

# PSYCHIATRIC SERVICES

## What do outpatients with schizophrenia and mood disorders want to learn about their illness?

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| Journal:            | <i>Psychiatric Services</i>                             |
| Manuscript ID:      | APPI-PS-00382-2012                                      |
| Manuscript Type:    | Regular Article   |
| Subject Categories: | Social psychiatry - PS0259, Outpatient clinics - PS0318 |
|                     |   |

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**What do outpatients with schizophrenia and mood disorders want to learn about their illness?**

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**Acknowledgments:**

The authors would like to thank BLIND and his team at BLIND for facilitating data collection in outpatient clinics.

**Disclosures:**

None for any author

**Correspondence:**

BLIND

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**Abstract***Objective:*

Psychiatric patients currently have access to a plethora of information about their illness. However, it is not clear what their precise information needs are, and therefore which information sources are worth investing in. To date there has been little systematic research exploring what psychiatric patients would like to learn about their illness. The present study aims to address this by answering the following: 1. What do outpatients with schizophrenia and mood disorder want to learn about their illness? 2. How do they want to learn about their illness?

*Methods:*

An exploratory survey of psychiatric outpatients was conducted between April 2011 and June 2012. Outpatients with a diagnosis of either schizophrenia/related (ICD10: F20-29) or mood disorder (ICD10: F30-39) were assessed after routine meetings with their psychiatrist. Interviews were conducted using open and closed questions in outpatient clinics across East London, UK. Open questions were analysed qualitatively and closed questions quantitatively.

*Results:*

Over two thirds of psychiatric outpatients would like to learn more about their illness. Overall, patient wishes for learning are mainly heterogeneous. However, both groups ranked 'the cause of the illness' as their top information need. Patients prefer to learn about their illness through one-to-one conversations with their psychiatrist.

*Conclusions:*

There is no 'one-size-fits-all' when it comes to educating patients about their illness. Healthcare professionals need to be sensitive to individual learning preferences. The results have implications for the training of psychiatrists. In particular, psychiatrists need to be equipped to address patient questions on 'the cause of the illness.'

## Background

Since at least the 1970s, the consumer movement has led patients to expect to have more of a say in their treatment (1). Evidence suggests that the majority of patients have a high desire for information regarding their medical care and want to take some part in discussing and deciding therapeutic decisions (2-4). This is reflected in the current United Kingdom (UK) legislation that seeks to put patients at the heart of the medical decision making process: ‘Shared decision-making will become the norm: No decision about me without me’ (5). In mental health care, there is encouraging evidence that providing psychiatric patients with information relating to the risks and benefits of medication, or choices of treatment, increases their engagement with services and compliance with treatment (6-8).

There is a wide consensus that patients need to be informed about their illness and provided with information relevant to their own circumstance, in order for them to become ‘active partners’ in their care (9). As such, various therapeutic interventions have been developed to meet patient information needs. ‘Psychoeducation’ (10, 11) describes any programme involving interaction between an information provider and service users or their carers, which has the primary aim of offering information about the condition. As to its role in mental health care, there is evidence that patients with bipolar disorder who attend psychoeducation groups are less likely to relapse, more likely to adjust to their symptoms post episodically and adhere to their medication (12-14). Guidelines of the National Institute of Clinical Excellence in the UK recommend for bipolar disorder that clinicians offer psychoeducation (15). For patients with schizophrenia, the evidence for effectiveness is less clear (16).

Despite a lack of consensus on whether psychoeducation is effective for all psychiatric patients, all patients still have a need and right to obtain information on their condition. This is reflected in the assortment of patient learning initiatives that health care providers and service user groups have produced in recent years. For example, ‘psychosis seminars’ – a model that started in Germany in the 1990’s and has gained increasing popularity in other European countries (17-20). The

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3 aim of psychosis seminars is for patients to meet together with healthcare professionals and family  
4 members/carers to discuss the illness from their perspective. Everyone is regarded as an expert with  
5 respect to their own role and experience. Additionally, service user-groups often run information  
6 exchange events, and provide useful information sheets on their websites (e.g.  
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11 <http://www.florid.org.uk/>).

