Service User Experience of Mental Health Provision in Leicester and Leicestershire and Rutland

A Research Project Designed, Delivered and Evaluated by Service Users and Carers

January2009

Commissioned by the Leicester City, Leicestershire and Rutland, Local Implementation Team through: The Peoples Forum, Open Assembly@Genesis and De Montfort University

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Introduction

This report sets out the results for a piece of research commissioned by the Leicester City, Leicestershire County and Rutland Local Implementation Teams prior to the formulation of two separate Local Implementation Teams.

Referred to as the “user led mental health research project” the work was undertaken by The Peoples Forum, Open Assembly@Genesis and De Montfort University working in collaboration to produce evidence that:

- Contributes to the shift in the mental health service culture towards service user centred care
- Moves away from a staff needs culture
- Cuts down on patient stay in ward settings
- Recognises, celebrates and shares good practice
- Provides feedback for staff
- Creates hope for recovery
- Smoothes the pathway from ward to home
- Is a catalyst for change

Background

The Service User Audit Group (SUAG) reports to the Local Implementation Teams in Leicester and Leicestershire.

This study developed from questions and concerns raised by members of The Service User Audit Group (SUAG), regarding the quality of care and treatment being delivered by services in Leicestershire, including Leicestershire Partnership NHS Trust (LPT). The study set out to explore the perceptions of those currently in receipt of those services, with the aim of celebrating good practice, and identifying areas where it could be improved. To this end this research could change practice and may be considered as Action Research.

8 Research Interviewers who have first hand personal experience of mental health services (or have been /are, a carer for someone), were employed by De Montfort University. They, together with the SUAG, shaped questions, undertook interviews, analysed the results and disseminated them. This Team were prepared for their role through a training programme where rehearsal of interview techniques using the questionnaire, and research protocol were considered. Collaboration with Welfare Rights and Psychology and Interpreting services together with ethical approval from two committees ensured the best interests of *all* participants were observed.

Research Methods

A mixed method was used, enabling quantitative and qualitative information to be gathered in the hope of providing conclusive data upon which service providers and commissioners might consider future change.

This data was collected through individual interviews lasting between 30 and 50 minutes, conducted in the place where the participant was receiving services. Interviewers used a questionnaire to guide discussions, and attempted to minimise interpretation, quoting verbatim where possible for the narrative responses. Data was translated to computer formats and analysed using the Statistical Package for Social Sciences v14 (SPSS).

Research Interviewers participated in the following ways:

- Steering the project
- Coding and data entry
- Data analysis and tabulation
- Report and presentation writing
- Presenting and disseminating the findings

The questionnaire was introduced during in face-to-face interviews with service users in a range of settings with the aim of targeting participants who had used services in the last 18 months.

Questionnaire Design

The SUAG identified the following areas for service user led discussion, audit and research:

- Service user views of needs, and the ways that they could be met,
- Staff attitudes to and communication with service users.
- Medication - information given to service users including potential side-effects and response to service user requests for assistance with side-effects.

  Service users met with the researcher over 6 sessions to consider and write the questions they needed. This generated enough questions for 2 questionnaires. Questionnaire 1 included the question areas the service users wanted to put into field first (medication staff attitudes and communication), and questionnaire 2 contained questions that could be used in a subsequent project (support, community care, seclusion, care planning and reviews). These questionnaires were reviewed by the members of the SUAG, and by the Research Director and Clinical Audit Group from the Leicestershire Partnership Trust together with researchers at De Montfort University. All feedback was discussed and a final draft of the questionnaires produced.

The quantitative questionnaire was used to gather service users' views of:

- The information available to service users during early illness and recent illness
- Their experiences with medication
- Their experiences of staff attitudes and communication

The questionnaire mostly included pre-coded questions. Open ended, qualitative questions were included at the end of each section to gather related information that has not been anticipated by the questionnaire.

Support and Risk Management for Interviewers

It was identified that there were three main types of support required by the service user interviewers through this project:

- Research Related Support
- Practical Support
- Emotional Support

Research Related Support

It was acknowledged that service user led research in mental health contains an inherent risk for those individuals conducting and participating in the research to experience mental distress. The Service Users involved in designing the research considered a number of measures to support interviewers and interviewees through the highs and lows of interviewing and hearing/re-living service user's stories. These measures are described below.

Research related support was provided by an experienced researcher. Service users worked with the researcher to design interviewer briefing sessions and briefing pack that will introduce service users to the skills they need to conduct the interviews. An 18 hour briefing programme was held over a number of days to develop teamwork and minimise risk to the participants and interviewers. The briefing sessions started from a point of view that the attendees had no research knowledge and considered tasks an interviewer would need to undertake including:

- Meeting up and preparation before entering the service/fieldwork site
- How to introduce yourself to the service manager and staff and behavioural etiquette
- To ask the service manager and staff how they deal with service user crises
- How to approach participants in the centre
- How to use an introduction script
- How to handle difficult situations
- Interviewing skills
- How to ask the questions
- What range of answers to expect to questions
- How to deal with queries
- Standardising the interviews and sticking to the script
- PowerPoint presentations and data analysis
- Role Play

Practical Support

A high level of practical support was required for interviewers.
The support required can be summarised under the headings:

- Lead Researcher (De Montfort University)
- Project Co-ordinator Support (Peoples Forum)
- Administrative Support (Peoples Forum)

The high volume of administration required the Project Co-ordinator and Lead Researcher to collaborate extensively. Tasks included production of briefing materials, maps, contact lists, processing travel expenses and pay claims, arranging interviews, producing schedules, processing queries and communicating with participating services about the study. In addition materials to promote and advertise the project were generated by the SUAG.

Emotional Support

An informal system of peer support existed within the interviewing team who developed a sense of camaraderie, and helped de-brief each other after the interview sessions. Good research governance dictated the inclusion of measures to support the Research Interviewers who encountered personal difficulties during their engagement with the project. This was provided by a Practice Therapist from the Common Mental Health Programme Service and a Consultant Psychologist from Psyworks Ltd. The Therapists were independent of the research project, and could provide the interviewers with an outlet to talk through any distressing experiences they encountered, and were available by telephone throughout the fieldwork period, during set times.

The professional support was **not** required at any time or by any Interviewer during the project.

Interviewer recruitment, reward and recognition
Interviewers were employed by De Montfort University, giving two options:

- The service user or carer participates voluntarily
- The service user or carer is directly employed

All interviewers, whether voluntary or paid, were covered by insurance policies for liability and indemnity insurance.
A member of the Welfare Rights Service joined SUAG for the duration of the project, providing advice and ongoing support. Research Interviewers were paid £9.98 per hour plus expenses, enabling minimal disruption of benefits where claimed. Interviewers had control over the number of hours they worked.

Sample
A sample of 173 mental health service users was achieved across those receiving services from statutory voluntary and independent services throughout Leicester and Leicestershire and Rutland. Participants self selected into the project following the distribution of posters and advertising materials prior to interview slots. A quota sampling approach was considered to assure equity across gender, ethnicity and age distributions, however this was not used.

Prior to the interview day, agreement from that particular service was gained for the interviews to go ahead. Participating services were sent an information pack two weeks prior to the interview day. Interviewers were provided with additional copies of all material to brief staff about the project. Packs included:

- A project summary
- What interviewers will be doing
- What we need to know from you (staff)
- What we expect from participants
- Consent to and withdrawing from the interview
- A poster advertising the interview day and availability of participant information sheets
- Participant information sheet (pictorial)
- Participant consent form
- A copy of the questionnaire

Interviewers spoke to staff before conducting any interviews to cover a wide range of housekeeping topics such as:

- What to do in case of a fire?
- What the local policy is for patients in crisis?
- What staff are on duty – what are their roles?
- Where are the toilets?
- Do they have any other rules for visitors or new staff they should be aware of?
- How they see the interviews best working – is there anyone who does not want to be interviewed?
- Where the interviews should take place?

In the staff handout we also suggested that staff make an announcement at the venue, to let users know that interviewers are around. The announcement should include:

- Interviewer names
- That the interviewers will be wearing badges
- That the interviewers are service users
- That the interviewers are friendly and won't bite

- That participant information sheets are available
- The interviews are confidential but anonymised answers would be contained in the eventual report

The handout made a recommendation that a quiet corner be set up for interviewing (if possible), as some participants may have wanted to give their answers in a quiet area so that they remain confidential. All respondents were given the choice about where they wanted to answer the questions.
Interviewers agreed with local staff before starting interviewing, what they want them to do in case they notice a service user in a state of crisis or if they became distressed during the interview. Interviewers were asked not to interview any service users who appeared to be in a state of distress or crisis. In addition to this, interviewers carried with them a handout on how to access further mental health support if participants should wish, from a range of services such as Focusline.

All interviewers ensured that participants read the participant information sheet. The participant information sheet made clear that participation is voluntary, that they can withdraw from the process at any time, and that participation does not affect the care they receive in any way. All participants were asked to read and sign the consent form before the interview commenced. 173 Consent forms were fully completed.

Analysis
Analysis of the results utilized the tools of SPSS, NVivo, Microsoft Excel and home produced databases. A range of frequency, and cross tabulations for all the questions were considered. Analysis styles were separated for both qualitative and quantitative methods to identify patterns and trends.

Quantitative Data Analysis
All data were initially inputted into Microsoft Excel, collated and then entered into SPSS v16. Both nominal and interval descriptive data were obtained, tabulated and presented as bar charts for a pictorial reference.

Inferential statistics
Within the data set were a bank of 19 interval level statements (Question 26 a to s), all of which explored different aspects of Service User satisfaction (1= false, 2= true some of the time, 3= true all of the time). After correction for orientation, so that increase in satisfaction was represented by an increase in score, the scores were analysed using Cronbach's alpha (initial value= 0.858). This measures the internal consistency of the data set. The data set was then analysed using exploratory factor analysis, to identify any subsets. This identified that three items did not contribute to the main factor. Removal of these items increased the alpha value to 0.876. As a general principal, a score greater than 0.7 represents a set of data which are internally consistent (Field 2007), and therefore can be summated. This means that the final 16 items (See Table page 110) can be summated with confidence to give an overall statistically valid measurement of service user satisfaction.

The summated set of scores was shown by Kolmogorov Smirnov testing to differ significantly from a normal distribution (p=0.13), and therefore non parametric interferential tests were used to explore the data further; Mann Whitney testing for comparison between two nominal variables, and Spearman's rho for two sets of interval data (Anthony 1999). These showed that neither gender (p=0.293) nor age (p=0.123), nor self reporting of belonging to an ethnic minority (p=0.395) were statistically significant, supporting the validity of the scale.

A range of other tests to cross reference and cross tabulate data were performed such as a Logistic Regression model to examine the influence of potential contributory factors across the data set, however these did not add any significant value and were discarded.

The statistical results were presented to the Service User Audit Group over a number of meetings to consider interpretations and observations which are included at the foot of each question.

Qualitative Data Analysis

The qualitative data extracted verbatim from questions 4b, 25, 30,34,39,40,46 and additional notes. This was initially placed in a database and some analysis was attempted using NVivo 8. The outcomes from this tool were unsatisfactory due to the limited narrative responses obtained from these particular questions, and the researchers reverted to a simplified content analysis.

As an approach to evaluation, content analysis is considered as quasi-evaluation because judgments need not be based on value statements (Neuendorf 2002), and as this research objective was aimed at presenting subjective lived experiences, the analysis of these responses is not an evaluation in this context.

The frequency of specific words and phrases were considered but no coding values were placed on these as it was felt that the words and comments were self explanatory, and where possible, have been incorporated to illustrate quantitative results.

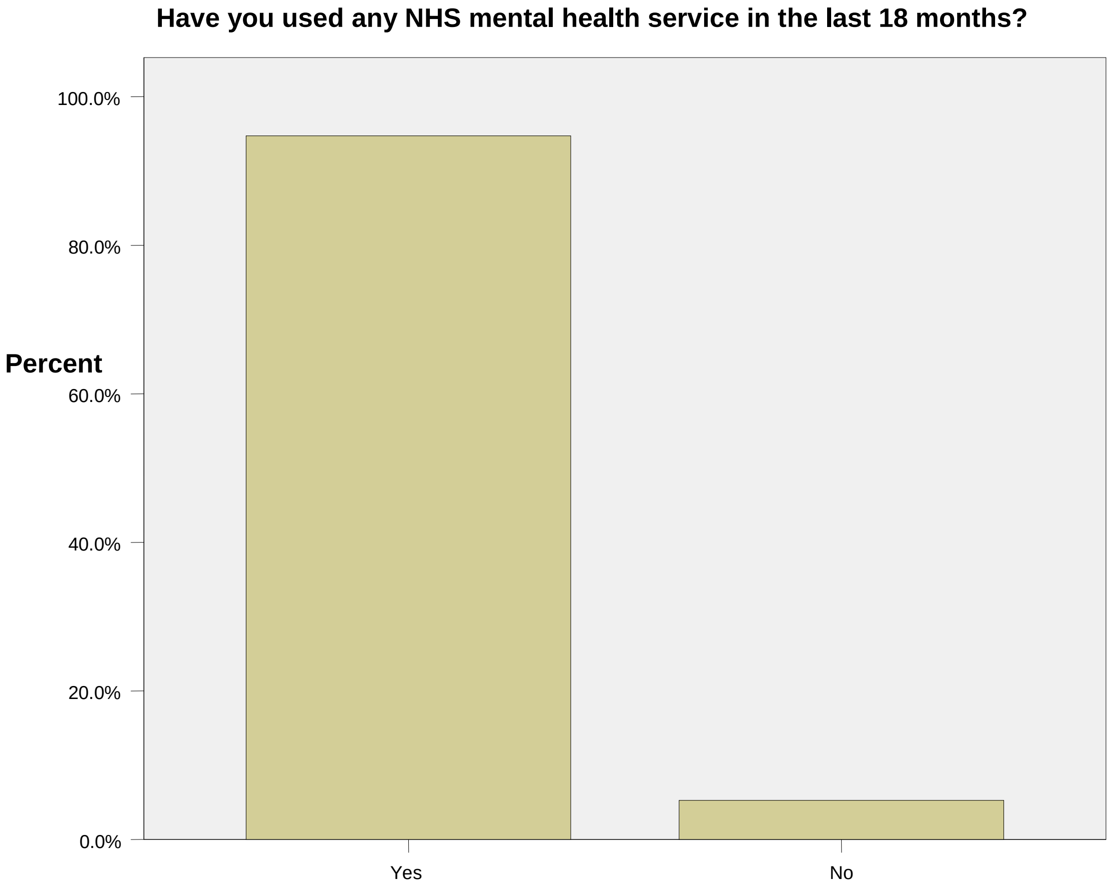
Respondents Experiences and Research Outcomes

Question 1

Have you used any NHS mental health service in the last 18 months?

Answered 171 (98.8%)
Missing Answers 2 (1.2%)

	Frequency	Percent
Yes	162	94.7
No	9	5.3



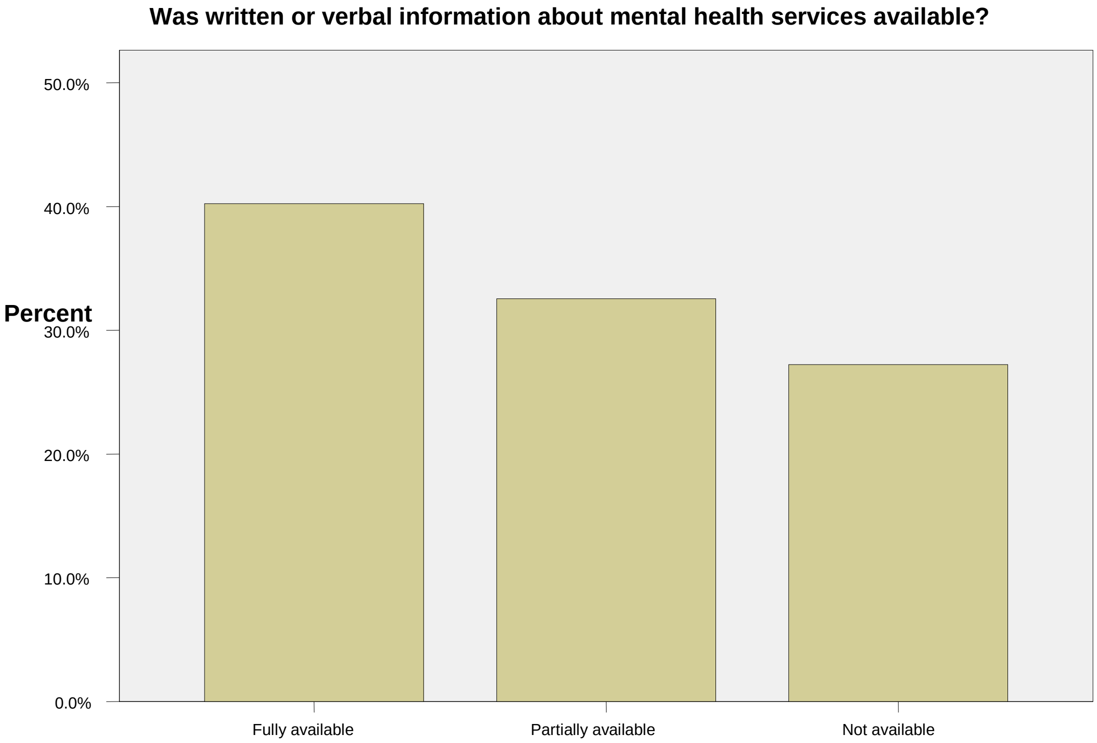
94.7% of respondents identified that they had used Mental Health services within the last 18 months. The 5.3% who answered “no” were interviewed within a setting for people with Mental Health problems, and were in fact users of that service.

On this basis we can assume that despite the negative responses all of those interviewed were in receipt of some type of Mental Health service.

Question 2
Was written or verbal information about mental health services available?

Answered 169 (97.7%)
Missing Answers 4 (2.3%)

	Frequency	Percent
Fully available	68	40.2
Partially available	55	32.5
Not available	46	27.2



The Service User Audit Group consider that the availability of information both written and verbal, should be considered an issue as 60% of respondents indicated that information was either not available (N=46) or only partly available (N =55).

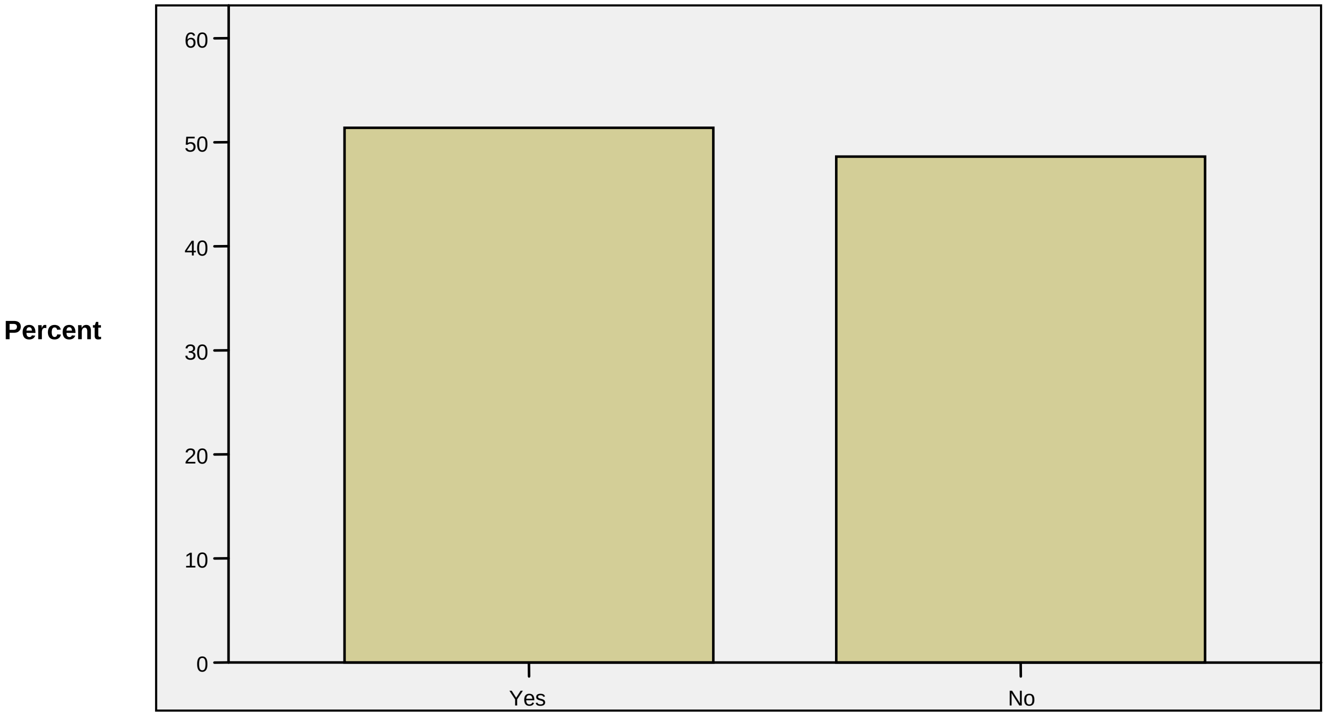
Cross calculations between ethnicity, age, gender and length of contact with services, revealed no significant differences or specific issues for these groups.

Question 3
Did someone help you find out about the services in the early stage of your illness?

Answered 144 (83.2%)
Missing Answers 29 (16.8%)

	Frequency	Percent
Yes	74	51.4
No	70	48.6

Did someone help you find out about the services in the early stage of your illness?

