treatment was not perceived to be working or was perceived to be causing harm
- The respondent lost “faith” or “confidence” in the doctor
- The doctor was unfamiliar or was not their “usual” doctor
- The respondent knew more about their condition and the available treatments
- The decision was a “serious one” (for example, one with potential hazards, long term implications)

**Role preference would be less active than usual if:**
- The respondent was seriously ill (for example, having an asthma attack) or physically incapacitated (for example, unconscious) at the decisional juncture
- The respondent was mentally incapable of participating in the decision making (for example, due to dementia)
- The respondent was faced with a decision regarding an aspect of care (for example, a treatment) about which they felt they knew little
- The disease was a “more serious” one than asthma (for example, cancer)
- The respondent felt there was only one option available/suitable, hence there was not really a choice to be made

Various ordinal logistic regression models were fitted to explore the prediction of most preferred role from age and highest level of education. The results suggested that the effect for age adjusted for education remained highly significant, while that for education adjusted for age tended to be significant for degree level and above and, to a lesser extent, for professional or work related qualifications compared with no formal qualifications.

**DISCUSSION**

The findings of this study confirm the results of previous work,²⁰⁻²² in showing that respondents had identifiable preferences, from active through to passive, regarding their level of participation in treatment decision making. The study adds new knowledge regarding contributors to these preferences, the role of demographic variables in determining role preferences, and the extent to which patients’ preferences were met. While the focus of this study was asthma, the findings address aspects of provider-patient consultations which may have relevance in other long term health problems.

The substantial mismatch between respondents’ most preferred and perceived decisional roles is the most notable finding in this study. This was especially marked in those preferring an active role. Most respondents felt they had little or no say in treatment decisions and, in common with the sample studied by Adams et al.,¹¹ many would have liked to be more involved. The communication skills of professionals are considered to be central to facilitating patient participation.²⁻²⁵ Our findings confirm this view, and many respondents identified communication as an area requiring improvement. Furthermore, it appears that, rather than
Involvement in treatment decisions in asthma 203

Box 4 Common themes regarding facilitators of patient involvement in treatment decision making

- Continuing care
- Health professionals having sufficient knowledge and information
- Health professionals’ being willing to listen and to acknowledge patients’ perspectives and insights
- Patients’ lack of knowledge regarding the condition
- Lack of time during consultations
- Patients’ being assertive and expressing their views and preferences
- Health professionals’ willingness to listen and to acknowledge patients’ expertise
- Patients’ recognizing and responding to the range of patient preferences and characteristics of the patient (for example, health professionals’ personal characteristics, the patient being in a life-threatening situation)
- Professional education and training in patient centred communication skills
- Workshops (jointly with service users)
- Use of taped consultations
- Recognizing and responding to the range of patient preferences and characteristics of the patient
- Partnerships working
- Use of specific shared decision-making training packages or programmes
- Use of personal involvement in treatment decisions

Table 3 Decisional role preferences by subgroup

<table>
<thead>
<tr>
<th>Most preferred role type (and role)</th>
<th>Care type</th>
<th>Age group</th>
<th>Duration of condition (years, n = 230)</th>
<th>Highest level of education (n = 230)</th>
<th>Socio-economic group (n = 139)</th>
<th>Asthma severity (after BTS/SIGN6)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Primary</td>
<td>Secondary</td>
<td>Older</td>
<td>None</td>
<td>Sub-degree</td>
<td>Degree</td>
</tr>
<tr>
<td></td>
<td>(n = 152)</td>
<td>(n = 78)</td>
<td>(n = 115)</td>
<td>(n = 133)</td>
<td>(n = 66)</td>
<td>(n = 45)</td>
</tr>
<tr>
<td>Active</td>
<td>36 (23.7)</td>
<td>24 (29.5)</td>
<td>13 (23.5)</td>
<td>31 (23.7)</td>
<td>9 (9.6)</td>
<td>10 (10.9)</td>
</tr>
<tr>
<td>A</td>
<td>10 (6.3)</td>
<td>21 (26.9)</td>
<td>16 (27.6)</td>
<td>16 (23.7)</td>
<td>13 (16.7)</td>
<td>24 (31.3)</td>
</tr>
<tr>
<td>B</td>
<td>26 (17.1)</td>
<td>4 (5.1)</td>
<td>2 (3.4)</td>
<td>24 (18.0)</td>
<td>8 (10.4)</td>
<td>13 (18.7)</td>
</tr>
<tr>
<td>Collaborative: C</td>
<td>63 (45.9)</td>
<td>48 (61.5)</td>
<td>97 (84.0)</td>
<td>6 (46.2)</td>
<td>15 (21.4)</td>
<td>26 (35.6)</td>
</tr>
<tr>
<td>Passive</td>
<td>37 (25.7)</td>
<td>22 (28.2)</td>
<td>15 (27.6)</td>
<td>25 (10.2)</td>
<td>4 (5.3)</td>
<td>10 (14.9)</td>
</tr>
<tr>
<td>D</td>
<td>39 (25.7)</td>
<td>22 (28.2)</td>
<td>25 (41.5)</td>
<td>31 (50.0)</td>
<td>16 (25.4)</td>
<td>28 (42.6)</td>
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<tr>
<td>E</td>
<td>24 (15.8)</td>
<td>8 (10.3)</td>
<td>1 (1.5)</td>
<td>18 (18.6)</td>
<td>6 (4.6)</td>
<td>16 (22.4)</td>
</tr>
<tr>
<td>Total</td>
<td>152 (100)</td>
<td>78 (100)</td>
<td>132 (158)</td>
<td>72 (100)</td>
<td>24 (100)</td>
<td>70 (100)</td>
</tr>
</tbody>
</table>