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14 Although it is encouraging that a variety of learning initiatives already exist, they are neither  
15 widely implemented nor standardised. This may be because it is not clear which of these  
16 interventions, if any, really meets the information needs of patients. To date, there has been little  
17 research on precisely what psychiatric patients really want to learn about their illness. Yet,  
18 establishing the wishes of these patients is essential in order to design both acceptable and effective  
19 learning opportunities and to include patients in the decision making process. To the authors'  
20 knowledge only one study has assessed the educational needs of psychiatric patients directly (21).  
21 Patients with schizophrenia and mood disorders were asked to rank educational topics in order of  
22 most importance. The highest topics were: 'getting what you need from the mental health system',  
23 'early warning signs of the illness and relapse' and 'psychiatric medications.' However, this data is  
24 now more than 20 years old and was based on a relatively small sample. The present study seeks to  
25 re-investigate the educational needs of patients with schizophrenia and mood disorders, as these are  
26 the most common disorders amongst psychiatric outpatients in secondary care. The aims of the  
27 present study are to: 1. Explore what outpatients want to learn about their illness. 2. Identify how they  
28 would like to learn this information.  
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## 45 **Methods**

### 46 *Study Design*

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49 The study was an exploratory survey of psychiatric outpatients using a questionnaire  
50 containing a mixture of open and closed questions. The study was granted ethical approval from the  
51 East of England NRES Ethics Committee (REC reference: 11/EE/0072).  
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### *Learning experiences questionnaire*

A 'learning experiences' questionnaire was developed by the authors for the purpose of this study (available on request). It was designed with the assistance of five service users diagnosed with a mood disorder or schizophrenia in East London, and piloted in outpatient clinics on a similar sample before being refined. The questionnaire covered four general domains: patient characteristics (age, gender, occupation, ethnicity, education, living situation, diagnosis, length of illness); previous experience of learning about their illness (what they have learnt, who have they learnt from, who was the most/least helpful); wishes for more learning (satisfaction with past information, wishes to learn more, topics they would like to learn more about, from whom/what format); and views of group learning interventions (previous/considered attendance at learning groups). Closed questions typically had multiple choice answers and open questions asked patients to elaborate on their choices. 'Satisfaction with past information' was scored on a Likert-type scale from 0-10, where 0 represented 'very unsatisfied' and 10 'very satisfied.'

### *Participants*

Participants were recruited from psychiatric outpatient clinics across the three boroughs of East London NHS Foundation Trust, UK (Newham; City and Hackney; Tower Hamlets). Patients included in the study were those who at time of approach: were a current adult patient in secondary mental health care, attending an outpatient clinic, aged 18 – 70, had a primary diagnosis of schizophrenia/related disorder (ICD-10: F20-29) or a mood disorder (ICD-10: F30- 39), had a sufficient command of English to understand the instructions and questions, and were able to provide written informed consent.

### *Procedure*

Psychiatrists and administrative staff in outpatient clinics were contacted by a researcher to establish whether any patients in the forthcoming clinic would fulfil the inclusion criteria. On the day of their appointment, eligible patients were approached by their psychiatrist about research

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3 participation. Interested patients were introduced to the researcher after their meeting with the  
4 psychiatrist. The researcher provided a complete description of the study and obtained written  
5 informed consent. Patients were guided through the questionnaire and received £10 upon completion.  
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7 Qualitative data were analysed using content analysis. Quantitative data were analysed using  
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9 descriptive statistics. Chi-square and t-tests were performed to analyse differences between diagnostic  
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11 groups. All data analysis was conducted using the statistical package SPSS (PASW Statistics 18).  
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## 15 16 **Results**

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19 Figure 1 shows a CONSORT diagram of the number of patients included and excluded in the  
20 study. Although 290 patients were screened as eligible during the period of April 2011 to June 2012,  
21 data were collected from a total of 202 patients (106: schizophrenia/related, 96: mood disorder) giving  
22 a 70% response rate. The remaining 88 who did not complete the questionnaire were either too unwell  
23 to participate (N = 31), did not want to take part in research (N =22), did not have the time (N = 15),  
24 were not approached due to clinician forgetfulness (N = 13), or had other reasons (N = 7).  
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### 31 32 *Patient characteristics*

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35 The characteristics of the sample (split by diagnosis) are summarised in Table 1.