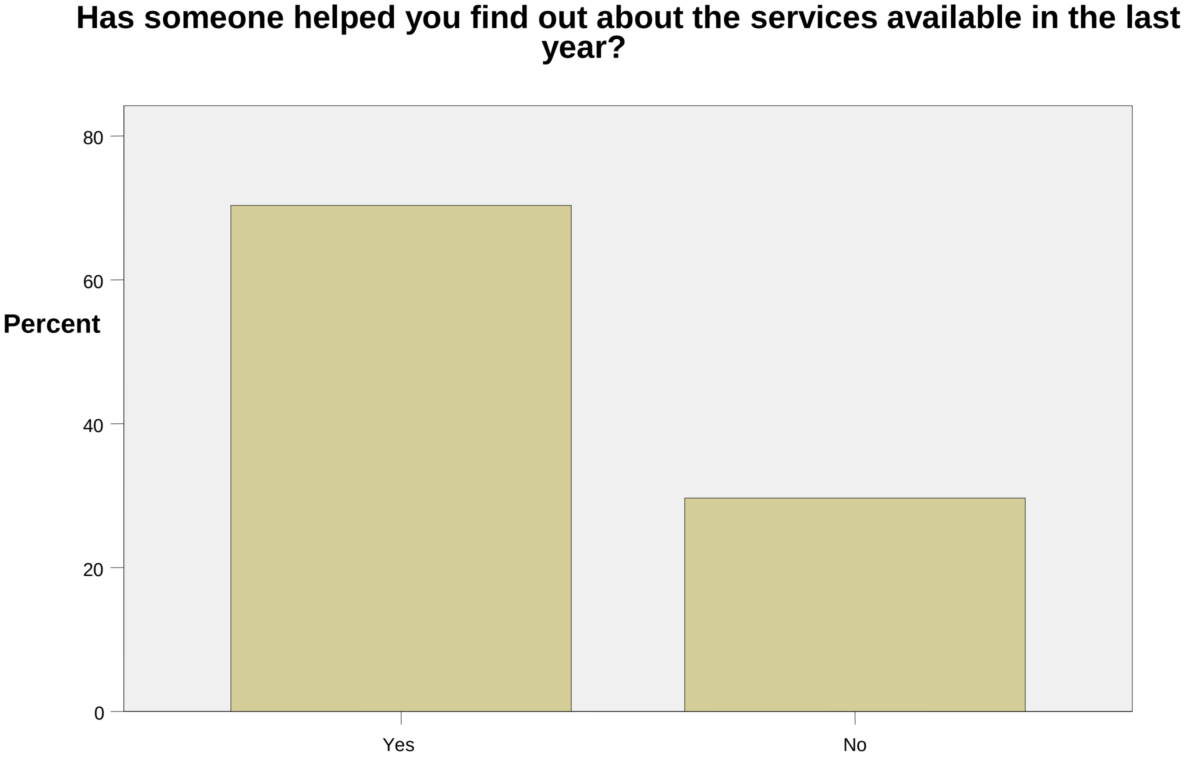


The 48.6% of respondents who claimed not to have received help in finding out about services in the early stage of their illness, have by some means, accessed the service.

Question 4 a
Has someone helped you find out about the services available in the last year?

Answered 145 (83.8%)
Missing Answers 28 (16.2%)

	Frequency	Percent
Yes	102	70.3
No	43	29.7



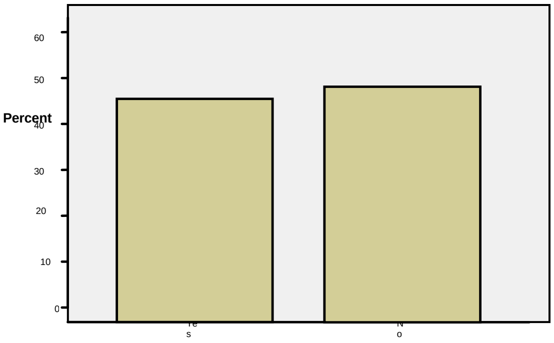
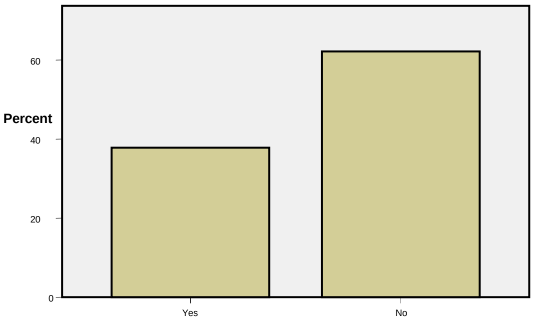
This graph shows that 70.3% (N= 102) of for respondents had received some form of help within the last year. It is noticeable that almost 29.7 % (N= 43) of respondents had not received help, yet were receiving services.

Question 4b
Who helped you find out about Mental Health Services that are available?

This answer required a qualitative response with the majority of those who responded giving one or two word answers.

Categories of responses identified professionals as the most helpful group (N=32), followed by parents (N= 8) and friends (N= 4). Friends (N= 4) and neighbors (N= 3) were cited as helpful. The voluntary sector (N=2), other service users (N=2) and partners (N=2) were also cited.

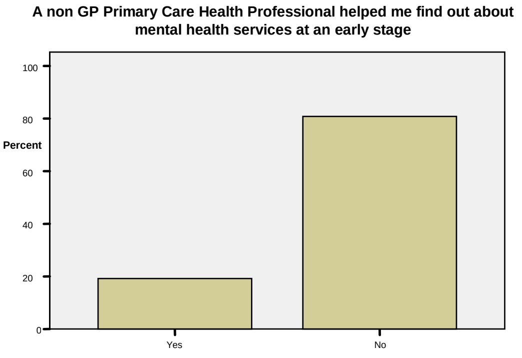
The limited conclusions that can be extrapolated from this information indicate that professional interventions seem to be the most prevalent, and the support of family, friends and neighbours has been influential for some.

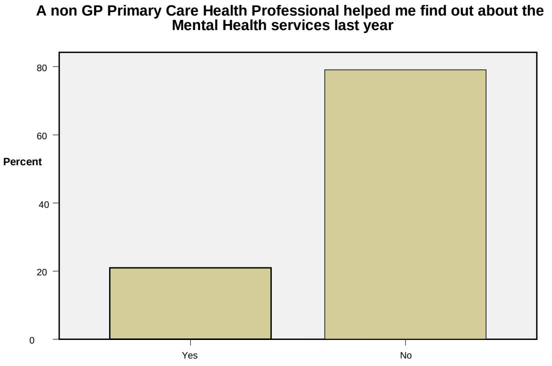
Question 4b a1			**Question 4b b1**		
A GP helped me find out about the mental health services at an early stage Answered 148 (85.5%) Missing Answers 25 (14.5%)			**The GP helped me find out about mental Health Services in the last year** Answered 148 (85.5%) Missing Answers 25 (14.5%)		
	Frequency	Percent		Frequency	Percent
Yes	72	48.6	Yes	56	37.8
No	76	51.4	No	92	60.2
A GP helped me find out about the mental health services at an early stage  			A GP helped me find out about the mental health services last year  		

4ba1 This graph demonstrates that just under half of respondents received help from their GP.
General practitioners are the cornerstone of primary care and the Service User Audit Group would reasonably expect this group of professionals to be the primary source of information and signposting for people at an early stage of their contact with Mental Health Services.

The Service User Audit Group suggest that G P’s should be enabled to provide appropriate information more effectively through improved training and better access to information about Mental Health Services. Understanding of the available service and treatment options will lead to more appropriate referrals, psycho-education and ultimately the opportunity for prospective patients to make informed choices. Good quality well written information should be readily available to enable GPs to pass on to prospective patients and their carers.

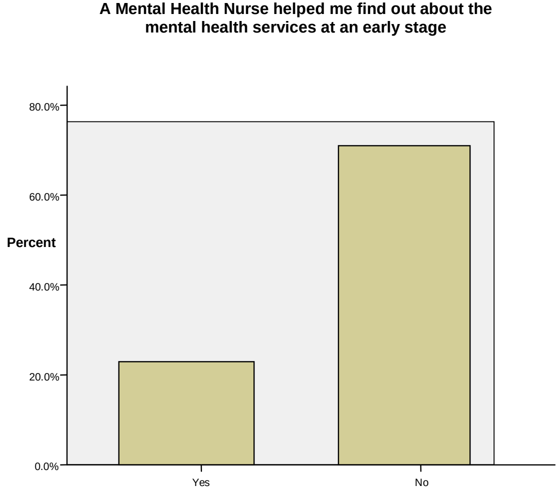
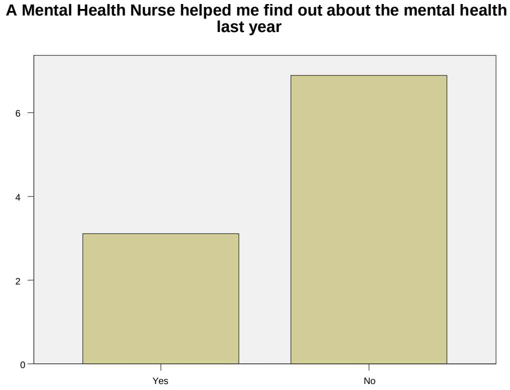
4bb1 During the last year respondents reported that 37.8% (N= 56) of the help they received was provided by G P’s. It is interesting to note that this represents a fall from 48.6 % (N= 72), who provided help at the early stage of person illness.

<table>
<tr><td colspan="3">Question 4b a2</td><td colspan="3">Question 4b b2</td></tr>
<tr><td colspan="3">A non GP Primary Care Health Professional helped me find out about mental health services at an early stage
Answered 146 (84.4)
Missing Answers 27 (15.6%)</td><td colspan="3">A non GP Primary Care Health Professional helped me find out in the last year
Answered 148 (85.5%)
Missing Answers 25 (14.5%)</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
<tr><td>Yes</td><td>28</td><td>19.2</td><td>Yes</td><td>31</td><td>20.9</td></tr>
<tr><td>No</td><td>118</td><td>80.8</td><td>No</td><td>117</td><td>67.6</td></tr>
<tr><td colspan="3">

.</td><td colspan="3">
</td></tr>
</table>

4ba2 80.8% (N= 118) of respondents felt they had not received help from a primary health care professional other than a GP. 19.2% (N= 28) stated they had received help

4bb2 In the last year 20.9% (N= 31) of respondents identified that a non GP primary Healthcare professional helped them find out about services. Supplementary information indicated that this help was received primarily from contact with the Common Mental Health Problem Service, however Research Interviewers reported difficulties in the understanding of the question from some respondents.

<table>
<tr><td colspan="3">**Question 4b a3**
A Mental Health Nurse helped me find out about the mental health services at an early stage</td><td colspan="3">**Question 4b b5**
A Mental Health Nurse helped me find out about the mental health services in the last year</td></tr>
<tr><td colspan="3">Answered 147 (85%)
Missing Answers 26 (15%)</td><td colspan="3">Answered 148 (85.5%)
Missing Answers 25 (14.5%)</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
<tr><td>Yes</td><td>34</td><td>23.1</td><td>Yes</td><td>46</td><td>31.1</td></tr>
<tr><td>No</td><td>113</td><td>76.9</td><td>No</td><td>102</td><td>68.9</td></tr>
<tr><td colspan="3">
</td><td colspan="3">
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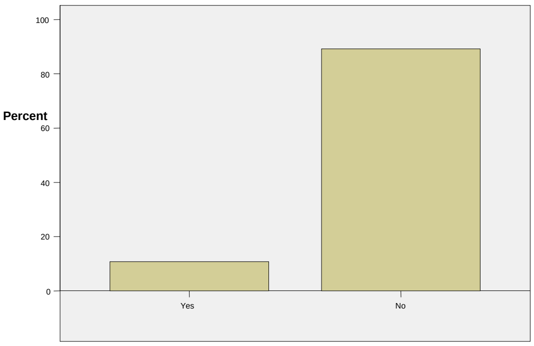
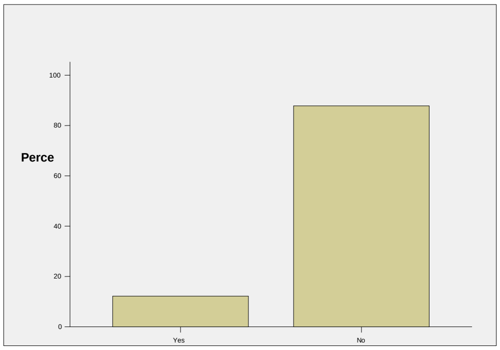
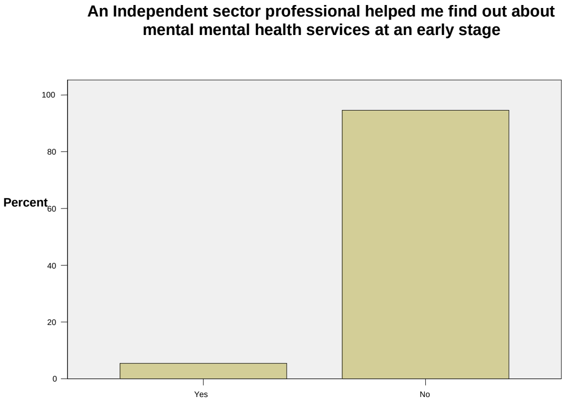
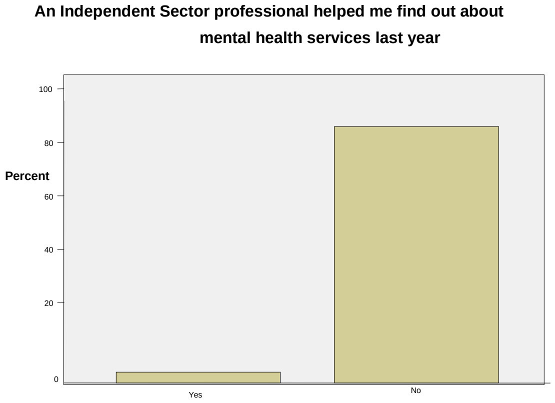
</table>

31.1 % (N= 46) of respondents indicated that a mental health nurse had helped them find out about services within the last year. This represents an increase from 23.1% (N= 34) who helped in the early stages, and may represent the accessibility of Mental Health nurses for someone who has not accessed secondary care.

<table>
<tr><td colspan="3">Question 4b a4</td><td colspan="3">Question 4b b4</td></tr>
<tr><td colspan="3">A Voluntary Sector professional helped me find out about the Mental Health Services at an early stage
Answered 148 (85.5%)
Missing Answers 25 (14.5%)</td><td colspan="3">A voluntary sector professional helped me find out about Mental Health Services in the last year
Answered 148 (85.5%)
Missing Answers 25 (14.5%)</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
<tr><td>Yes</td><td>16</td><td>10.8</td><td>Yes</td><td>18</td><td>12.2</td></tr>
<tr><td>No</td><td>132</td><td>89.2</td><td>No</td><td>130</td><td>87.8</td></tr>
<tr><td colspan="3">A Voluntary Sector professional helped me find out about the mental health services at an early stage

 </td><td colspan="3">A Voluntary Sector professional helped me find out about the mental health services last year

 </td></tr>
</table>

4ba4 It is important to acknowledge who are able to signpost access to a range of services. However only 10.8% (N= 16) of respondents to this question, acknowledged the role of the voluntary sector in finding out about Mental Health Services at an early stage.

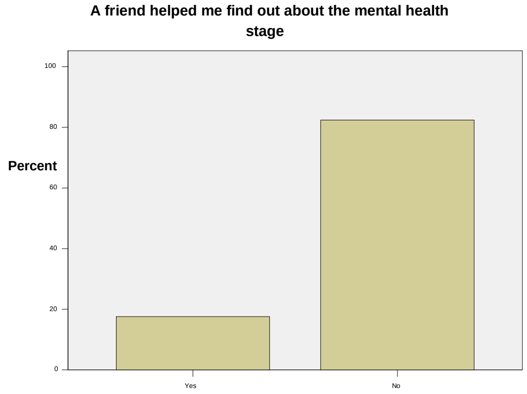
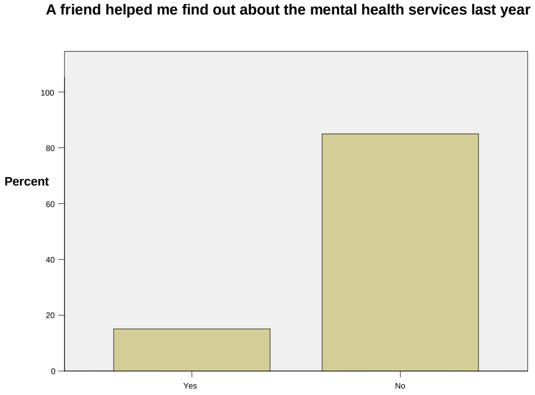
4bb4 12.2% (N= 18) of respondents indicated that the voluntary sector had helped them find out about services within the last year.

Question 4b a5			**Question 4b b5**		
An Independent sector professional helped me find out about the mental health services at an early stage Answered 148 (85.5%) Missing Answers 25 (14.5%)			**An independent sector professional helped me find out about mental Health Services in the last year** Answered 147 (85%) Missing Answers 26 (15%)		
	Frequency	Percent		Frequency	Percent
Yes	16	10.8	Yes	6	4.1
No	132	89.2	No	141	81.5
					

Only 5.4% (N= 8) of respondents acknowledged the independent sector as helping find out about the services at an early stage.

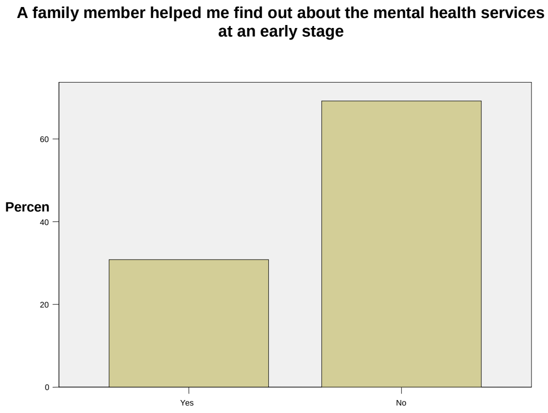
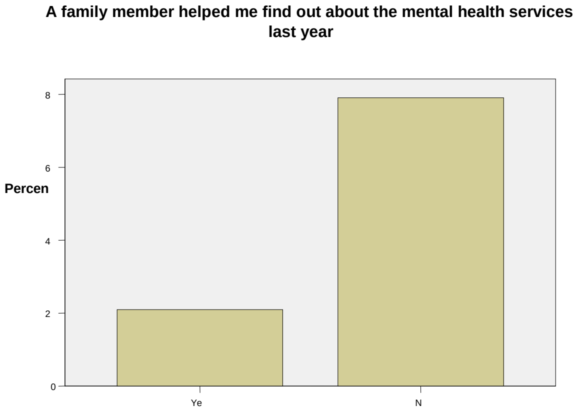
Anecdotal evidence from Research Interviewers suggested that respondents were not able to differentiate between voluntary and independent sector providers.

Only 4.1% suggested that the independent sector have provided help in the last year. As with Question 4b a5 anecdotal evidence from Research Interviewers suggested that respondents were not able to differentiate between voluntary and independent sector providers

<table>
<tr><td colspan="3">Question 4 b a6</td><td colspan="3">Question 4b b6</td></tr>
<tr><td colspan="3">A friend helped me find out about the mental health services at an early stage
Answered 148 (85.5%)
Missing Answers 25 (14.5%)</td><td colspan="3">A friend helped me find out about mental Health Services in the last year
Answered 146 (84.4%)
Missing Answers 27 (15.6%)</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
<tr><td>Yes</td><td>26</td><td>17.6</td><td>Yes</td><td>22</td><td>15.1</td></tr>
<tr><td>No</td><td>122</td><td>82.4</td><td>No</td><td>124</td><td>84.9</td></tr>
<tr><td colspan="3">
</td><td colspan="3">
</td></tr>
</table>

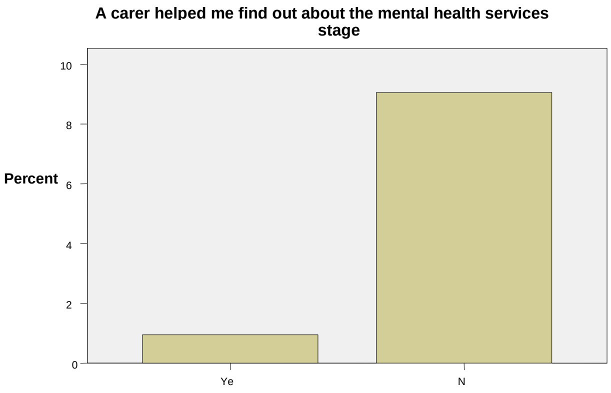
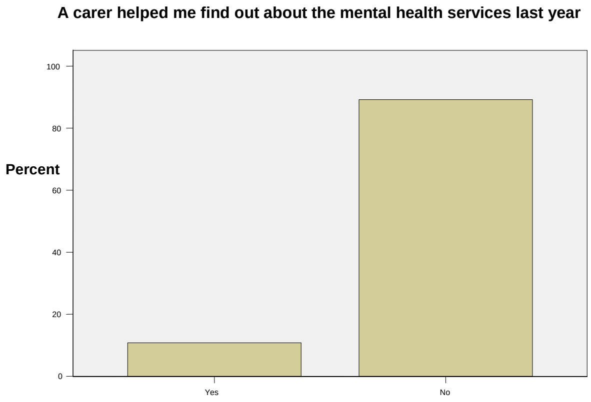
4ba6
The role of friends as providers of information acknowledged by 17.6 % (N= 26) of respondents. It is interesting to note that the percentage of answers that cited friends providing help, is more than the totals for the voluntary and independent sectors combined.

15.1% (N= 22) of respondents indicated that they have been helped by friends to find out about services in the last year.