Numbers in parentheses are percentages.

*Younger age group: < mean age (52 years); older age group: > mean age.

1Calculated only for those currently in work (n = 139). 1 and 2, professional and managerial; 3–5, technical, administrative and self-employed; 6 and 7, routine and semi-routine.
special interest in asthma care and/or a nurse led asthma clinic. The most commonly cited organisational barrier to patient participation was lack of time during consultations. It has been suggested that a consultation of at least 20 minutes’ duration is required to facilitate patient participation. With health care under increasing pressure, it is hard for health professionals to find time for asthma patients who need it, suggesting the need to consider alternative means of providing asthma patient review and education. Telephone consultations have been shown to be time efficient and cost effective means of providing asthma education and review management. Other alternatives such as lay/peer led asthma patient education need to be validated before widespread introduction.

Asthma is a long term condition (mean 22 years in this sample) in which self-management and participation in treatment decision making are encouraged—for example, recent guidelines recommend providing individualised written asthma action plans as these promote self-management and involvement in decision making with resultant improvement in outcomes. It was therefore interesting to see that some 40% of patients most preferred one of the passive decisional roles (card D or E from the CPS). These patients’ decisional role preferences might seem to be at variance with current thinking among health professionals, policy makers, and patient advocacy groups. However, examination of rationales for role preference reveals a more complex picture. The most passive option (card D) was least preferred by nearly half the respondents. Furthermore, twice as many of those preferring a passive role chose card D—which involves some, if limited, patient involvement—rather than card E where the patient entirely defers decision making to health professionals. Thus, most respondents wanted some input into decision making. Typically, this extended to individuals feeling included in the decision and having their views respected. While most respondents in this sample were happy to defer overall control of treatment decision making to professionals, our data encourage the notion of partnership.

It is important to identify individual role preferences. Role preference was not strongly associated with demographic variables and may change at different times and in different situations; thus, an individual who would wish to be passive in an emergency situation might feel able to be more actively involved in treatment decision making on a day to day basis. The low overall response rate is acknowledged as a limitation. However, this largely resulted from inclusion of “difficult to reach” groups. Given the higher response rates from affluent areas, had we not over-represented socially deprived areas in the primary care sites (by having five out of 10 from socially deprived areas), responses would have been very skewed towards affluent, well educated individuals whose views may not have been representative of the full social and educational spectrum. As can be seen from table I, our chosen approach ensured that viewpoints from a range of educational and social backgrounds were represented. This cross sectional study involved only adults and was racially homogenous. Further work is needed in children/adolescents and also in other ethnic groups. Longitudinal data would also show how role preferences change over time and in different circumstances.

In conclusion, the findings from this study suggest that adults with asthma are readily able to identify their preferred level of involvement in treatment decision making and that this could not be predicted from demographic variables or measures of disease severity. Most patients wished to have some involvement in treatment decision making, but not necessarily to control it. Most considered that they were less involved in treatment decision making than they would have preferred. Respondents identified patient related, provider related, and practical/organisational barriers to participation, highlighting the need for professional and patient education regarding partnership working, skilful communication, and innovative approaches to service delivery.

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Involvement in treatment decisions in asthma

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