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38 Insert Table 1 about here

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41 More males with schizophrenia and more females with mood disorder were interviewed.  
42 However, these differences were not statistically significant. Mean ages were 45.9 years (11.0 SD) for  
43 patients with schizophrenia, and 44.2 years (SD 12.3) for mood disorder. Again this difference was  
44 not significant. The majority were of white ethnic background, unemployed, had no formal  
45 qualifications, and were just as likely to be living alone as with others. Patients had been suffering  
46 from their illness for an average of 13.9 (SD10.5) years. Those with schizophrenia were marginally  
47 more likely to have been unwell for a longer period of time (15.2 years vs. 12.5 years), although not  
48 statistically different.  
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3 *Previous patient learning experiences*  
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6 Patients reported moderate satisfaction with the amount of information they currently receive  
7 about their illness, scoring an average (mean) of 6.5 (SD 2.7) on the satisfaction scale. Although the  
8 full range of scores were used, the data was negatively skewed with the median value at 7, suggesting  
9 that patients tended to rate in the higher portion of the scale more than consistently across it.  
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14 Table 2 shows from whom or where patients have received the most information about their  
15 illness.  
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22 The majority of patients (84%, N = 170/202), named the psychiatrist as one of their main  
23 sources of information. 54% (N = 92/170) of those who identified the psychiatrist as one of their  
24 sources also labelled them the most helpful. The most frequent reasons why were: 's/he provides  
25 simple, clear explanations' (N = 17), and 'teaches me something specific' (N = 16). 60% of patients  
26 who identified the General Practitioner (GP) as an information source also labelled them the least  
27 helpful (N = 52/86). The most frequent reason given was that 'they don't have enough time for you'  
28 (N = 14).  
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37 *Current learning needs as identified by patients*  
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40 Over two-thirds of patients (68%, N = 138/202) reported that they would like to learn more  
41 about their illness. The top reasons given by the other 32% (N = 64/202) as to why they did not wish  
42 to learn more were: 'I am satisfied with what I know already' (N = 37), and 'knowing more would be  
43 detrimental to my condition' (N = 10). There was a significant relationship between 'wanting to learn  
44 more about their illness' and 'diagnosis'.  $\chi^2(1, N = 202) = 3.78, p = .05$ . Patients who had a diagnosis  
45 of schizophrenia were less likely to want to learn more about their illness. 38% of patients with  
46 schizophrenia didn't want to learn more about their illness (N = 40/106), in comparison to 25% of  
47 patients with mood disorder (N = 24/96).  
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3 In terms of specific information provision, patients identified that in the past they have learnt  
4 the most about 'the general nature of the illness' (58% of patients with schizophrenia, N = 62/106  
5 vs. 72% with mood disorder, N = 68/95<sup>1</sup>) and 'medication' (68%, N = 72/106 vs. 61%, N = 58/95)  
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8 However, there seems to be some discrepancy between the information patients have received in the  
9 past and their current learning needs. Table 3 displays the topics patients would like to learn more  
10 about.  
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19 Although patient wishes are mostly heterogeneous, the top information need, consistent  
20 across diagnostic categories, was 'the cause of the illness' (rated by 62% of patients with  
21 schizophrenia, N = 41/66, vs. 57% with mood disorder, N = 41/72).  
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26 When asked from whom/where patients would like to learn more about their illness, the  
27 majority of patients mentioned they would like to learn more from a psychiatrist (74% of patients with  
28 schizophrenia, N = 49/66 vs. 76% with mood disorder, N = 55/72), followed by a GP (44%, N =  
29 29/66 vs. 49%, N = 35/72). This information is displayed in Table 4.  
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38 In terms of information delivery and format, Table 5 illustrates how patients would like this  
39 information to be given to them.  
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46 The vast majority would prefer to learn about their illness through one-to-one conversations  
47 with their chosen professional (92% of patients with schizophrenia, N = 61/66 vs. 84% with mood  
48 disorder, N = 65/72). Printed leaflets and information packs followed as second and third preferences.  
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50 Again there was little difference between the preferences of diagnostic groups here, although patients  
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55 <sup>1</sup> One patient with a mood disorder reported that they had never learnt anything about their illness in the past,  
56 therefore total N = 95 rather than 96 in this instance.  
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3 with mood disorder were significantly more likely to want to receive information via email (21%, N =  
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5 15/72 vs. 6%, N = 4/66).  $\chi^2(2, N = 138) = 10.11, p = .006$ .