Question 4 b a7			**Question 4b b7**		
A family member helped me find out about mental health services at an early stage Answered 146 (84.4%) Missing Answers 27 (15.6%)			**A family member helped me find out about mental Health Services in the last year** Answered 148 (85.5. %) Missing Answers 25 (14.5%)		
	Frequency	Percent		Frequency	Percent
Yes	45	30.8	Yes	31	20.9
No	101	69.2	No	117	79.1
					

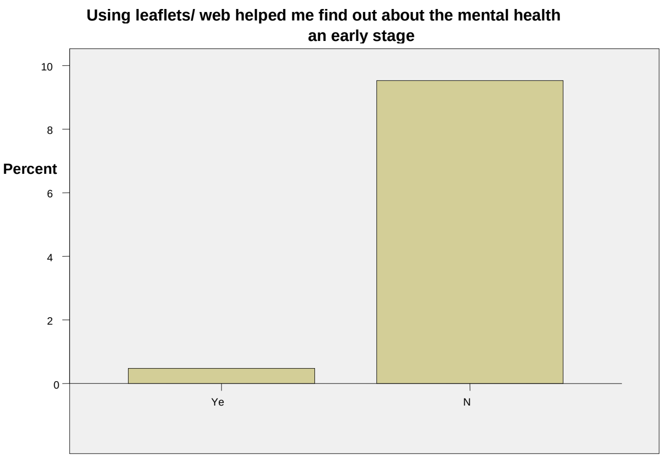
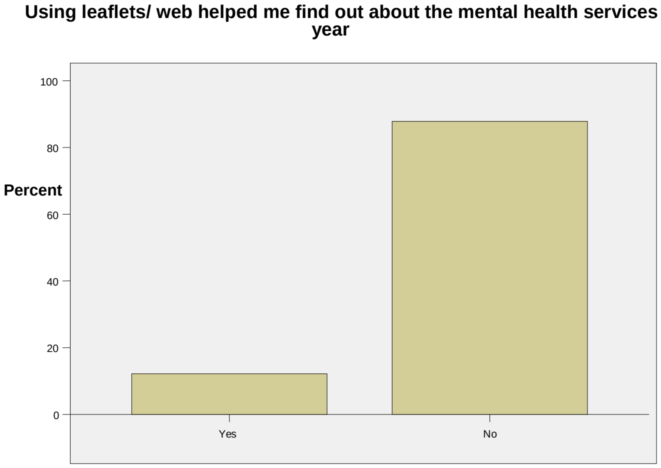
4ba7 The role of family members in the provision of information is clear. Family members helped 30.8 % (N= 45) of respondents compared to 48.6% (N= 72) helped by a GPs and 23.1% (N= 34) helped by a mental health nurses in the early stages of the persons illness, despite the disparity in training and access to information.

4bb7 20.9 % (N= 31) of respondents felt they had been helped by a family member in the last year.

Question 4b a8			**Question 4b b8**		
A carer helped me find out about mental health services at an early stage Answered 148 (85.5%) Missing Answers 25 (14.5%)			**A carer helped me find out about mental Health Services in the last year** Answered 148 (85.5%) Missing Answers 25 (14.5%)		
	Frequency	Percent		Frequency	Percent
Yes	14	9.5	Yes	16	10.8
No	134	90.5	No	132	89.2
					

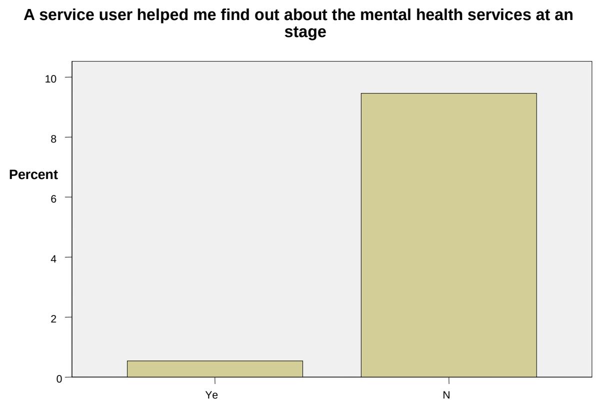
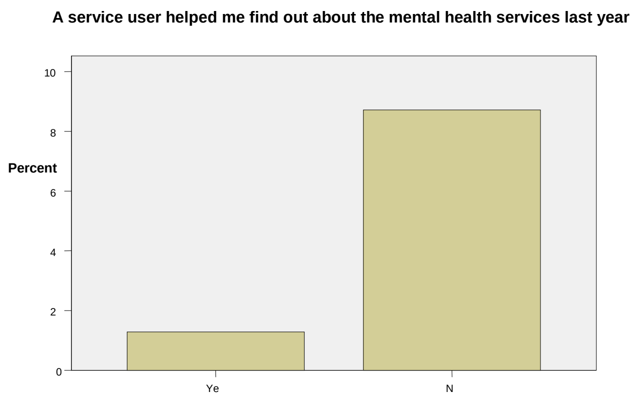
4b a8 Only 9.5 % (N= 14) of carers were acknowledged as helping find out about mental Health Services at an early stage.
These results are influenced by the fact that in some cases the carer was a family member or friend.

4b b8 10.8% (N= 16) of respondents indicated that they have been helped by a carer. Again, these results are influenced by the fact that in some cases, the carer was a family member or friend.

Question 4b a9			**Question 4b b9**		
Using leaflets/ web helped me find out about mental health services at an early stage Answered 148 (85.5%) Missing Answers 25 (14.5%)			**Using leaflets /web helped me find out about mental Health Services in the last year** Answered 148 (85.5.%) Missing Answers 25 (14.5%)		
	Frequency	Percent		Frequency	Percent
Yes	7	4.7	Yes	18	12.2
No	141	95.3	No	130	87.8
					

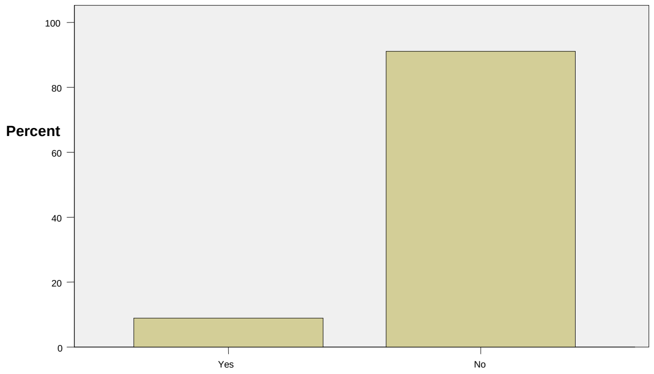
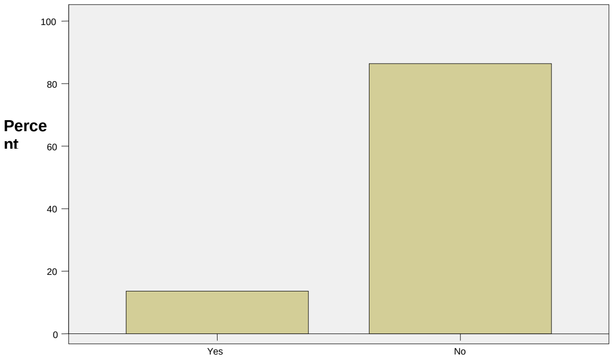
4ba9 The use of leaflets and the World Wide Web accounted for only 4.7 % (N= 7) of respondents answers.
The Service User Audit Group feel that this low figure could be the result of a number of factors:
Availability of hard copy information is not available in the places where potential service users can access it.
The LPT website should be improved with links to the voluntary sector.
Service users may have reduced access to the internet.

4bb9 Written material such as leaflets or Internet based information accounted for 12.2% (N= 18) of responses

Question 4b a10			**Question 4b b10**		
A service user helped me find out about the mental health services at an early stage Answered 148 (85.5%) Missing Answers 25 (14.5%)			**A service user helped me find out about mental Health Services at the last year** Answered 148 (85.5%) Missing Answers 25 (14.5%)		
	Frequency	Percent		Frequency	Percent
Yes	8	5.4	Yes	19	12.8
No	140	94.6	No	130	87.2
A service user helped me find out about the mental health services at an stage 			A service user helped me find out about the mental health services last year 		

4ba10 Help from other service users in the early stages of treatment access was reported to be quite low 5.4% (N= 8). This may be because during the early stages of a person's illness, access to other service users is inhibited because they are not known.

4bb10 The help of fellow service users impacted upon 12.8 % (N= 19) of respondents. This represents an increase from 5.4% who helped at an early stage of the person's involvement with Mental Health Services.

<table>
<tr><td colspan="3">Question 4b a11</td><td colspan="3">Question 4b b11</td></tr>
<tr><td colspan="3">Other helped me find out about Mental Health Services at an early stage
Answered 146 (84.4%)
Missing Answers 27 (15.6%)</td><td colspan="3">Other helped me find out about Mental Health Services in the last year
Answered 47 (85%)
Missing Answers 26 (15%)</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
<tr><td>Yes</td><td>13</td><td>8.9</td><td>Yes</td><td>20</td><td>13.6</td></tr>
<tr><td>No</td><td>133</td><td>76.9</td><td>No</td><td>127</td><td>73.4</td></tr>
<tr><td colspan="3">Other helped me find out about the mental health services at an early stage
 </td><td colspan="3">Other helped me find out about the mental health services last year
 </td></tr>
</table>

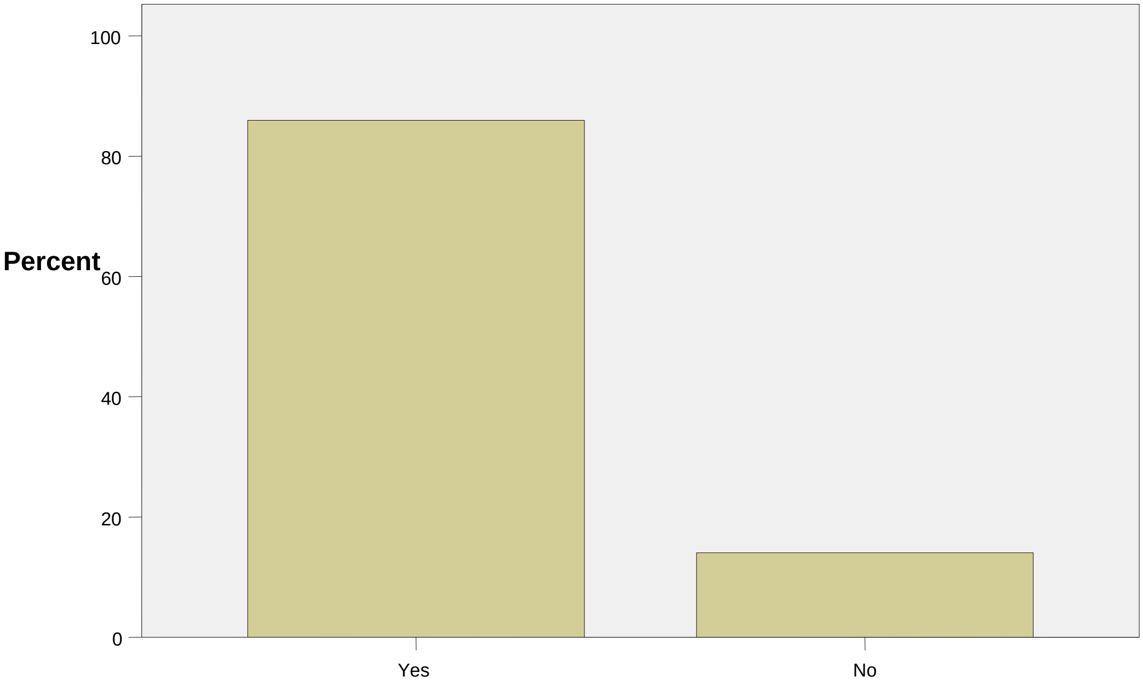
Other information (not specified), assisted 13.6 % (N= 20), of respondents.
It is clear from these responses that the provision of information and signposting is not clear. The Service User Audit Group suggest that Leicestershire Partnership Trust should redouble its efforts to ensure that statutory, voluntary and independent sectors are provided with current information about how to access services, and the pathways of care. In addition information should be made widely available through leaflets and the Internet to enable a better understanding of the services provided and the process of admission for prospective patients. It is also clear that General Practitioners require encouragement to better understand the process for referral, and provide more helpful information for those seeking it. In addition it is worthy to note that the help from GPs subsides following referral and this is of concern.

Question 5
Were you referred to a mental health practitioner?

Answered 171 (98.8%)
Missing Answers 2 (1.2%)

	Frequency	Percent
Yes	147	86
No	24	14

Were you referred to a mental health practitioner?



86% (N= 147) of respondents suggested that they were referred, however 14% (N= 24) answered this question negatively.
Although 24 said they were not referred to a Mental Health Practitioner they were receiving a service.

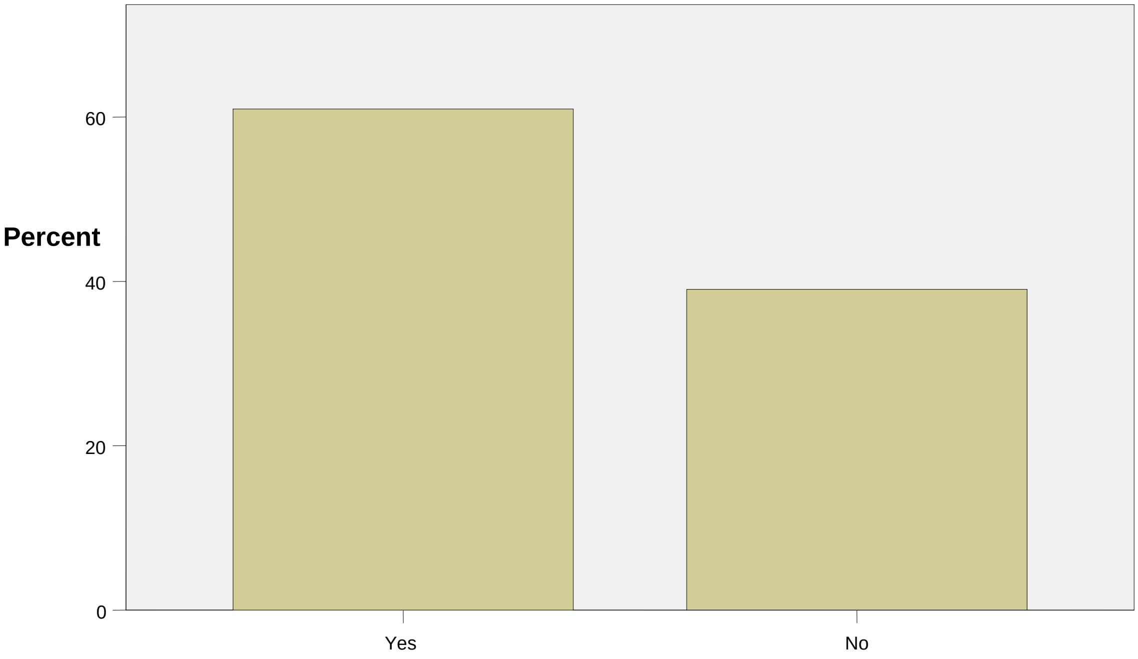
Question 6

Do you feel you should have been referred to a mental health practitioner earlier?

Answered 164 (94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
Yes	100	61
No	64	39

Do you feel you should have been referred to a mental health practitioner earlier?



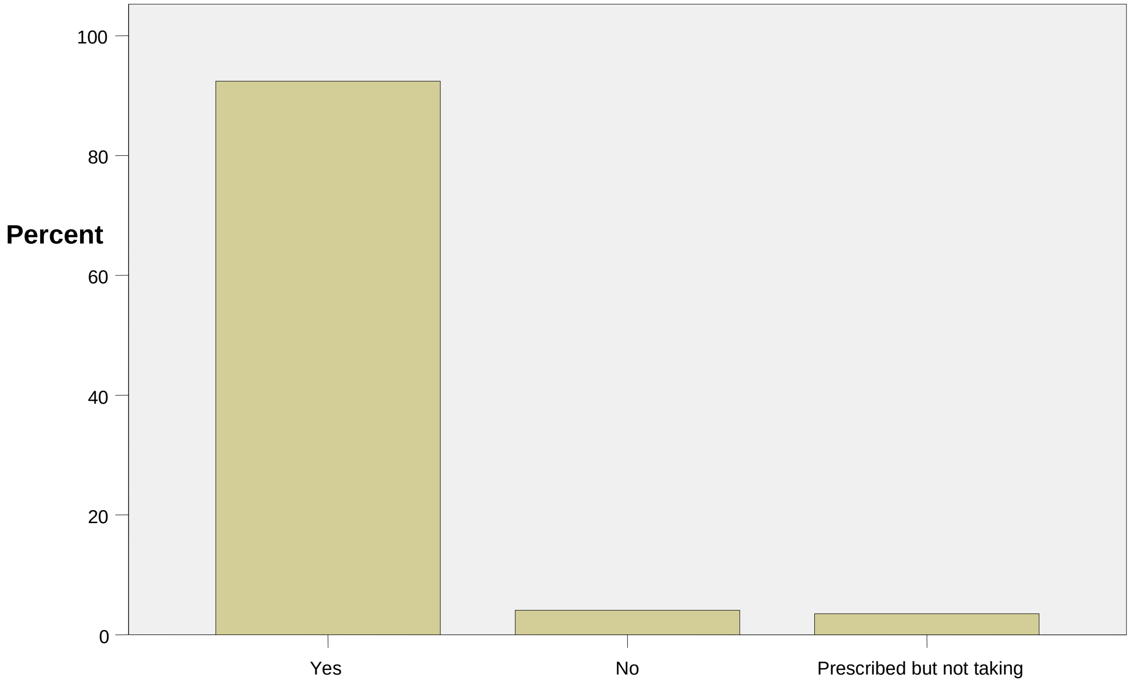
61 % of respondents (N= 100), felt they should have been referred earlier. The responses to this question may be seen as justification for the instigation and development of early intervention services. The Service User Audit Group suggest that a primary care should provide easier access to secondary and in patient provision, developing a self referral process where appropriate.

Question 7
Are you currently on any medication for your mental health problem?

Answered 171 (98.8%)
Missing Answers 2 (1.2%)

	Frequency	Percent
Yes	158	92.4
No	7	4.1

Are you currently on any medication for your mental health problem?



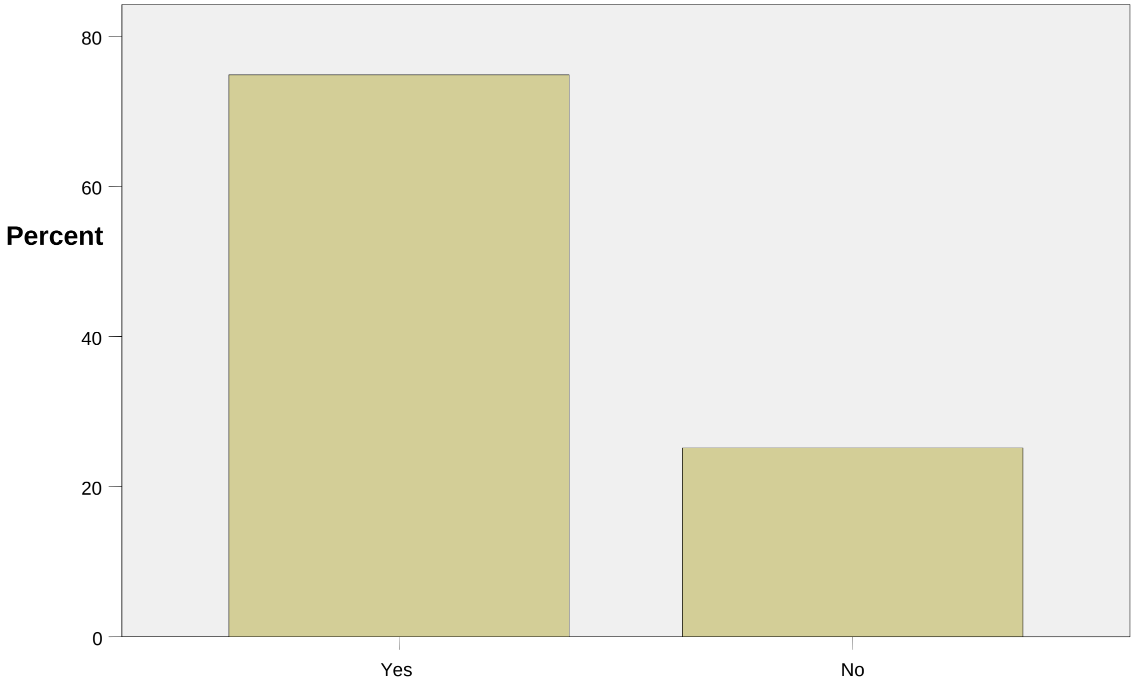
92.4% of respondents (N= 158) provided to the positive response. This indicates that Mental Health Services in Leicester, Leicestershire and Rutland, rely heavily on the prescription of, and compliance with medication based treatment.

Question 8
Is information about your medication available?

Answered 167 (96.5%)
Missing Answers 6 (3.5%)

	Frequency	Percent
Yes	125	72.3
No	42	24.3

Is information about your medication available?



The majority of respondents 74.9% (N= 125) suggested that information was available. However 25.1% (N= 42), felt that it was not. The Service User Audit Group considers this latter figure to be unacceptable. It is recognized however that a person suffering from a mental health problem may have a reduced capacity to either recognise of understand information which may be presented to them. Information should be presented in a variety of ways to enable universal access.

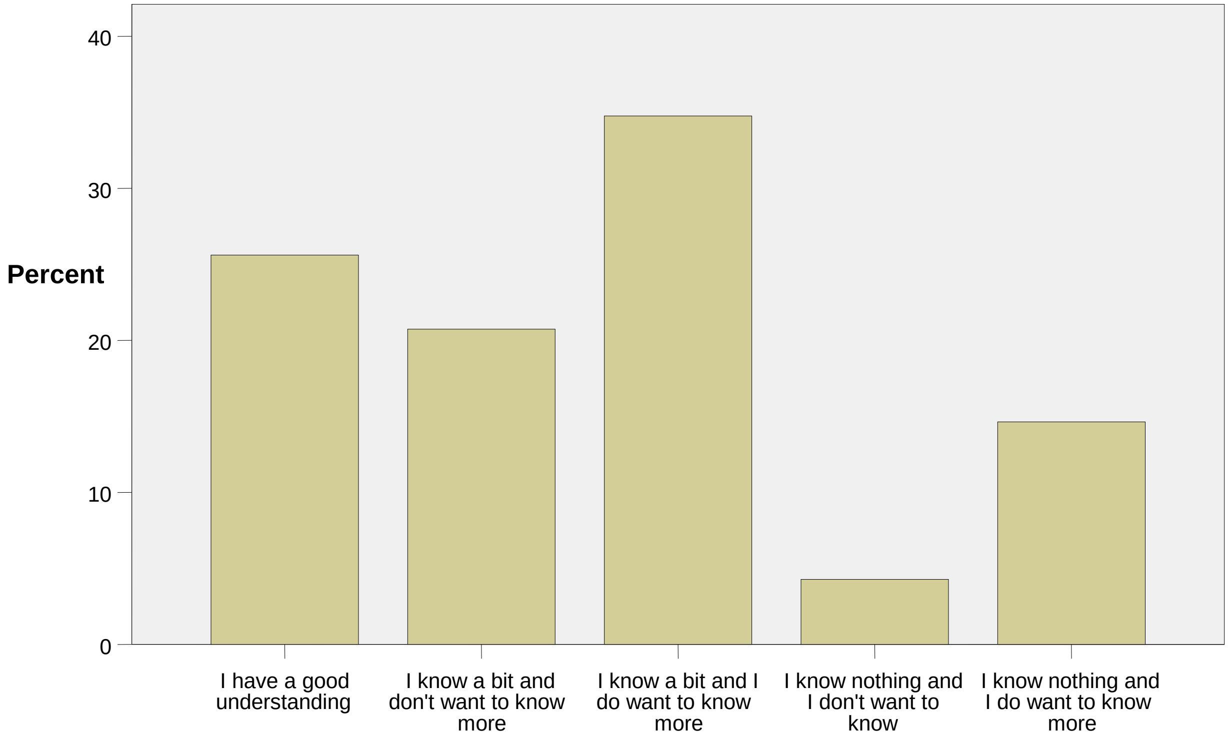
Despite the majority of respondents having access to information about medication the following table in question 9 indicates that the information failed to instil a clear understanding.

Question 9

Answered 164 (94.8%)
Missing Answers 6 (3.5%)

	Frequency	Percent
I have a good understanding	42	25.6
I know a bit and **don't** want to know more	34	20.7
I know a bit and I **do** want to know more	57	34.8
I know nothing and I **don't** want to know more	7	4.3
That I know nothing and I **do** want to know more	24	14.6

How much do you know about the medication you are on?



This is Likert scale generated responses ranging from having a good understanding, to knowing nothing and not wanting to know more. Considering the knowledge base of respondents this question identified that 35.3% (N= 81) of respondents wanted to know more. This indicates that the Trust could do better in providing an understanding and knowledge base for patients taking medication. Information of some description seems available but the level of understanding gained from it is inconsistent.

The Service User Audit Group suggest that increased levels of understanding will lead to patients making an informed choice, greater empowerment and ultimately better adherence and concordance to any medication regime.

The balance to these figures identifies 81.1% (N= 133) of respondents as having either a good understanding or some knowledge. Only 25.6 % (N= 42) of the total respondents felt they have a good understanding.

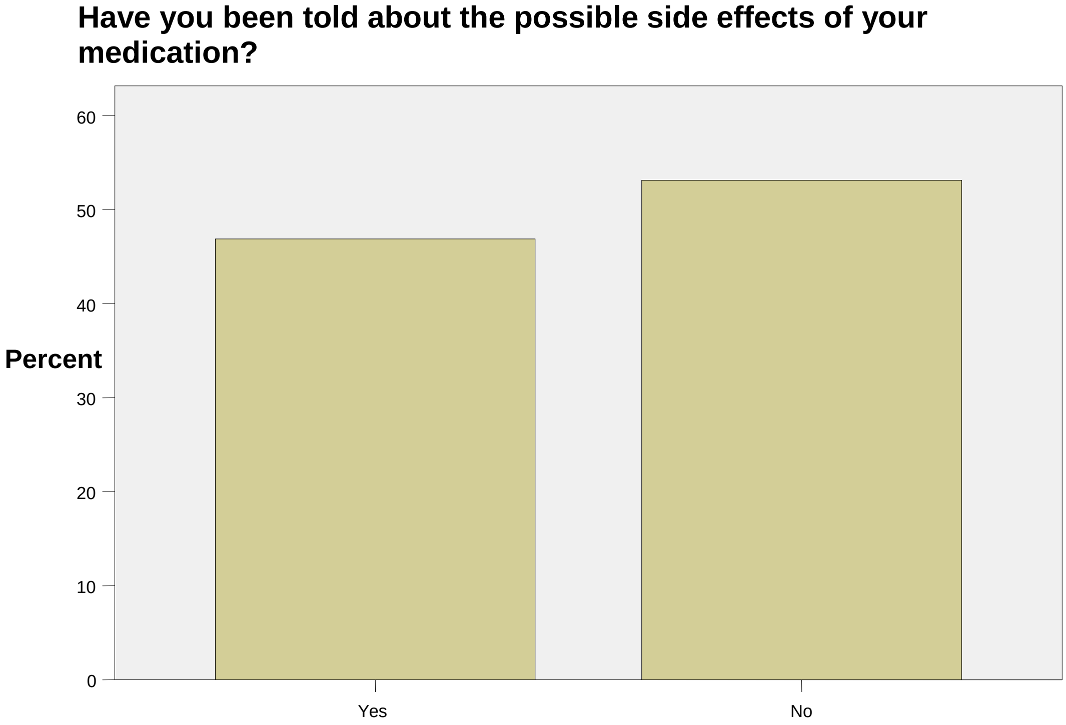
The Service User Audit Group recommend an increased number of medication groups based on wards and day centres. These would provide an opportunity to explore medication issues with peers, and be given appropriate information, together with explanation and a forum to explore individual reactions. The group also recommend that patients have access to the reference documents used by prescribers such as the British National Formulary (BNF). In addition, Pharmacy services should provide more simple fact sheets for patients, carers and relatives. The Trust should endeavour to not only provide information about medication at the outset of treatment, but also ongoing updates relating to side effects, indications, contra indications and jointly monitor the effects upon the individual.

Question 10

Have you been told about the possible side effects of your medication?

Answered 164 (94.8%)
Missing Answers 6 (3.5%)

	Frequency	Percent
Yes	75	46.9
No	85	53.1



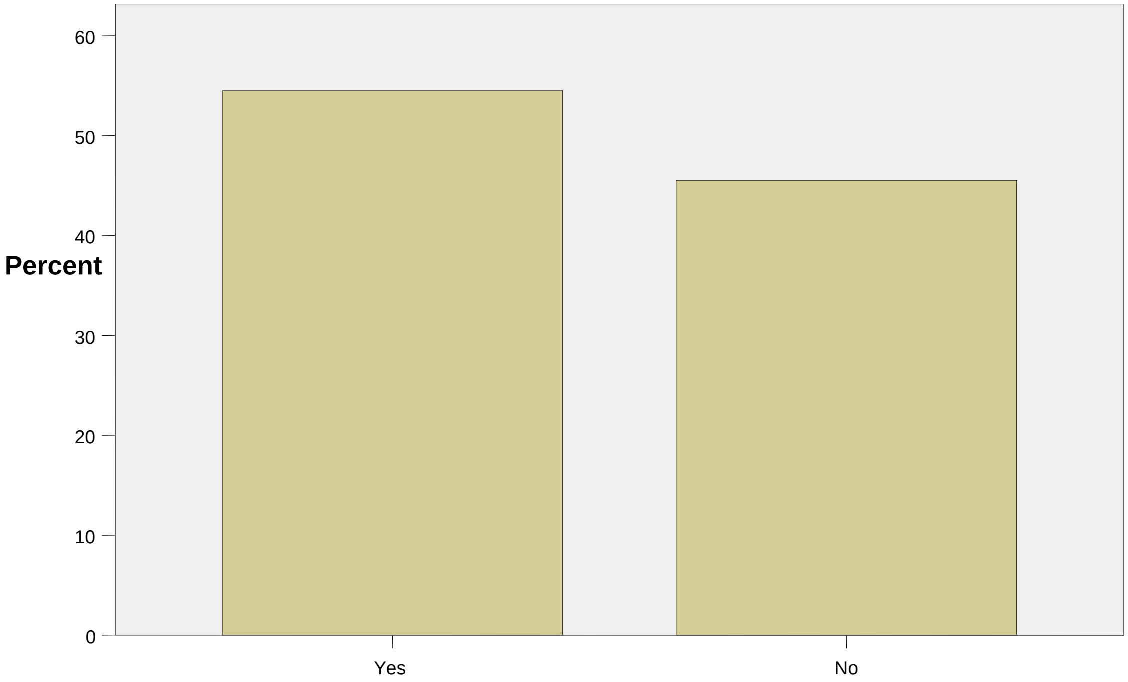
53.1% (N= 85) of respondents denied been told about the side effects of their medication. This should represent a concern to Leicestershire Partnership Trust and all providers of care. The responsibility for providing information about side effects should rest firmly with the prescriber (Doctor or Nurse Prescriber), however the Service User Audit Group recognise that this task could be delegated to the multi disciplinary team, and in particular the patient’s Primary Nurse or Key Worker. The health and safety implications for patients not knowing the side effects of their medication are far reaching in that, the patients may place themselves at risk by driving if a side effect is drowsiness, or eating contra indicated foods for example.

Question 11
Do you think the side effects outweigh the benefits of your medication?

Answered 145 (83.8%)
Missing Answers 28 (16.2%)

	Frequency	Percent
Yes	79	54.5
No	66	45.5

Do you think the side effects outweigh the benefits of your medication?



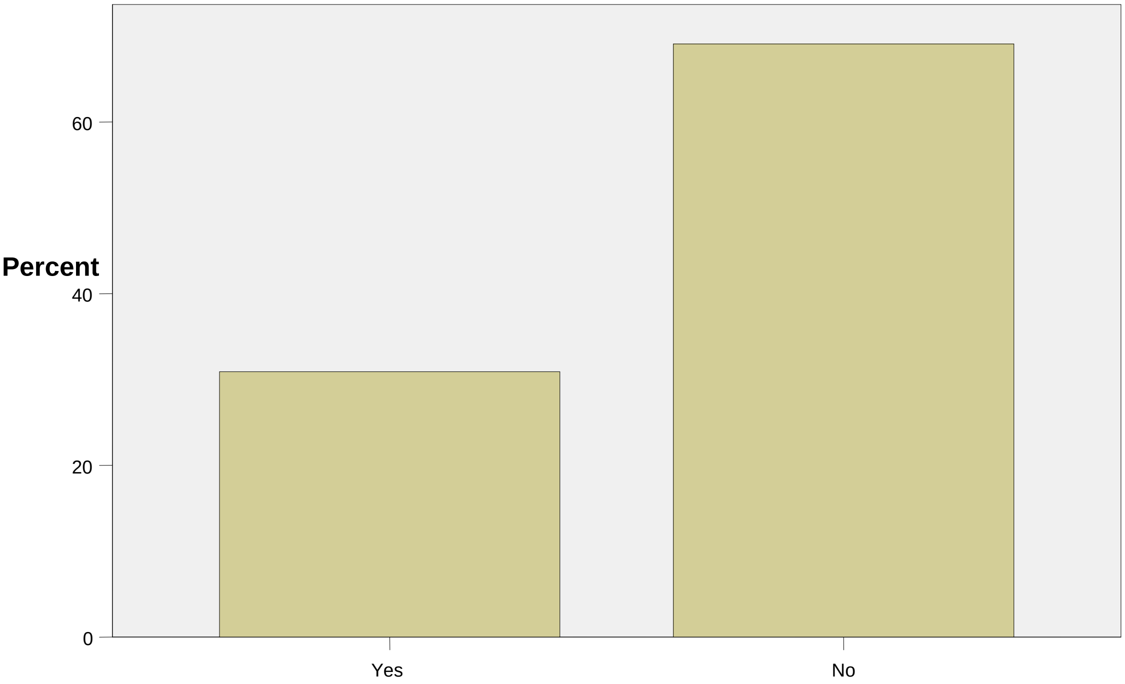
Unfortunately the majority of respondents reported that they had difficulty understanding this particular question and because of this, these results may not represent a true picture. Research Interviewers attempted to explain the meaning of the question and managed to gather a response rate of 83.8 %.(N= 145), 54.5% (N= 79) of respondents considered the side effects to outweigh the benefits. Conversely 45.5% (N= 66) felt the benefits outweighed the side effects. The result of this question is further compromised by the fact that information and understanding about side effects is not universal and therefore the capacity to respond accurately to this question is inhibited. (If you don't know what the side effects are, how can you comment?).

Question 12
Were you given information about alternative medications?

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
Yes	51	30.9
No	114	69.1

Were you given information about alternative medications?



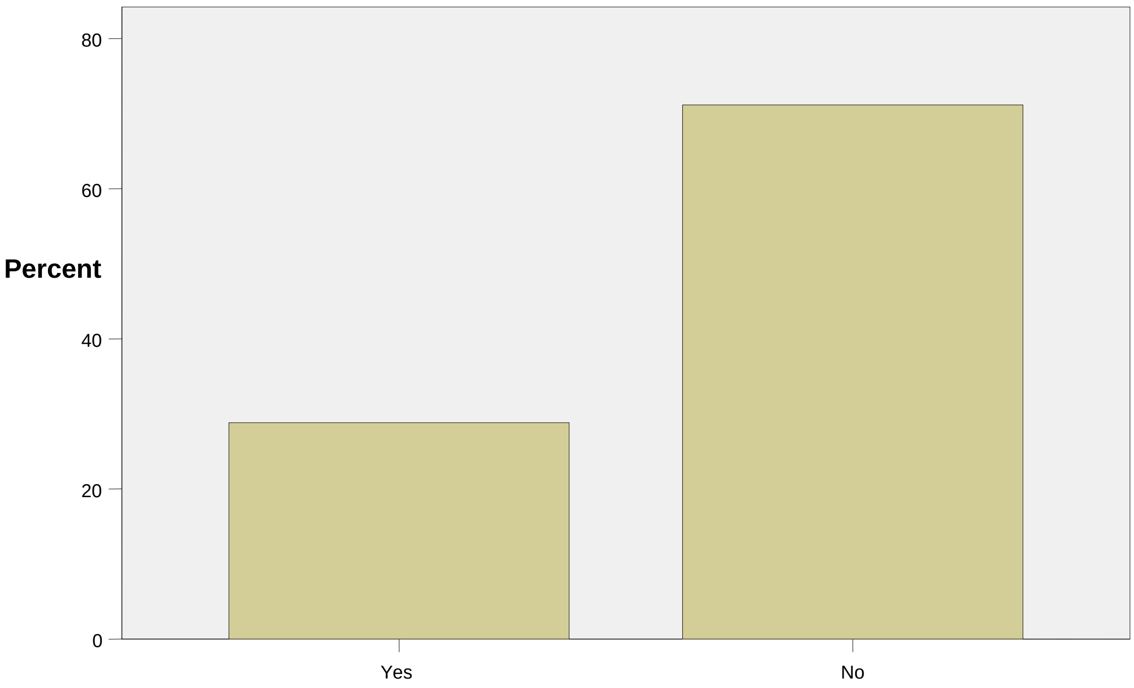
69.1% (N= 114) of respondents were not offered any information about alternative medications. This response rate correlates directly with the answers for question 13 which relate to choice. The Service User Audit Group wish to see the issue of choice addressed as a matter of priority

Question 13
Were you given a choice about the medication you are on?

Answered 163 (94.2%)
Missing Answers 10 (5.8%)

	Frequency	Percent
Yes	47	28.8
No	116	71.2

Were you given a choice about the medication you are on?



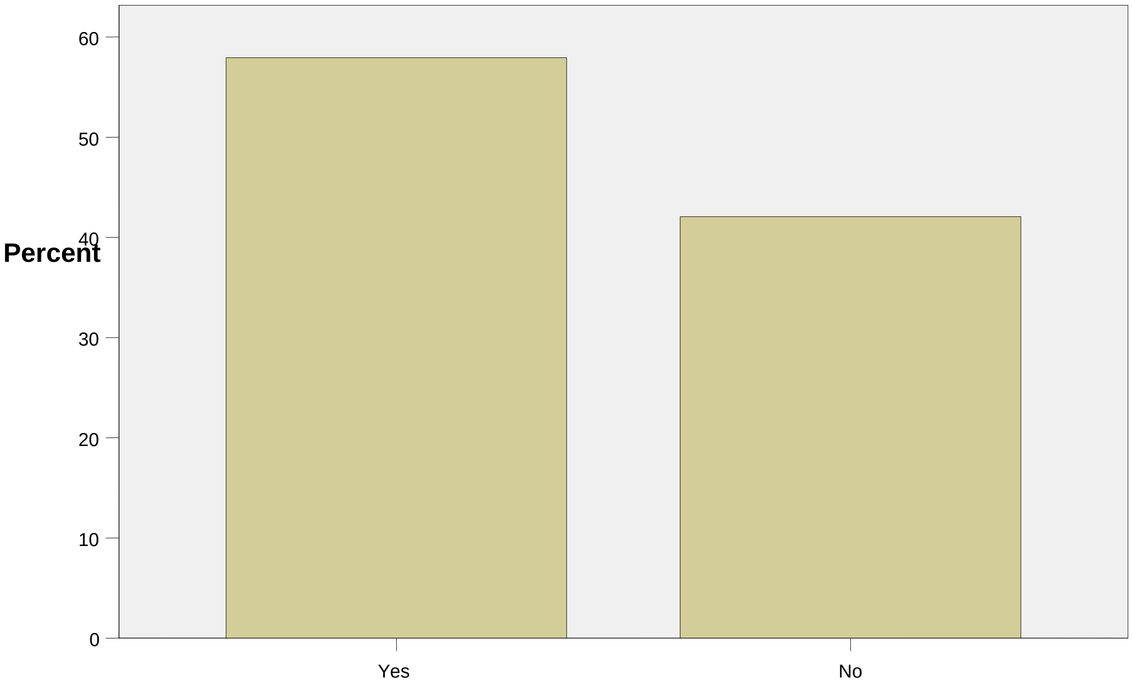
71.2 % (N= 116) of respondents declared they were not given any choice. The Service User Audit Group recognises the correlation between offering a choice and the increased workload of explaining the benefits and drawbacks of a particular medicine, together with the associated time delay for this consultation process. This is however obviated by increased empowerment and personal efficacy. If prescribers are to participate in an improved therapeutic relationship then offering choice goes some way to achieving this.

Question 14
Did you have the opportunity to discuss the medication you are on?

Answered 164 (94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
Yes	95	57.9
No	69	42.1

Do you/ did you have the opportunity to discuss the medication you are on?



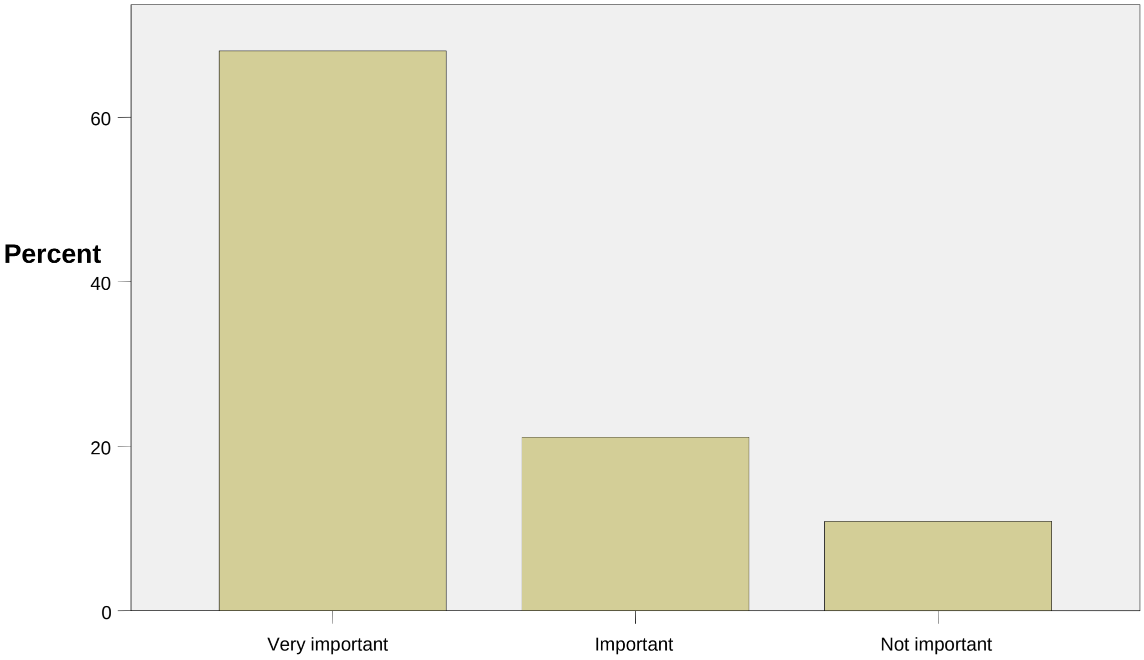
57.9% (N= 95) had an opportunity to discuss leaving 42.1% (N= 69) who were not given this opportunity. These results indicate that the opportunity to discuss medication did not involve alternatives or choices for some of those respondents. This implies that the discussion may have been one way, because a significant proportion of respondents had already highlighted a lack of information, discussion and choice. The Service User Audit Group suggest that these factors undermine feelings of empowerment within respondents and the broader patient population and should be addressed as a matter of priority.