#### 6 7 8 *Patient views of group learning interventions*

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11 The majority of patients reported never having attended a learning group before; specifically  
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13 neither a psychosis seminar (75% of patients with schizophrenia, N = 80/106 vs. 91% with mood  
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15 disorder, N = 87/96) or a psychoeducation group (93% vs. 91%). However, a small proportion of the  
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17 patients who hadn't been before would consider attending a psychosis seminar (48% of patients with  
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19 schizophrenia, N = 38/80 vs. 47% with mood disorder, N = 41/87) or psychoeducation group in the  
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21 future (58% vs. 60%). Patients would consider attending a psychoeducation group to 'learn and  
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23 understand more' (reason given by 40% of patients with schizophrenia, N = 23/57 vs. 29% with mood  
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25 disorder N = 15/52), or a psychosis seminar to 'share own and hear other people's experiences of the  
26  
27 illness' (37% of patients with schizophrenia, N = 14/38 vs. 34% with mood disorder, N=14/41). Other  
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29 patients however, were put off attending either group because of 'the format of the sessions.' (10% of  
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31 patients with schizophrenia, N = 8/84 vs. 21% with mood disorder, N = 17/81).

### 32 33 34 **Discussion**

#### 35 36 37 *Main Findings*

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39 The majority of psychiatric outpatients want to learn more about their illness. However, a  
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41 third of overall patients do not, and this was more likely in patients with schizophrenia. Although  
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43 patients have received some information in the past about their illness, specifically, patients with both  
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45 schizophrenia and mood disorders wish to learn more about 'the cause of the illness.' They would  
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47 ideally like to learn this information through one-to-one conversations with their psychiatrist,  
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49 supplemented by information packs and leaflets.

#### 50 51 52 53 *Strengths and Limitations*

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3 The main strengths of this research are that we systematically asked patients about their  
4 learning experiences and wishes, the questionnaire was not focused on evaluating one specific  
5 educational approach, and that we included patients with both schizophrenia and mood disorders. In  
6 addition, the sample size was much larger than the only other study investigating psychiatric patient  
7 learning experiences (21) which interviewed 60 patients.  
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14 However, the study has also limitations. The sample was limited to outpatients in secondary  
15 mental health care in East London. All patients were also interviewed directly after seeing their  
16 psychiatrist, which may have influenced their ‘most helpful source’ responses. It is also unclear  
17 whether outpatients in rural areas, in inpatient settings, in primary care and in other countries share  
18 the same experiences and wishes. In this exploratory study we did not adjust the statistical tests of  
19 difference between the two diagnostic groups for multiple testing.  
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### 27 *Implications*