Question 15
How important is it you to discuss your medication with a health professional?

Answered 166 (96%)
Missing Answers 7 (4%)

	Frequency	Percent
Very important	113	68.1
Important	35	21.1
Not Important	18	10.8

How important is it to you to discuss your medication with a health professional?



The majority of respondents (89.2%, N= 148)) felt that discussion of the medication was either important for very important.
This result demonstrates the disparity between the wishes of the person receiving treatment and the service they are receiving. The Service User Audit Group recommends that informed discussions take place, at the outset of treatment and during reviews of that treatment, enabling better understanding and providing an opportunity for the patient’s opinions to be considered.

Question 16 a,b,c,d

How often would you like to discuss your medication with a health professional?

The responses to questions 16 b,16 C and 16 D may be affected by the respondents' assumption that answering question 16 A, completed this section. Research Interviewers reported that respondents recognized the need to comply with the appointment system, and not overburden service resources.

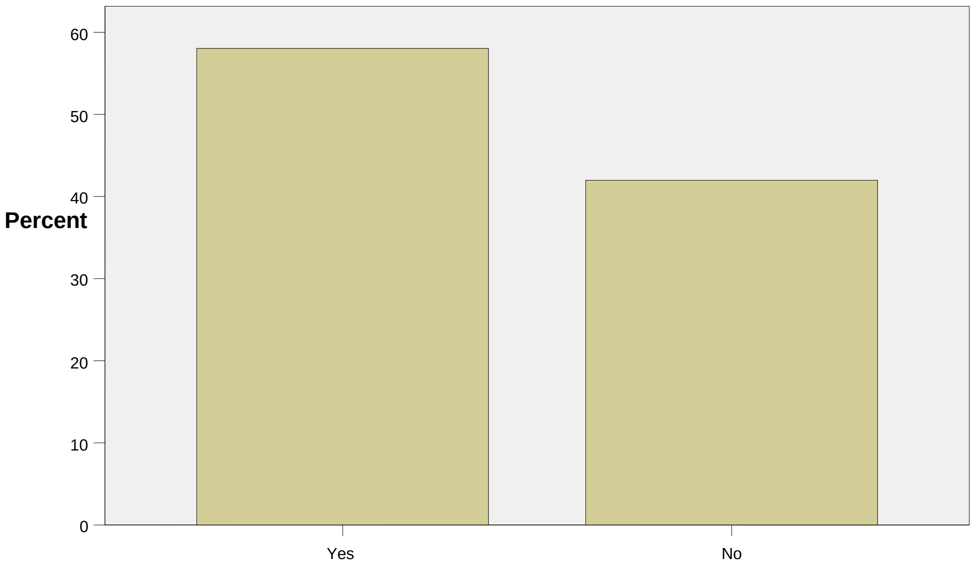
Question 16a

I would like to discuss my medication with a Health Care professional whenever I like

Answered 162 (93.6%)
Missing Answers 11 (6.4%)

	Frequency	Percent
Yes	94	58
No	68	42

I would like to discuss my medication with a health care professional whenever I like



58% (N= 94) of respondents suggested that they would like to discuss the medication with a Health Care professional whenever they wanted.

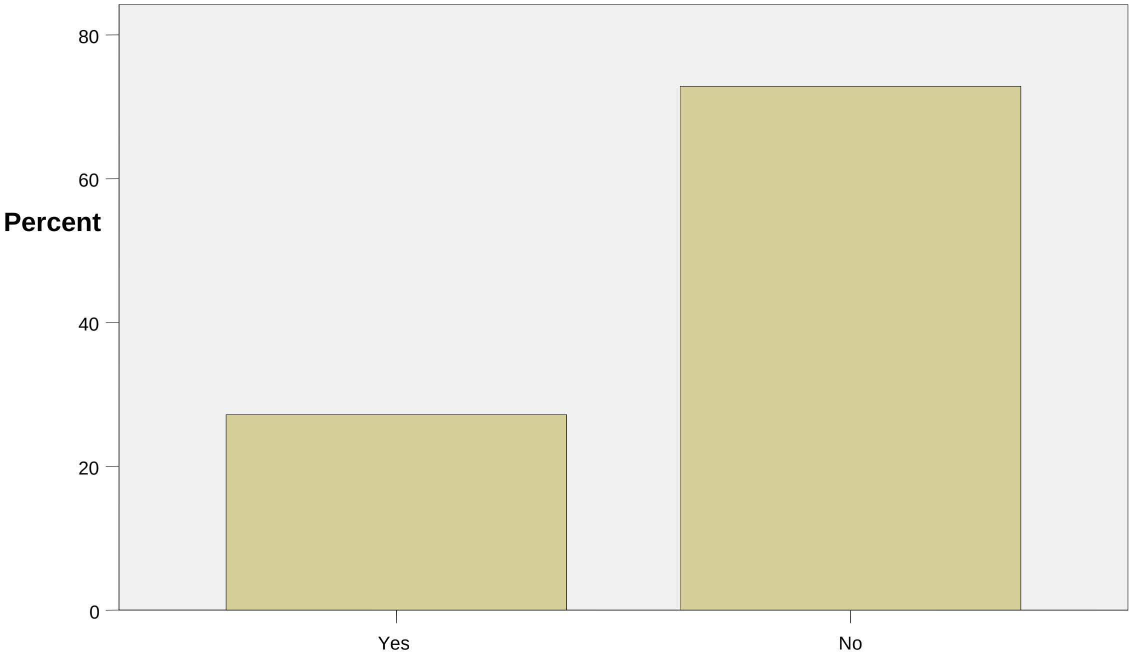
Question 16b

I would like to discuss my medication with a Health Care professional when my medication changes.

Answered 162 (93.6%)
Missing Answers 11 (6.4%)

	Frequency	Percent
Yes	44	27.2
No	118	72.8

I would like to discuss my medication with a health care professional when my medication changes



27.2% (N= 44) of respondents suggested that they would like to discuss the medication with a Health Care professional when their medication changed.

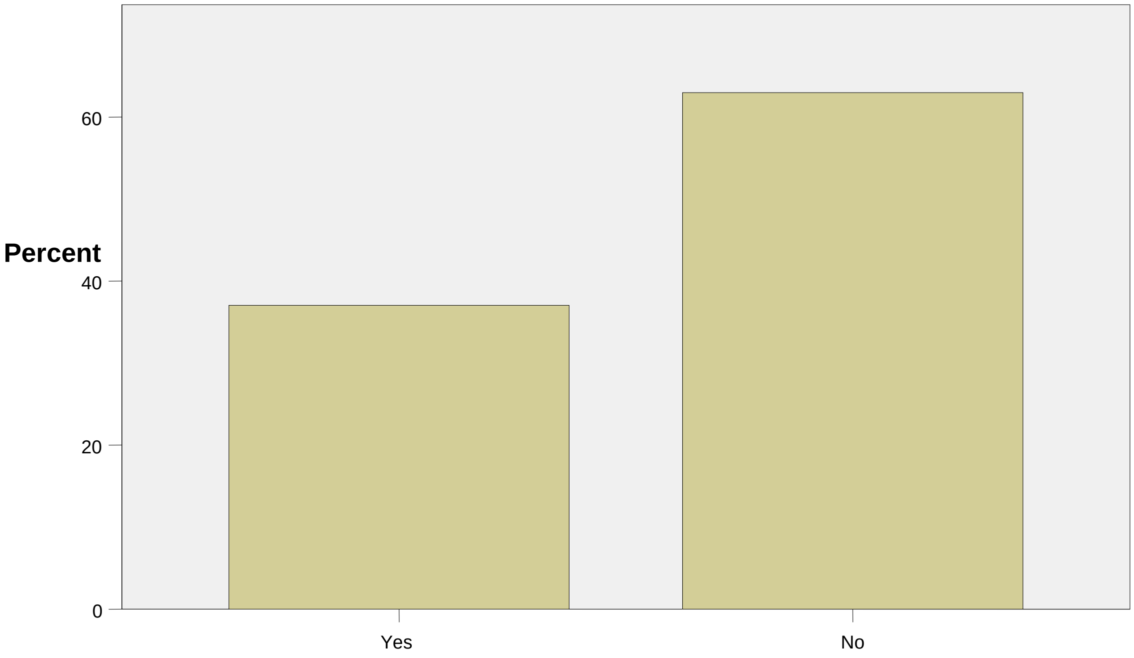
Question 16c

I would like to discuss my medication with a Health Care professional when I have a problem with it.

Answered 162 (93.6%)
Missing Answers 11 (6.4%)

	Frequency	Percent
Yes	60	37
No	102	63

I would like to discuss my medication with a health care professional when I have a problem with it



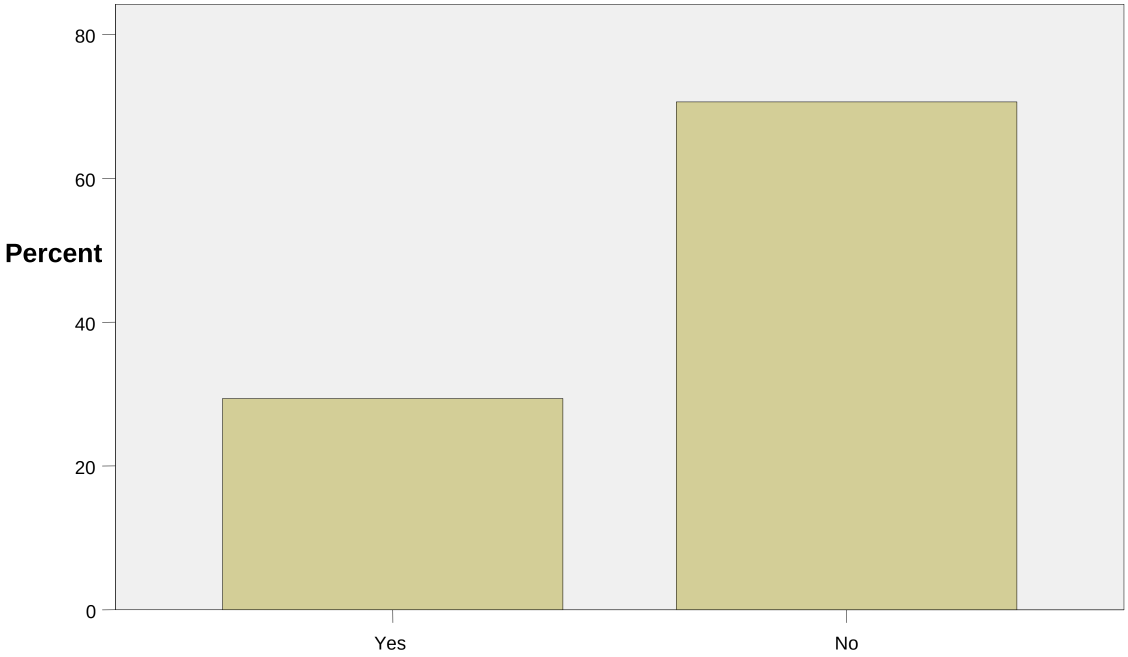
37% (N= 60) of respondents suggested that they would like to discuss the medication with a Health Care professional when there was a problem. It was considered by the Service User Audit Group that those who answered no to this question may well be acknowledging the futility of initiating a discussion about their medication outside of a formal review.

Question 16d
I would like to discuss my medication with a Health Care professional when I have an appointment.

Answered 160 (92.5%)
Missing Answers 13 (7.5%)

	Frequency	Percent
Yes	47	29.4
No	113	70.6

I would like to discuss my medication with a health care professional when I have an appointment



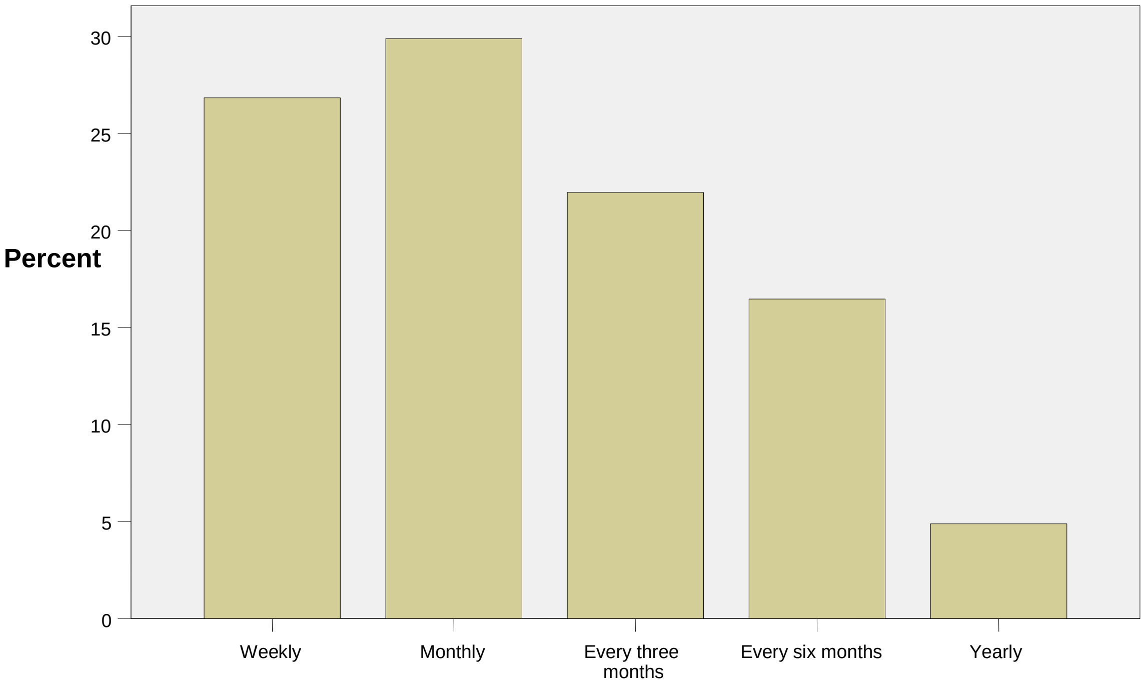
29.4% (N= 47) of respondents suggested that they would like to discuss the medication with a Health Care professional when they had an arranged appointment, however the Service User Audit Group feel that waiting for an arranged appointment is disempowering.

Question 17
If you had a medication review meeting how often should it be?

Answered 160 (92.5%)
Missing Answers 13 (7.5%)

	Frequency	Percent
Weekly	44	26.8
Monthly	49	29.9
Every three months	36	22
Every six months	27	16.5
Yearly	8	4.9

If you had a medication review meeting, how often should this be?

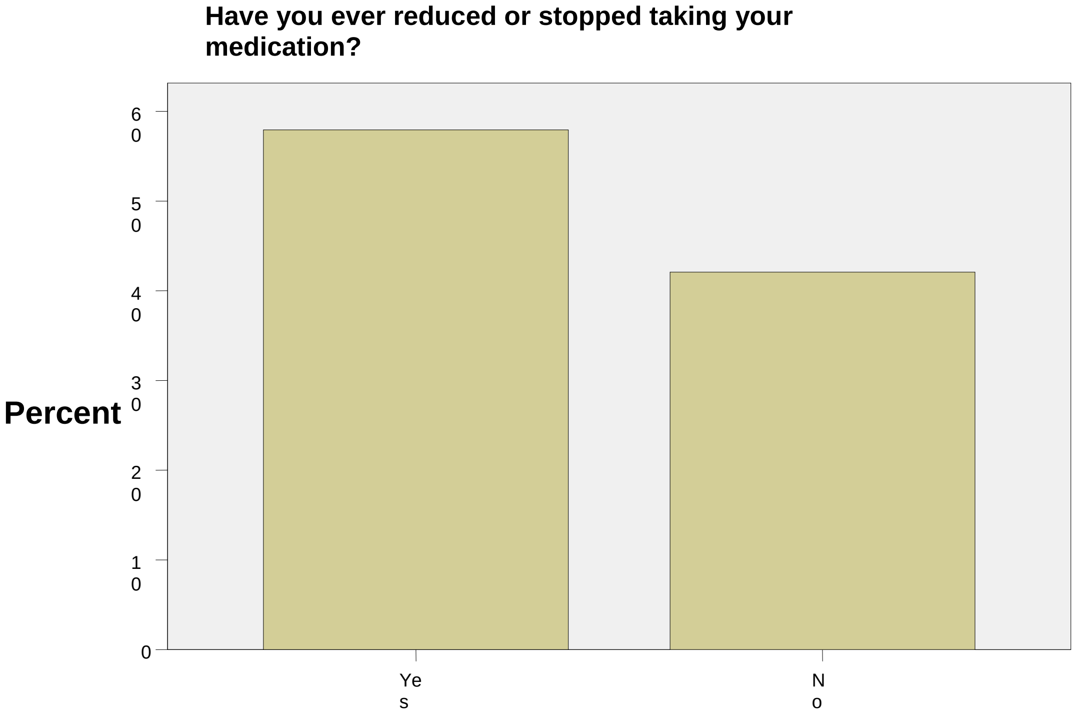


The range of responses spanned weekly, monthly, three monthly, six monthly and. The most popular answers for weekly and monthly 26.8% (N= 44) and 29.9% (N= 49) respectively. Although there are no conclusive results pertaining from this question, it is clear that medication review is an important factor of care for the person taking medication, and pre arranged meetings however often undermine the opportunity to discuss medication issues when it suits the person who is taking it.

Question 18
Have you ever reduced or stopped taking your medication?

Answered 164 (94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
Yes	95	57.9
No	69	42.1



57.9% (N= 95) confirmed they had reduced or stopped taking medication, and leaving 39.9% who had fully complied. The Service User Audit Group feels that these responses underscore the need for informed choice and better information.

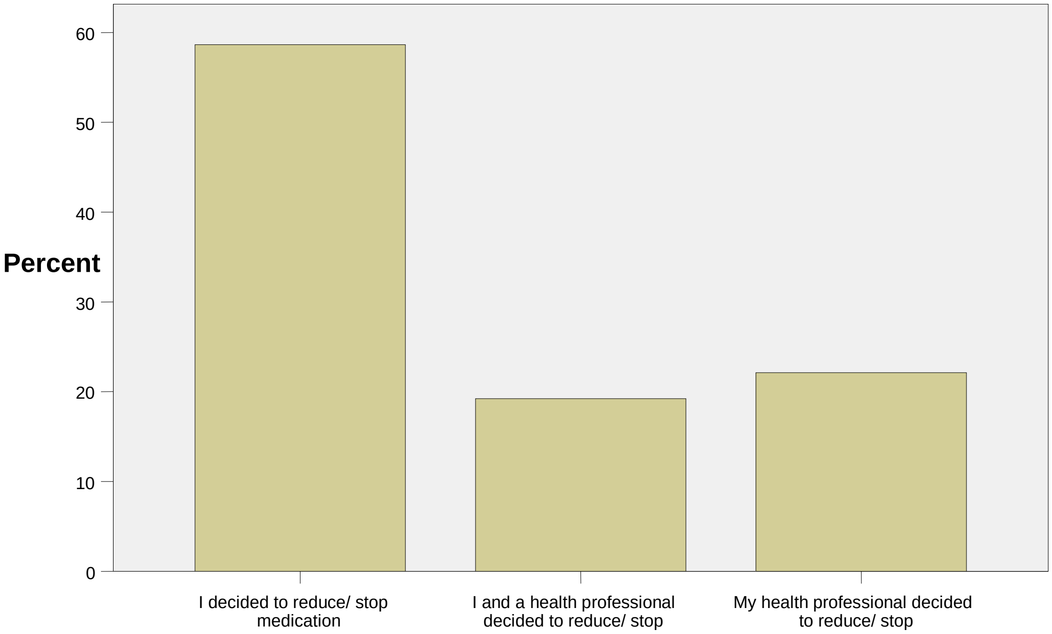
Question 19
On the last occasion you reduced or stopped taking medication it was due to:

Answered 104 (60.1%)

Missing Answers 69 (39.9%)

	Frequency	Percent
I decided to reduce/stop medication	61	58.7
I and a Health professional decided to stop or reduce the medication	20	19.2
My health professional decided to reduce/stop Medication	23	22.1

On the last occasion I reduced or stopped taking medication it was due to:



Responses to this question were comparatively poor with 39.9 %(N=69) not responding. Of those who did respond, 58.7% (N= 61) had decided to reduced or stopped taking medication alone, whilst 19.2% s (N= 20) stopped in collaboration with a health professional and 22.1 % (N= 23) decided to stop or reduce the medication on the advice of a professional.

The Service User Audit Group suggest that the uptake for this question may have been affected by a desire by the respondent not to "incriminate themselves", and factors such as the availability of choice may mean that patients would be less likely to attempt reduction or stopping medication without consultation..