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30 The findings show that outpatients currently receive most of their information on  
31 ‘medication’ and ‘the general nature of the illness’. These results are consistent with Mueser’s study  
32 on learning preferences (21) and a study investigating the topics psychiatrists and patients tend to  
33 discuss in outpatient clinics (McCabe et al, 2012). The latter found that approximately half of all  
34 decisions made in psychiatric outpatient consultations are medication related. However, our results  
35 also suggest that patients are not primarily interested in learning about their medication. Rather, they  
36 are interested in gaining more information on ‘the cause of the illness.’ Perhaps, psychiatrists feel  
37 more confident talking about medication as opposed to the cause. With respect to medication,  
38 psychiatrists can explain the known effects and side effects whilst they might struggle to outline the  
39 causes of illness. Causes are likely to be multi-factorial and impossible to specify with certainty for  
40 individual patients. Indeed Baillie et al. (22) found that psychiatrists vary widely in their views of the  
41 aetiology of mental disorders, and tend to hold disorder specific views. Therefore patients are more  
42 likely to encounter different answers to the question of cause depending on their illness and  
43 psychiatrist.  
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3 A clear implication of the findings is that no 'one size fits all' approach will meet the  
4 information needs of all patients. Attempts to roll out existing approaches - such as psychoeducation  
5 groups - to all patients are likely to fail since they are simply not in line with what all patients want.  
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7 When established methods such as psychoeducation groups are evaluated or new initiatives  
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9 developed, researchers and clinicians should be aware that each approach is likely to appeal only to a  
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11 limited clientele.  
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16 A considerable number of patients do not want any more information. This may or may not  
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18 be a rational attitude but clinicians should be aware of it and consider these wishes when  
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20 communicating with patients, in particular those with schizophrenia. Future research may explore  
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22 how information that is seen as acceptable and useful can be provided for these patients.  
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25 Although much information is available on the internet or through other sources, psychiatrists  
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27 – at least for the time being – are still seen as the most important source of information for psychiatric  
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29 outpatients. The evidence is encouraging, as it suggests that psychiatrists cannot be fully replaced by  
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31 the internet or other professionals as the primary source of information. Patients appear to trust their  
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33 psychiatrists when it comes to reliable information about their illness, which reflects the high level of  
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35 trust patients have towards psychiatrists as found in previous research (1, 23).  
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38 The results have at least two clinical implications. Firstly, psychiatrists should actively  
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40 dedicate time to information giving within their outpatient consultations. Sufficient time must be  
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42 allocated to psychiatric consultations so that psychiatrists can explain and discuss what patients want  
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44 to know rather than simply refer to leaflets and websites. Secondly, with respect to training,  
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46 psychiatrists should be trained in how to address patients' needs for information that go beyond  
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48 medication and include the 'cause of illness.' In the absence of simple explanations for the cause of  
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50 schizophrenia and mood disorders, appropriate strategies to address patients' wishes should be  
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52 developed and taught in training.  
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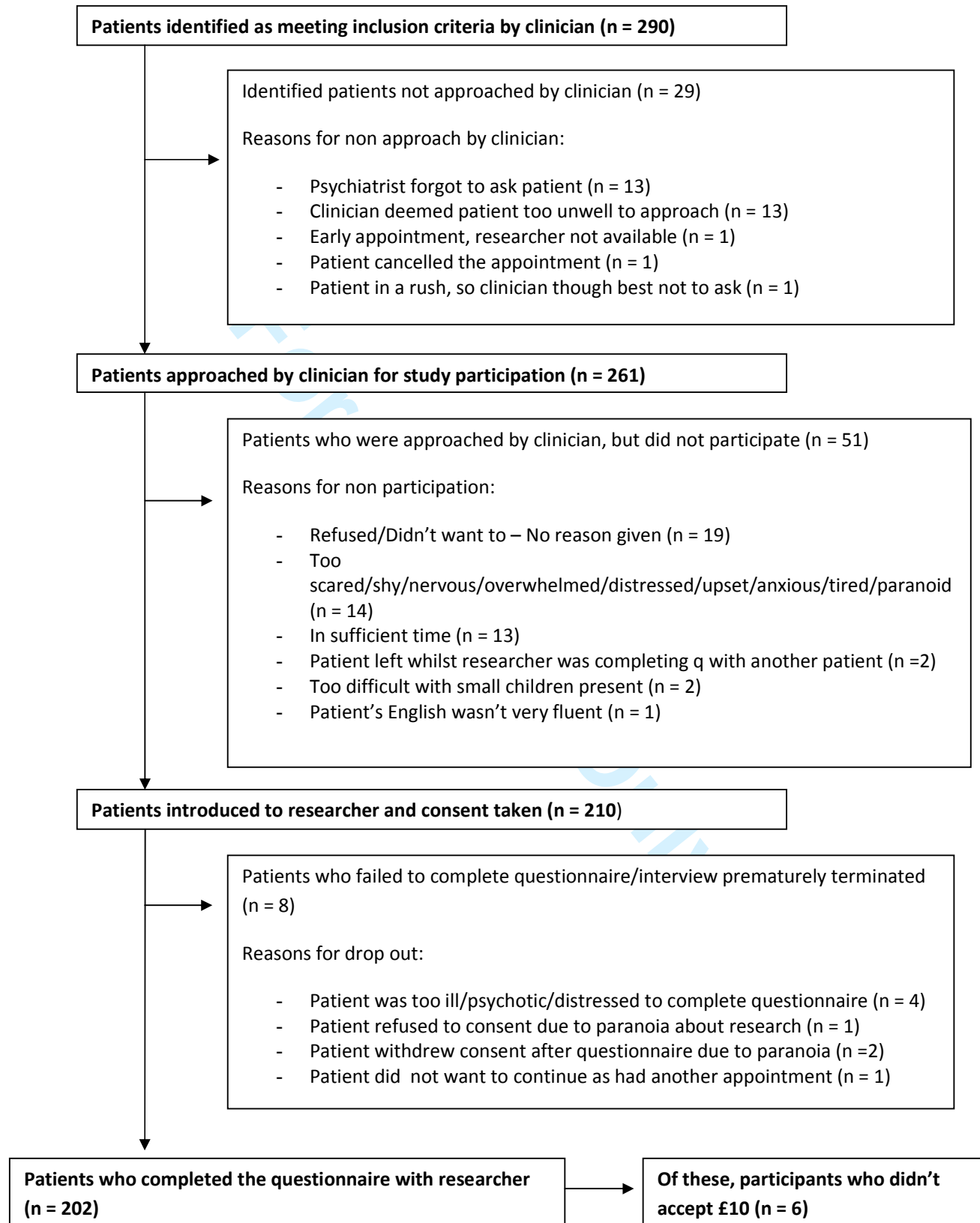
## 55 Conclusions