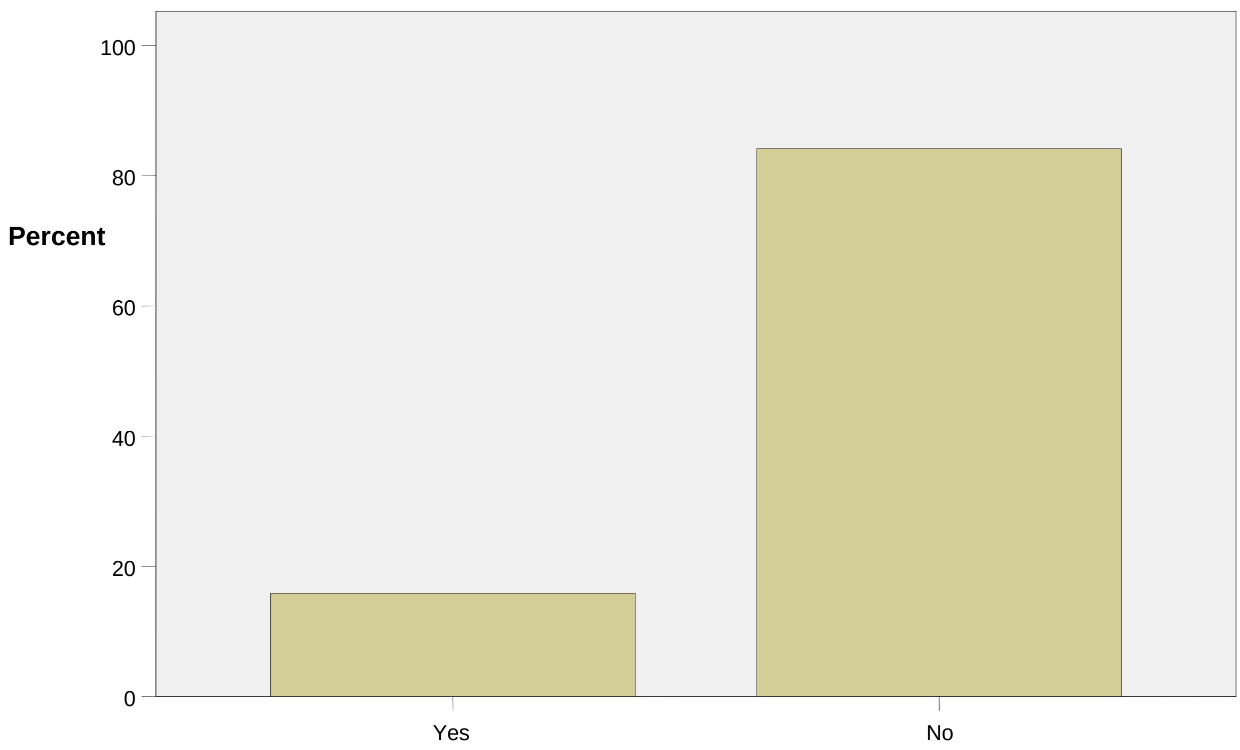
Question 20

Have you ever had your medication stopped against your will?

Answered 120 (69.4%)
Missing Answers 53 (30.6%)

	Frequency	Percent
Yes	19	15.8
No	101	84.2

Have you ever had your medication stopped against your will?



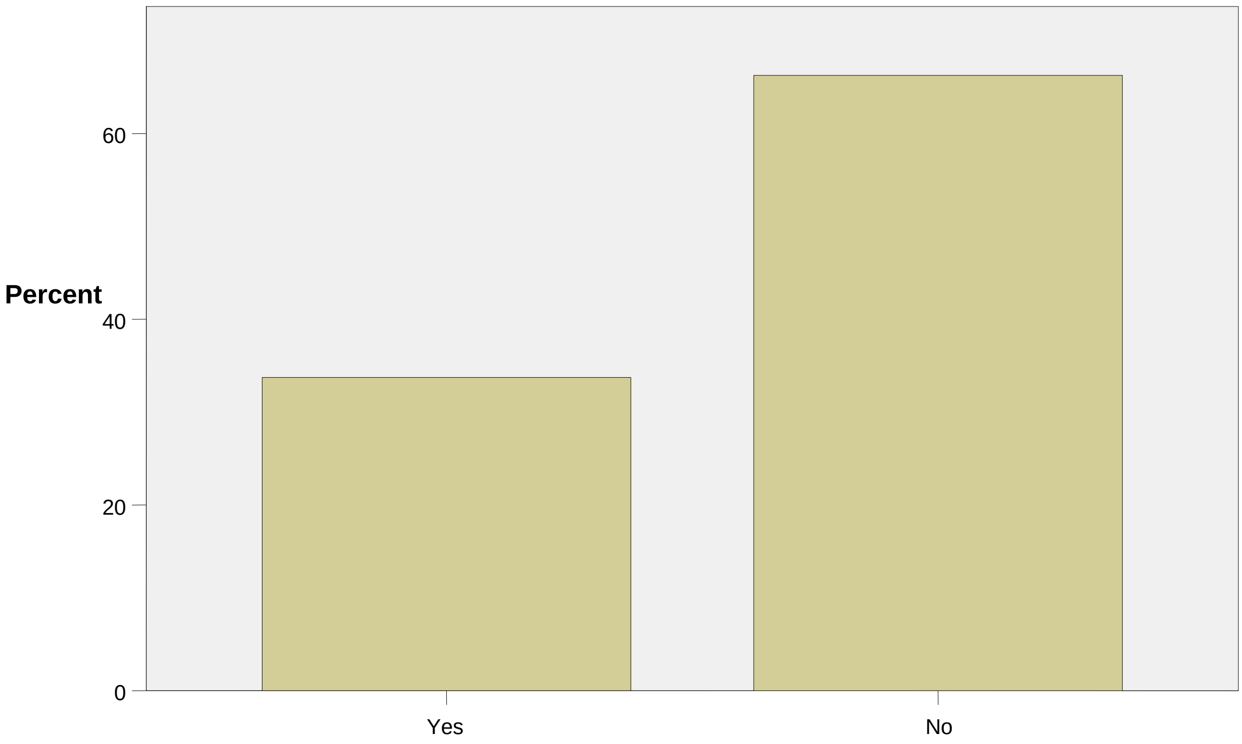
Again the response rate was low with 30.6 % (N=53) missing. The majority of those who did respond (84.2 %, N = 101)) had never had medication stopped against their will.

Question 21
Have you ever been forced to take medication against your will?

Answered 163 (94.2%)
Missing Answers 10 (5.8%)

	Frequency	Percent
Yes	55	33.7
No	62.4	66.3

Have you ever been forced to take medication against your will?



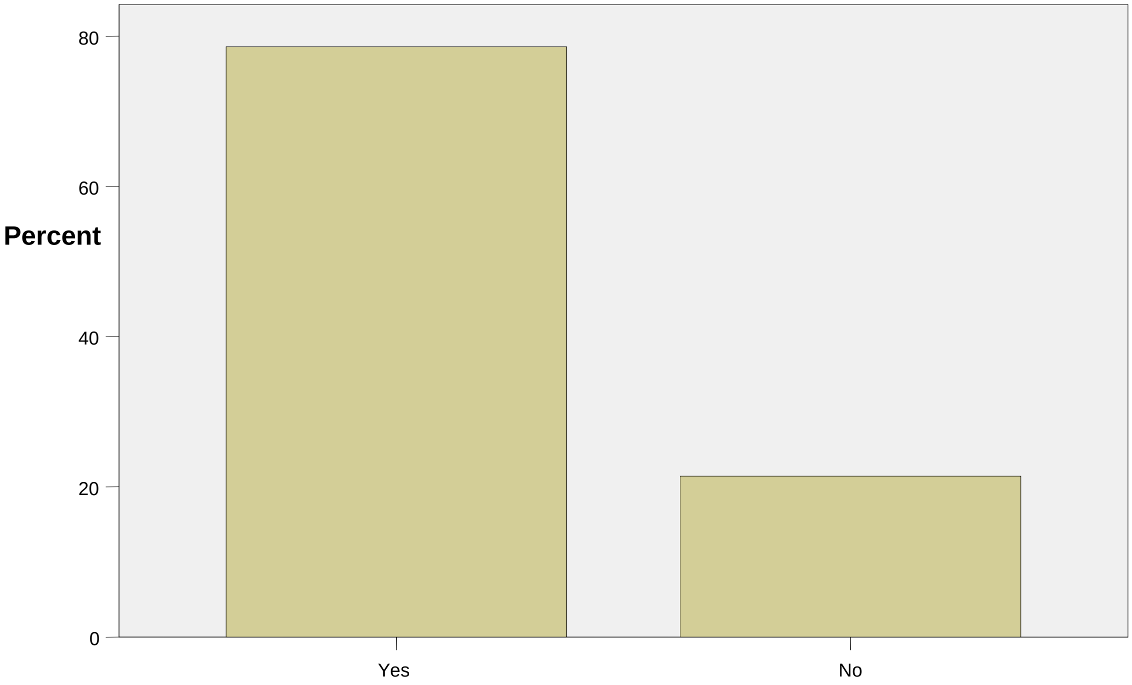
33.7% (N= 55) of respondents suggested that they had been forced to take medication against their will.
The implications of one third of respondents feeling that hey have been forced to take medication against their will is a factor which prescribers need to consider. Being forced to take medication will undermine the therapeutic relationship for informal and detained patients alike.

Question 22
Do you know your diagnosis?

Answered 168 (97.1%)
Missing Answers 5 (2.9%)

	Frequency	Percent
Yes	132	78.6
No	36	21.4

Do you know your diagnosis?



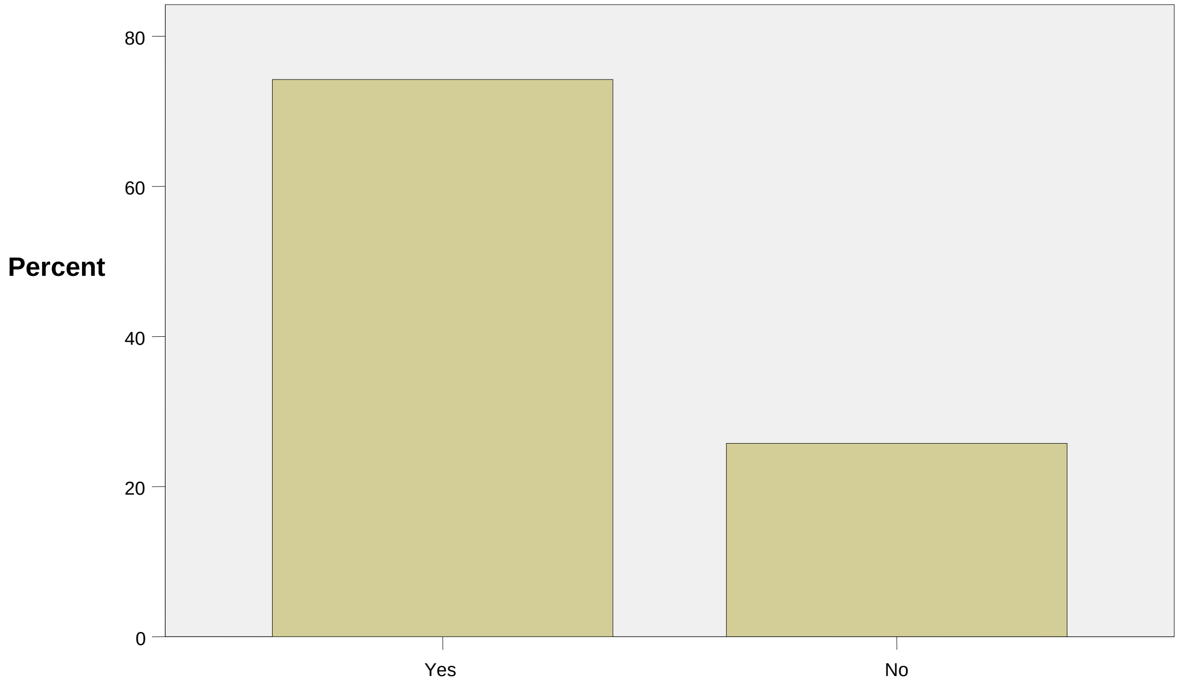
78.6 per cent (N= 132) indicated that they knew their diagnosis, however if perhaps the more important figure is that of 21.4% (N=36) of respondents did not know their diagnosis. The Service User Audit Group feel that the proportion of respondents who do not know their diagnosis is unacceptably high and mental Health Service providers should be reminded how important it is to share information and fully explain the rationale and evidence behind any treatment.

Question 23
Did you want to know your diagnosis in the early stages of your illness?

Answered 66 (38.2%)
Missing Answers 107(61.8%)

	Frequency	Percent
Yes	49	74.2
No	17	25.8

Did you want to know your diagnosis in the early stages of your illness?



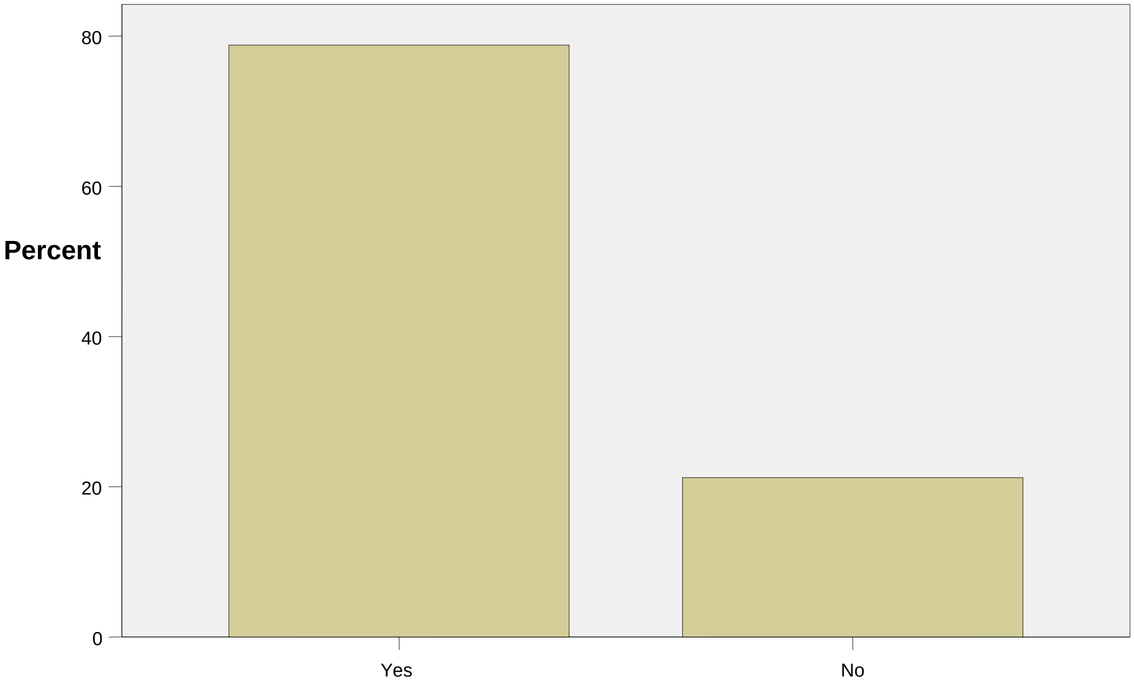
74.2% (N=49) felt that knowing ones diagnosis at an early stage to be important to them.

Question 24
Do you want to know your diagnosis now?

Answered 66 (38.2%)
Missing Answers 107 (61.8%)

	Frequency	Percent
Yes	52	78.8
No	14	21.2

Do you want to know your diagnosis now?



Only 21.2% (N= 14) of respondents didn’t want to know their diagnosis at the time of interview. The uptake for this question was low with 61.8% (N= 107) declining to answer.

Question 25

Question 25 Are there any other medication issues you would like to tell us about?

This answer required a qualitative response and verbatim quotations are listed below:

- Present medication is effective keeps me on an even keel
- Not happy with medication at moment will talk to consultant
- I would like to know side effects for the future
- Antipsychotic medication has individual problems.
- Difficult to understand side effects. Physical problems interacts with outside things i.e. age etc
- When recover from lack of sleep, antipsychotic drugs give alternative psychosis which stops dopamine. So no high anymore. The drug causes psychosis so slow withdrawal is better. Old medication makes you flat and can not feel happy even if you want to.
- Medication not working. Side effects taking over. Side effects give the impression of diagnosed illness. E.g. irritability– injection = more irritable
- I would like to know long term effects of Lithium
- When sectioned doctors take me off my normal medication and put me on a different medication. Causes too much side effects and keeps me in hospital longer
- On medication for heart trouble. The Mental Health medication sometimes is not compatible
- I have found a medication that suits.
- I am satisfied with what I am taking
- Satisfied with what I take
- First lot of medication made me feel ill. Psychiatrist changed it without consulting me but I am satisfied with this one

A mixed set of responses both positive and negative.

Question 26 to what extent are the following statements accurate on a scale of 1 to 3 where one = false and three = true all of the time?

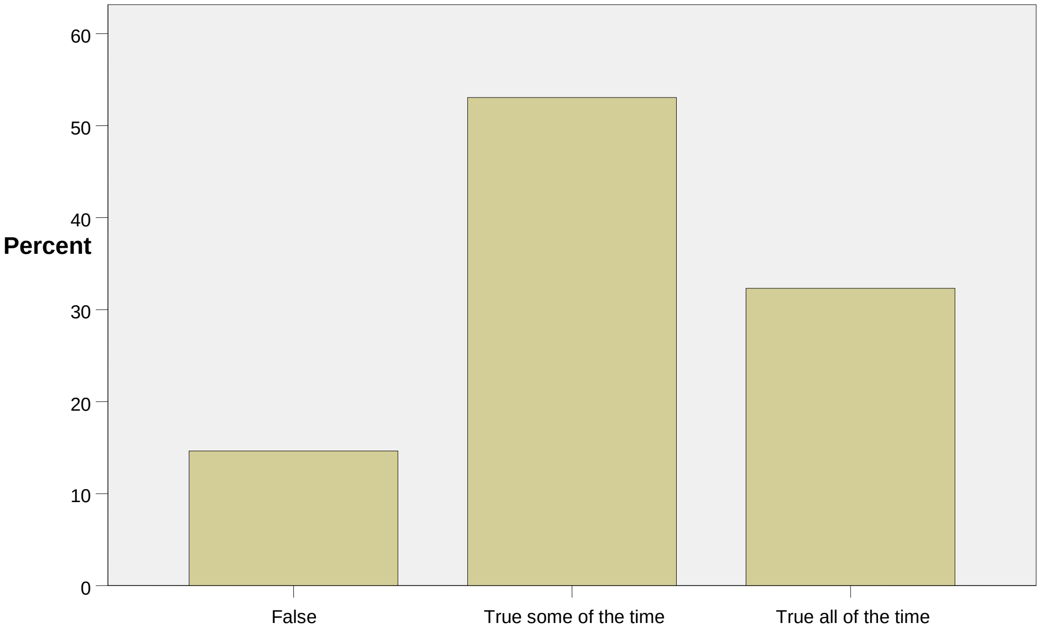
Question 26a

The staff are available to help Service Users take control of their condition

Answered 164 (94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
False	24	14.6
True some of the time	87	53
True all of the time	53	32.3

Staff are able to help Service Users take control of their condition



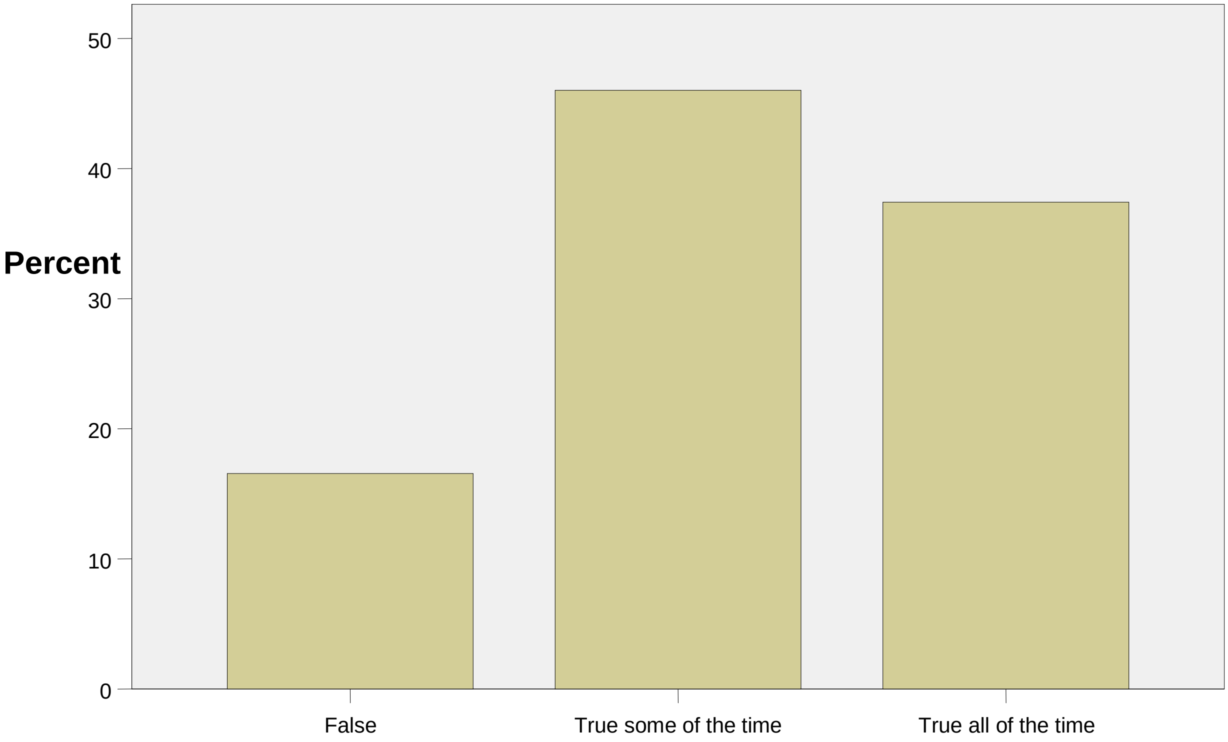
The percentage of respondents who felt that staff were able to help them take control of their condition was 85.3% (N= 140) being true some, or all of the time. The Service User Audit Group commends service providers for their efforts in enabling staff to instil this perception within respondents.

Question 26b
Staff are available to service users when they need someone to talk to

Answered 163 (94.2%)
Missing Answers 10 (5.8%)

	Frequency	Percent
False	27	16.6
True some of the time	75	46
True all of the time	61	37.4

Staff are available to service users when they need someone to talk to



78.7% (N= 136) of respondents if had suggested that staff were available either some or all of the time. This combination of answers seems to contradict the qualitative responses elicited through question number 39 in which a considerable proportion of respondents suggested that increased staffing numbers would increase availability.
It is acknowledged that recent staff increases within Leicestershire Partnership Trust have improved the protected time offered to patients.

Question 26c

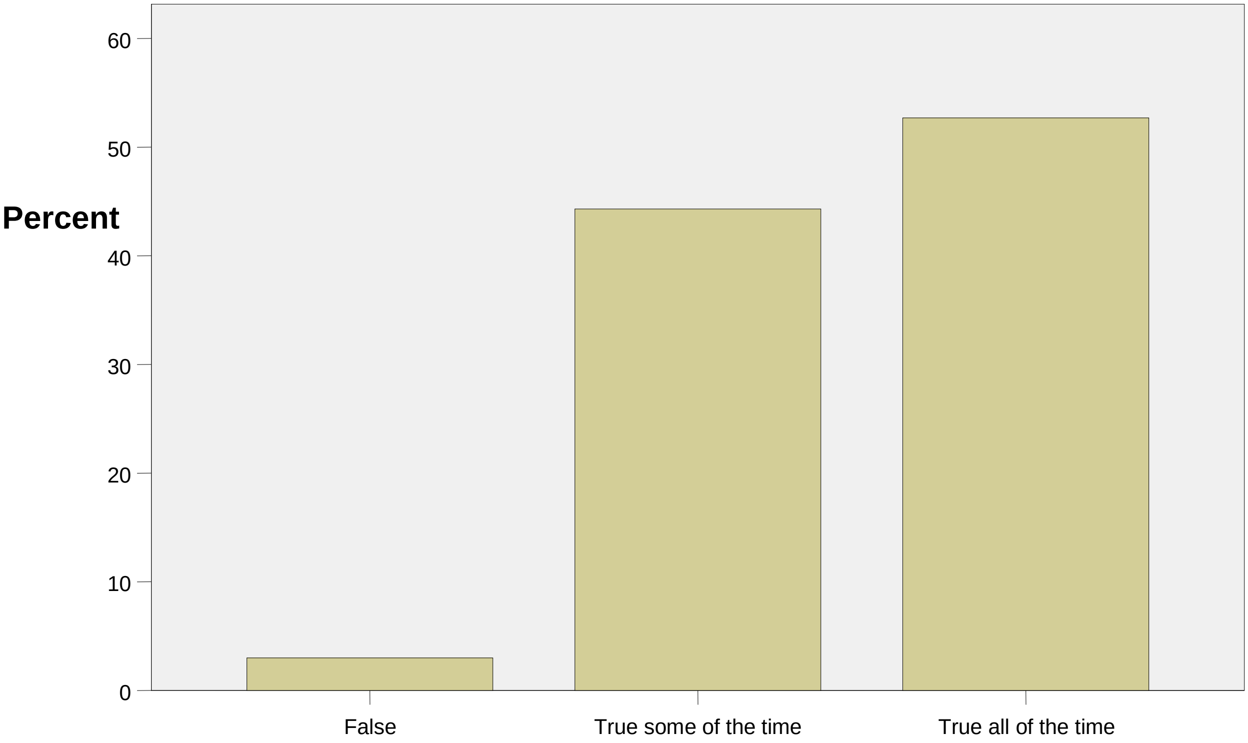
Staff are friendly and approachable

Answered 167 (96.5%)

Missing Answers 6 (3.5%)

	Frequency	Percent
False	5	3
True some of the time	74	44.3
True all of the time	88	52.7

Staff are friendly and approachable



97% of respondents (N=162) felt that staff were friendly and approachable. Leaving only 3% (N= 5) who felt they were not.
The Service User Audit Group feels this is an excellent result for providers of Mental Health Services.

Question 26d
Staff treat Service Users as their equals

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
False	38	23
True some of the time	67	40.6
True all of the time	60	36.4

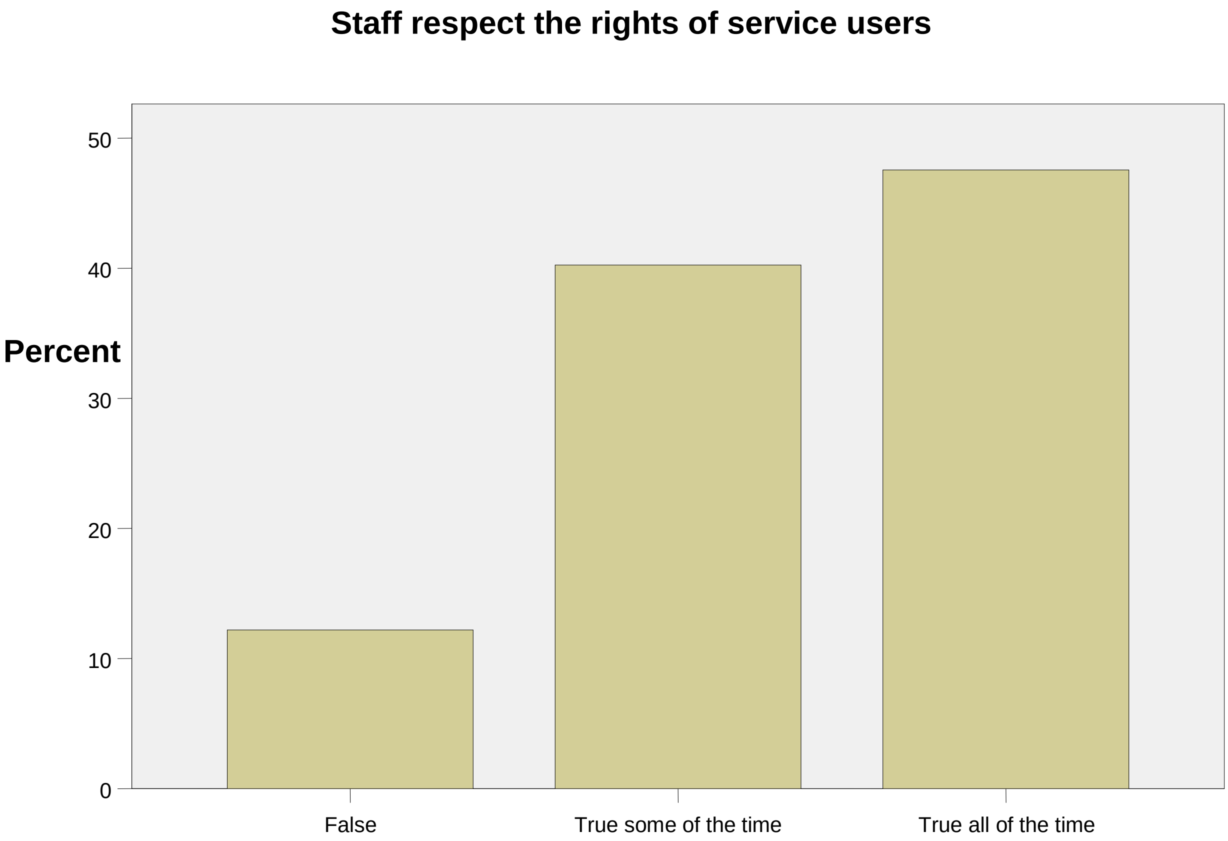
Staff treat Service Users as their equals

77% of respondents (N=127) felt that staff treat service users as their equals. 23% (N= 38) who felt they did not. Again the Service User Audit Group feels this is a good result for providers of Mental Health Services. The Group felt that those who answered false may benefit from a more transparent, open access to staff, information and choice.

Question 26e
Staff respect the rights of Service Users

Answered 164 (94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
False	20	12.2
True some of the time	66	40.2
True all of the time	78	47.6



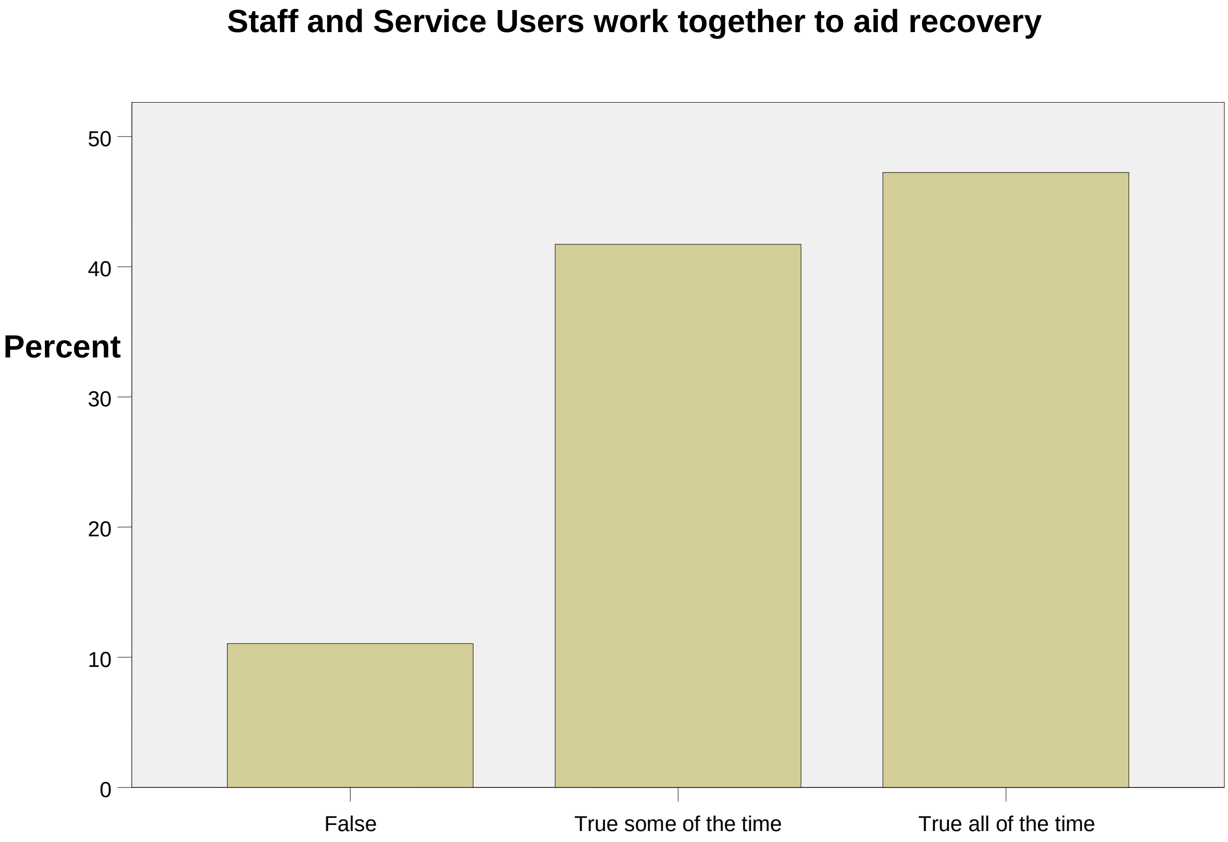
87% of respondents (N=144) felt that staff respected service users rights. 12.2% (N= 20) felt they did not.

Feeling one’s rights are respected, is a critical element of self efficacy and empowerment, and these results reflect the significant improvements that have taken place in recent years.

Question 26f
Staff and Service Users work together to aid recovery

Answered 163 (94.2%)
Missing Answers 10 (5.8%)

	Frequency	Percent
False	18	10.4
True some of the time	68	39.3
True all of the time	77	44.5

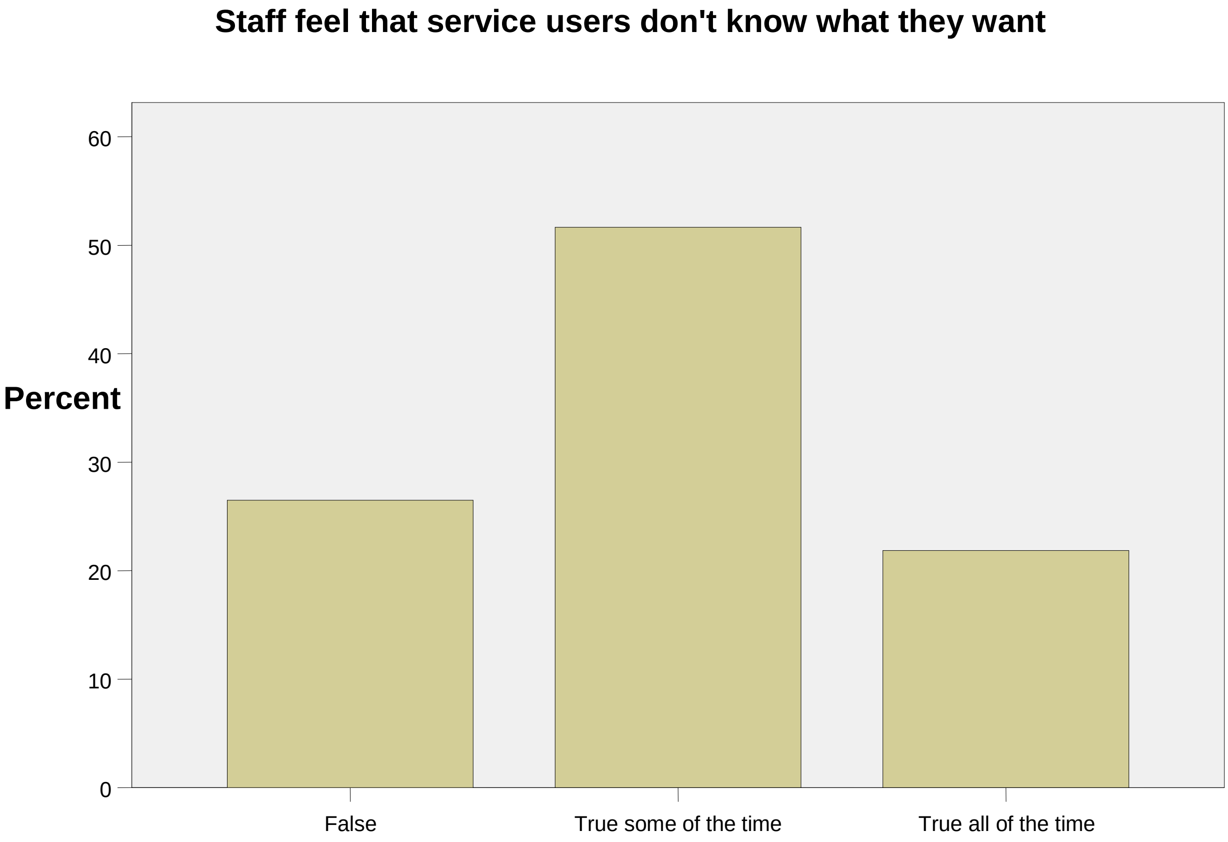


This result represents a high degree of collaboration where 88.9% of respondents (N=145) felt that staff and service users work together to aid recovery. 11% (N= 18) felt they did not.
The partnership between staff and Service Users working together is seen by the Service User Audit Group as a key component to aid recovery, and this is an excellent result for providers of Mental Health Services.

Question 26g
Staff feel that Service Users don’t know what they want

Answered 151 (87.3%)
Missing Answers 22 (12.7%)

	Frequency	Percent
False	40	26.5
True some of the time	78	51.7
True all of the time	33	21.9



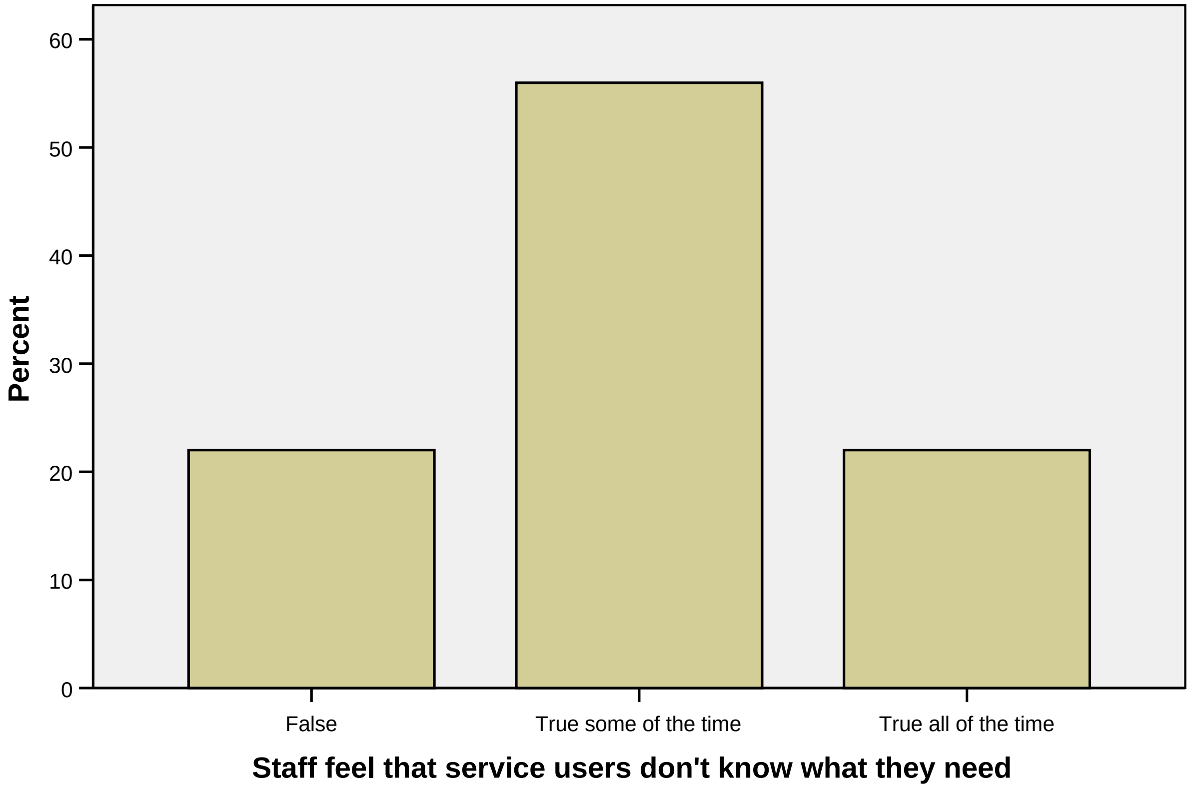
It is the perception of 73.6% of respondents (N=111) that staff feel service users don’t know what they want, and this is disappointing in the light of answers for question 26 f where there is a high degree of collaboration. 26.5% (N= 40) considered staff feel service users do know what they want. The Service User Audit Group feel that staff should regularly check out what the Service Users want by asking direct questions during the assessment process and throughout the time the person receives care. Wants should be placed in context to identify needs.

Question 26h
Staff feel that Service Users don’t know what they need

Answered 159 (91.9%)
Missing Answers 14 (8.1%)

	Frequency	Percent
False	35	20.2
True some of the time	89	56
True all of the time	35	20.2

Staff feel that service users don't know what they need



78% of respondents (N=124) expressed the opinion that staff feel service users don’t know what they need. 22% (N= 35) considered staff feel service users do know what they need.