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3 Learning needs of patients seem to be relatively heterogeneous across the diagnostic groups  
4 of schizophrenia and mood disorders. Psychiatrists are the most valued information source by these  
5 patients. Psychiatrists therefore need to be aware of the learning needs of their patients as well as  
6 recognising the importance of their own role in providing this information. Investment into the  
7 training of psychiatrists may help to narrow the gap on under-addressed issues such as the cause of the  
8 illness. The key message from patients seems to be that despite a plethora of options for learning  
9 about their illness, there is no substitute for one-to-one contact time with their psychiatrist.  
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Figure 1. CONSORT flow diagram of patients recruited into the study



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**Table 1**

Patient characteristics in absolute numbers and percentages for the two diagnostic groups

|                               |                        | Schizophrenia |          | Mood Disorder |          |
|-------------------------------|------------------------|---------------|----------|---------------|----------|
|                               |                        | (N = 106)     |          | (N = 96)      |          |
| <b>Patient Characteristic</b> |                        | <b>N</b>      | <b>%</b> | <b>N</b>      | <b>%</b> |
| Gender                        | Male                   | 61            | 58       | 45            | 47       |
|                               | Female                 | 45            | 42       | 51            | 53       |
| Ethnicity*                    | White Background       | 40            | 38       | 53            | 55       |
|                               | Black Background       | 35            | 33       | 18            | 19       |
|                               | Asian Background       | 29            | 27       | 22            | 23       |
|                               | Mixed Background       | 2             | 2        | 3             | 3        |
| Occupation                    | Unemployed             | 75            | 71       | 60            | 63       |
|                               | Employed               | 15            | 14       | 19            | 20       |
|                               | Retired                | 6             | 6        | 7             | 7        |
|                               | Volunteer              | 8             | 8        | 3             | 3        |
|                               | Student                | 2             | 2        | 7             | 7        |
| Education*                    | None                   | 50            | 47       | 25            | 26       |
|                               | GCSEs or equivalent    | 31            | 29       | 30            | 31       |
|                               | Undergraduate          | 13            | 12       | 16            | 17       |
|                               | Postgraduate           | 8             | 8        | 16            | 17       |
|                               | A-levels or equivalent | 4             | 4        | 9             | 9        |
| Living Situation              | Alone                  | 59            | 56       | 42            | 44       |
|                               | With others            | 47            | 44       | 54            | 56       |

\*Significant relationship with diagnosis at the  $p < .05$  level

**Table 2**

Most appreciated sources of past information as identified by patients - in absolute numbers and percentages for the two diagnostic groups

|   | Schizophrenia |          | Mood Disorder |          |
|---|---------------|----------|---------------|----------|
|   | (N* = 106)    |          | (N* = 96)     |          |
| <b>Most appreciated sources of past information</b> | <b>N</b>      | <b>%</b> | <b>N</b>      | <b>%</b> |
| Psychiatrist  | 90            | 85       | 80            | 83       |
| General Practitioner                                | 41            | 39       | 45            | 47       |
| Internet  | 16            | 15       | 36            | 38       |
| Professional carer <sup>§</sup>                     | 31            | 29       | 19            | 20       |
| Other <sup>Δ</sup>                                  | 24            | 23       | 25            | 26       |
| Psychologist  | 19            | 18       | 29            | 30       |
| Family member                                       | 24            | 23       | 21            | 22       |
| Printed leaflets                                    | 12            | 11       | 20            | 21       |
| Other patients                                      | 8             | 8        | 7             | 7        |
| Learning groups                                     | 7             | 7        | 8             | 8        |

N\* = Patients could identify as many sources as were applicable to them, therefore N = 106 or 96 remains true for each item.

<sup>§</sup>Professional carer = paid members of the patient's care team such as: Social worker, Care coordinator etc.

<sup>Δ</sup>Other = Books, Church, Friends, Journals, Letters, Magazines, Mental health charities, No-one, Own research, Other professionals, Radio, Ward visits.

N.B. There were no significant relationships between information sources and diagnosis

**Table 3**

Topics patients would like to learn more information about - in absolute numbers and percentages for the two diagnostic groups

|   | Schizophrenia<br>(N* = 66) |          | Mood Disorder<br>(N* = 72) |          |
|---|----------------------------|----------|----------------------------|----------|
| <b>Topics patients would like to learn more about</b> | <b>N</b>                   | <b>%</b> | <b>N</b>                   | <b>%</b> |
| The cause of the illness                              | 41                         | 62       | 41                         | 57       |
| The general nature of the illness                     | 37                         | 56       | 35                         | 49       |
| Other forms of potential treatment                    | 32                         | 48       | 38                         | 53       |
| Information about medication                          | 28                         | 42       | 34                         | 47       |
| What support is available (social, financial)         | 25                         | 38       | 35                         | 49       |
| Experiences of other patients with the same illness   | 31                         | 47       | 27                         | 38       |
| Something else <sup>Δ</sup>                           | 24                         | 36       | 27                         | 38       |

N\* = 138 patients wanted to learn more information about their illness, therefore N = 66 and 72. Again, patients could identify as many topics as were applicable to them, therefore N= 66 or 72 remains true for each item.

<sup>Δ</sup> 'Something else' included topics such as: How to cope with their illness, How to cure it, Information about things they could do to speed their recovery, Specific information about their diagnosis, Information about how the illness changes over time, Specific questions about their own experience, Information about 'Why them?'.

N.B. There were no significant relationships between topics and diagnosis

**Table 4**

From whom/where patients would like to learn more about their illness - in absolute numbers and percentages for the two diagnostic groups

|  | Schizophrenia<br>(N* = 66) |          | Mood Disorder<br>(N* = 72) |          |
|--|----------------------------|----------|----------------------------|----------|
| <b>From whom/where patients would like to learn more</b> | <b>N</b>                   | <b>%</b> | <b>N</b>                   | <b>%</b> |
| Psychiatrist   | 49                         | 74       | 55                         | 76       |
| General Practitioner                                     | 29                         | 44       | 35                         | 49       |
| Psychologist   | 19                         | 29       | 30                         | 42       |
| Professional carer <sup>§</sup>                          | 22                         | 33       | 15                         | 21       |
| Learning groups  | 15                         | 23       | 18                         | 25       |
| Other patients   | 10                         | 15       | 10                         | 14       |
| Internet   | 7                          | 11       | 12                         | 17       |
| Family member  | 5                          | 8        | 2                          | 3        |
| Other <sup>Δ</sup>                                       | 4                          | 6        | 2                          | 3        |

N\* = 138 patients wanted to learn more information about their illness, therefore N = 66 and 72. Patients could identify as many sources as were applicable to them, therefore N = 66 or 72 remains true for each item.

<sup>§</sup>Professional carer = paid members of the patient's care team such as Social worker, Care coordinator etc.

<sup>Δ</sup>'Other' included sources such as: Films, Researchers, Books, Co-workers, Conferences/Workshops, Other professionals.

N.B. There were no significant relationships between new information sources and diagnosis

**Table 5**

How patients would like to be given new information about their illness - in absolute numbers and percentages for the two diagnostic groups

|   | Schizophrenia |          | Mood Disorder |          |
|---|---------------|----------|---------------|----------|
|   | (N* = 66)     |          | (N* = 72)     |          |
| <b>Best format to learn about their illness</b> | <b>N</b>      | <b>%</b> | <b>N</b>      | <b>%</b> |
| One-to-one conversations                        | 61            | 92       | 65            | 84       |
| Printed leaflets                                | 28            | 42       | 29            | 40       |
| Information packs                               | 23            | 35       | 30            | 42       |
| Mixed group discussions                         | 18            | 27       | 24            | 33       |
| Email*  | 4             | 6        | 15            | 21       |
| Telephone conversation                          | 8             | 12       | 4             | 6        |
| Other <sup>Δ</sup>                              | 7             | 11       | 5             | 7        |
| Text message                                    | 3             | 5        | 5             | 7        |

\* 138 patients wanted to learn more information about their illness, therefore N = 66 and 72. Patients could identify as many sources as were applicable to them, therefore N = 66 or 72 remains true for each item.

<sup>Δ</sup> 'Other' included sources such as: Anything, Internet, Seminars, Interactive workshops, Books, Letters

\*Significant relationship with diagnosis at the p<.05 level