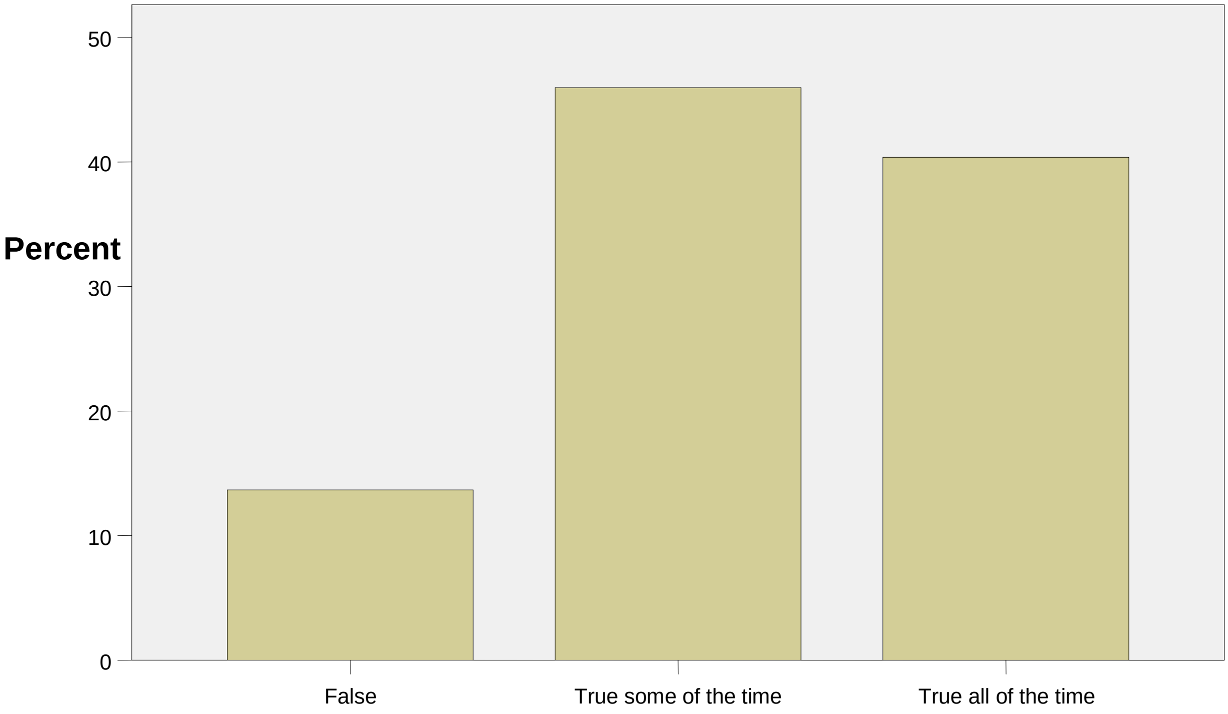
Question 26i

Staff feel that Service Users need to be encouraged to take more responsibility for their mental health

Answered 161(93.1%)
Missing Answers 12 (6.9%)

	Frequency	Percent
False	22	12.7
True some of the time	74	42.8
True all of the time	65	37.6

Staff feel that Service Users need to be encouraged to take more responsibility for their mental health

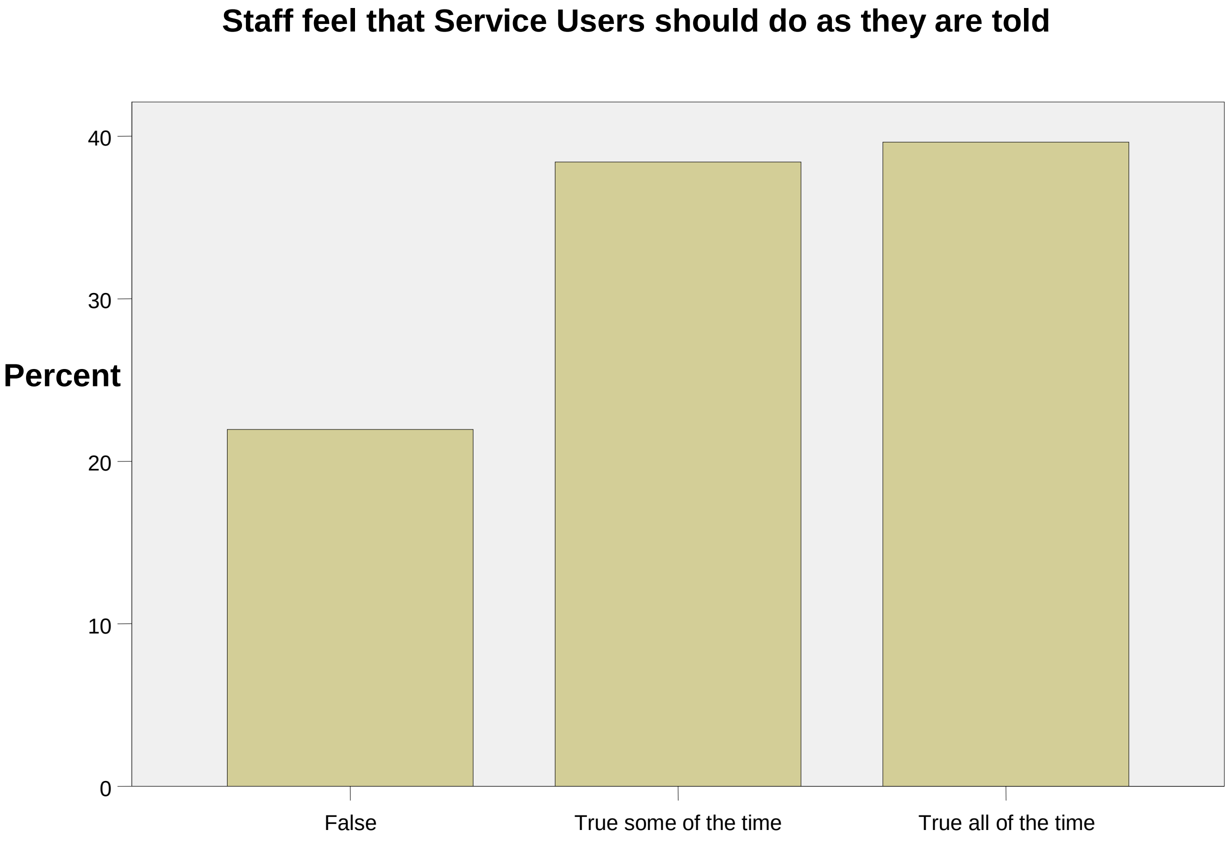


86.4% of respondents (N=139) expressed the opinion that staff feel service users need to be encouraged to take more responsibility for their mental health. If we assume that information, knowledge and understanding are key to the assumption of responsibility (See Questions 8, 9, and 10 for example) then service providers need to respond to this result by providing better information.

Question 26j Staff feel that Service Users should do as they are told

Answered 164 (94.8%)
Missing Answers 9(5.2%)

	Frequency	Percent
False	36	22
True some of the time	63	38.4
True all of the time	65	39.6



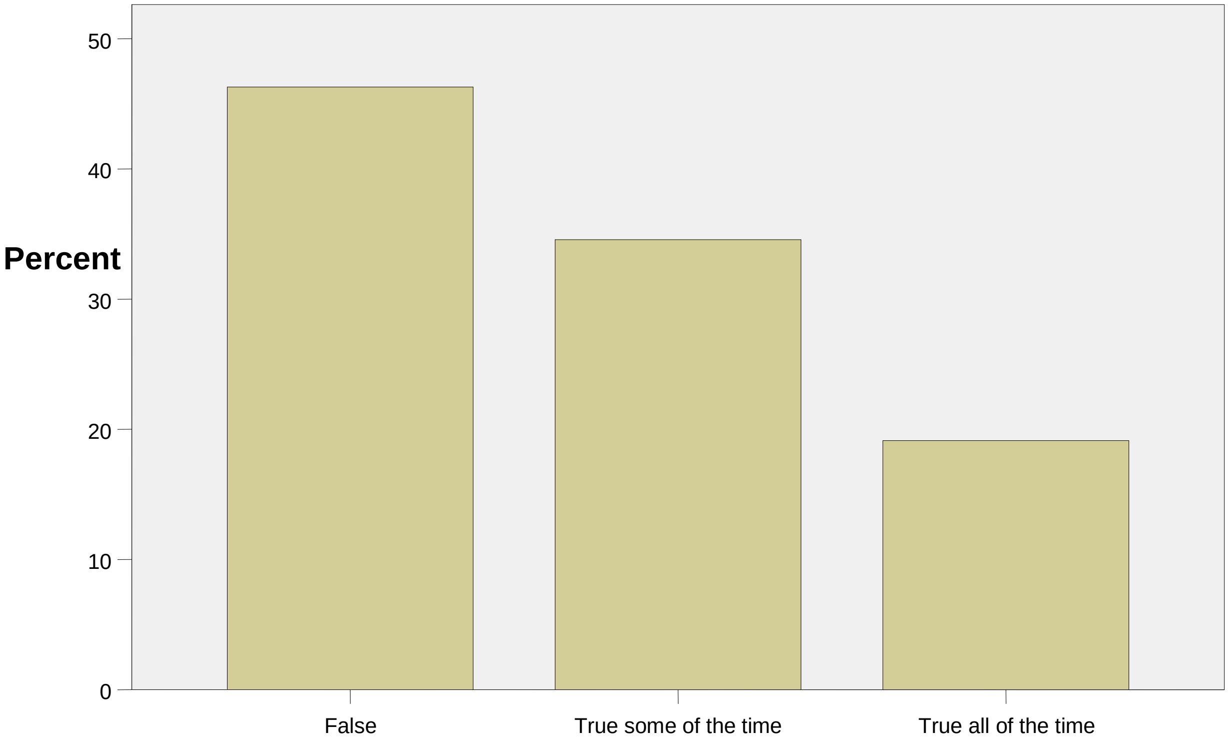
74% of respondents (N=128) expressed the opinion that staff feel service users should do as they are told, some of the time or all of the time. The Service User Audit Group recognise that routine and procedures are in place for the smooth functioning of a ward for example, and do not believe these responses reflect a draconian regime. Answers to question number 33 for example demonstrate a high degree of efficacy in being able to challenge staff.

Question 26k Staff feel that Service Users should be seen and not heard

Answered 162 (93.6%)
Missing Answers 11 (6.4%)

	Frequency	Percent
False	75	46.3
True some of the time	56	34.6
True all of the time	31	19.1

Staff feel that Service Users should be seen and not heard



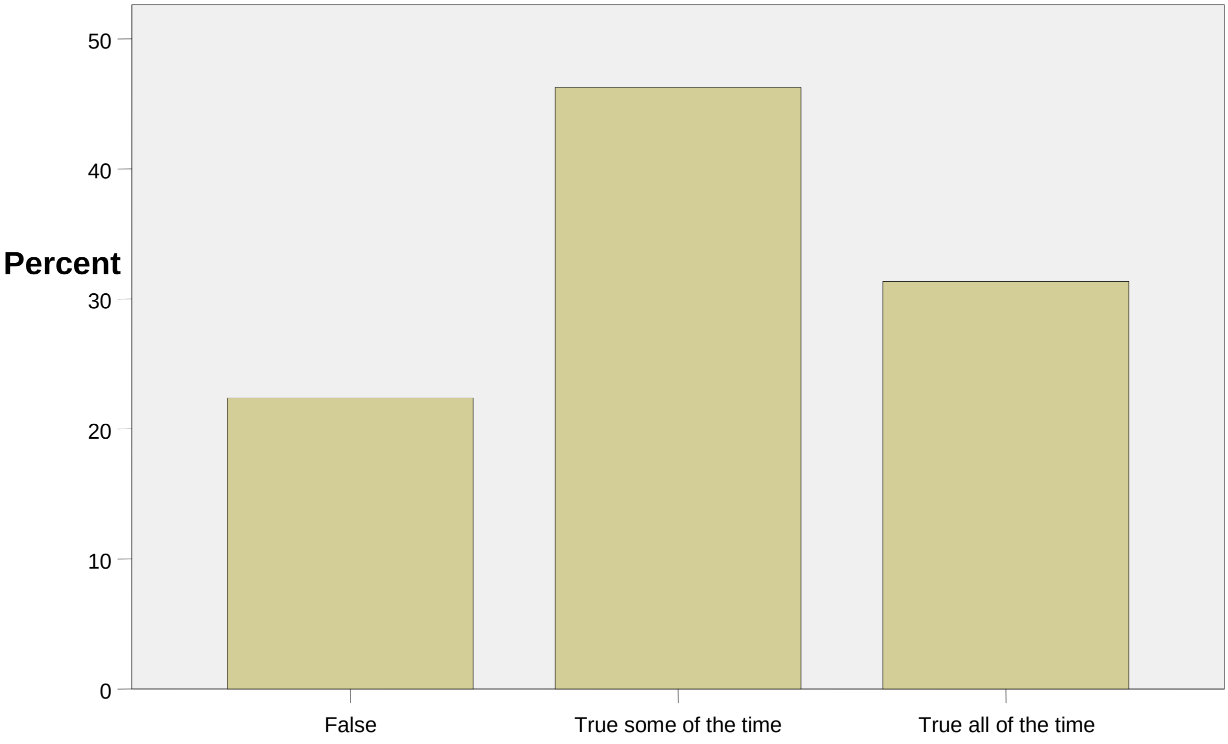
53.7% of respondents (N=87) expressed the opinion that staff feel service users should be seen and not heard. These responses seem to represent a perception that service users are a burden to staff and to some extent contradicts previous answers.

Question 26l Staff do not feel able to question orders given to them by senior staff

Answered 134 (77.5%)
Missing Answers 39 (22.5%)

	Frequency	Percent
False	30	22.4
True some of the time	62	46.3
True all of the time	42	31.3

Staff do not feel able to question orders given to them by senior staff



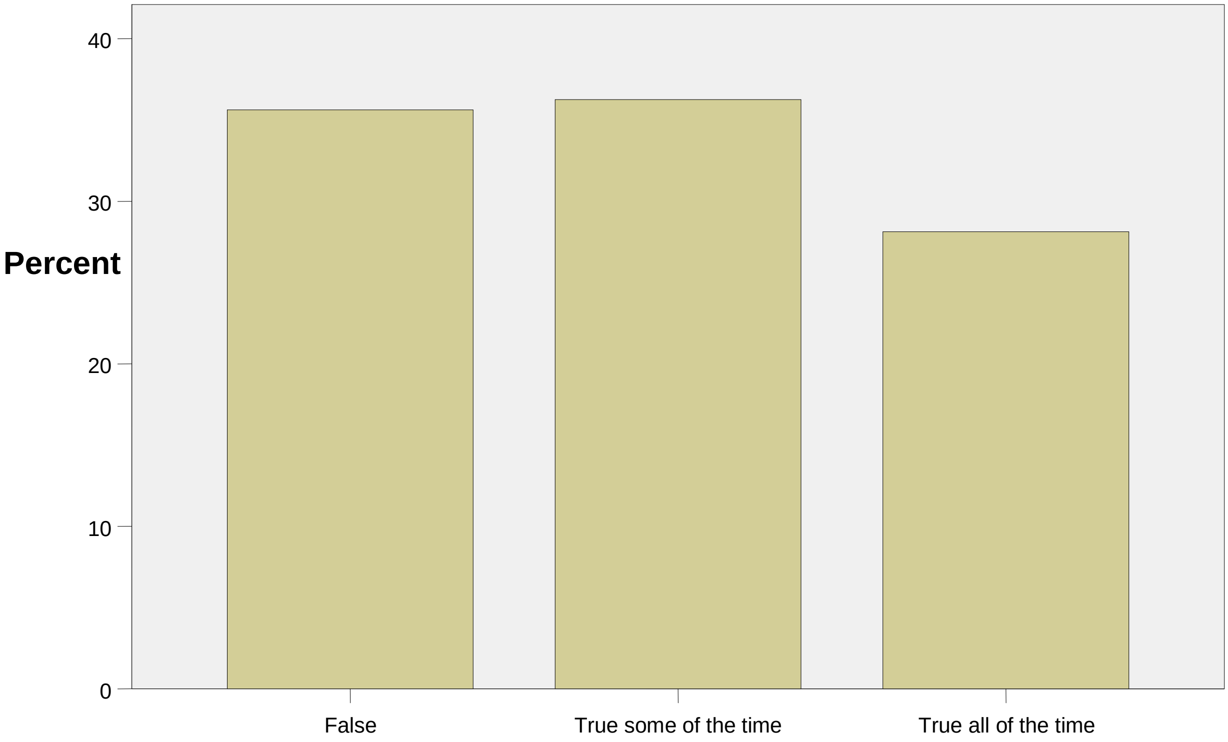
77.6% of respondents (N=104) expressed the opinion that staff do not feel able to question orders given to them by senior staff.
The Service User Audit Group feels that there may be an empathetic alliance between junior staff and patients in that they are equally disempowered. Service providers should enable increased opportunities for users to explore “orders” or decisions within ward fora and community meetings.

Question 26m Staff treat the label / diagnosis and not the person

Answered 160 (92.5%)
Missing Answers 13 (7.5%)

	Frequency	Percent
False	57	35.6
True some of the time	58	36.3
True all of the time	45	28.1

Staff treat the label (diagnosis) and not the person



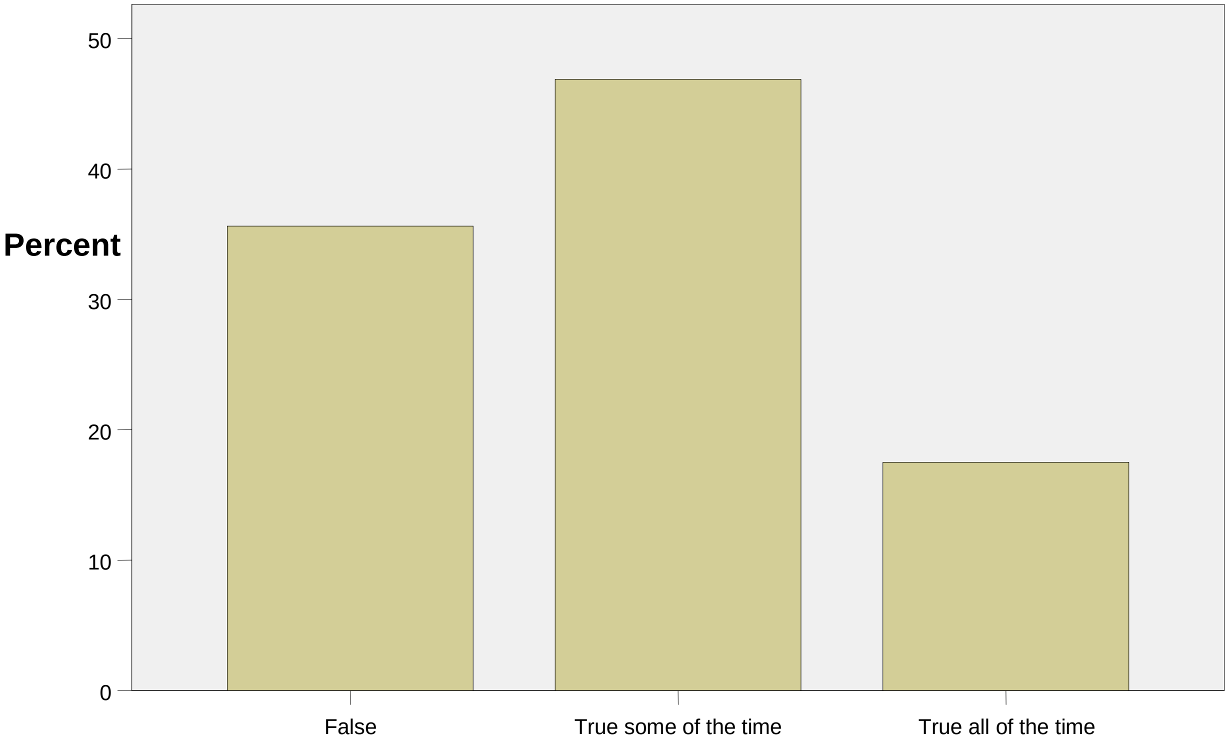
64.4% of respondents (N=103) expressed the opinion that staff treat the “label” and not the person. The Service User Audit Group recognises that the recovery model is being implemented and anticipate an improvement in these perceptions over time.

Question 26n Staff feel that Service Users are manipulative

Answered 160 (92.5%)
Missing Answers 13 (7.5%)

	Frequency	Percent
False	57	35.6
True some of the time	75	46.9
True all of the time	28	17.5

Staff feel that Service Users are manipulative

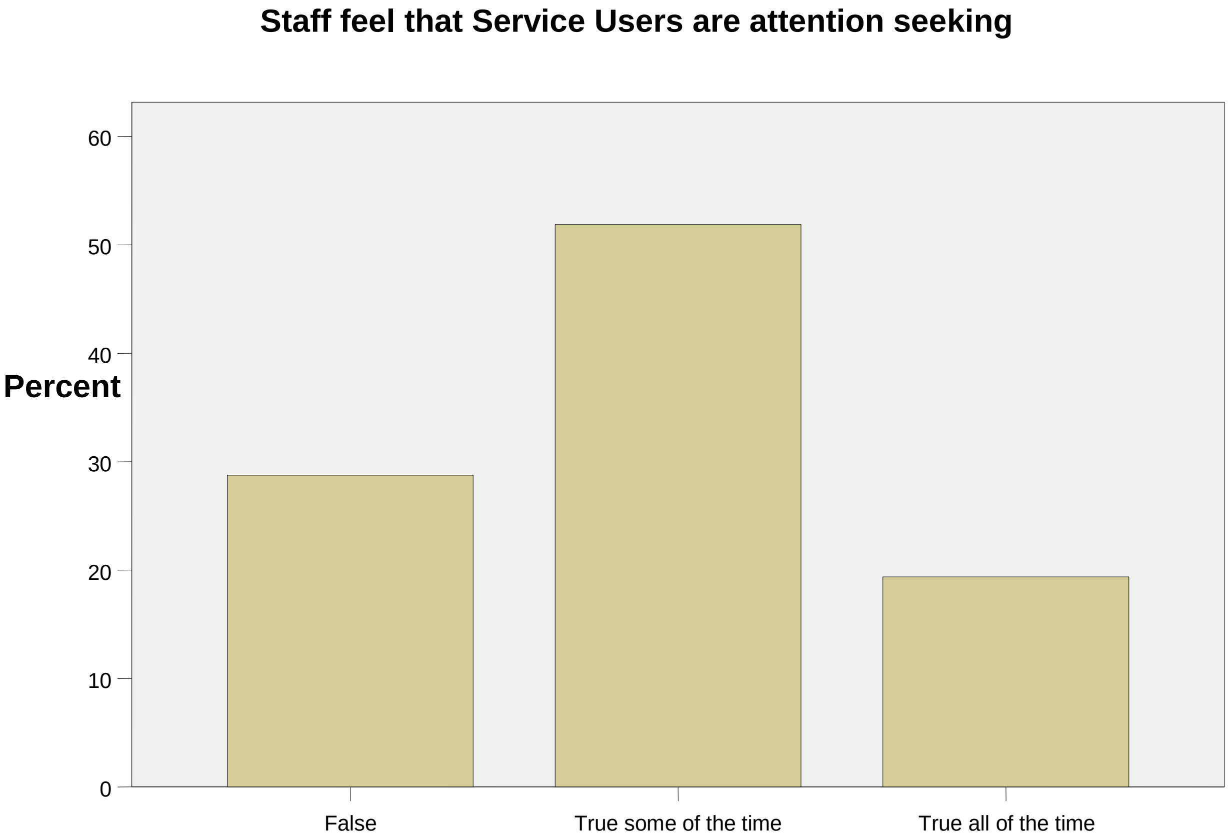


64.4% of respondents (N=103) expressed the opinion that staff feel service users are manipulative. The Service User Audit Group feel that most people attempt to influence a positive outcome for themselves, and these results do not necessarily reflect a negative position.

Question 26o Staff feel that Service Users are attention seeking

Answered 160 (92.5%)
Missing Answers 13 (7.5%)

	Frequency	Percent
False	46	28.8
True some of the time	83	51.9
True all of the time	31	19.4



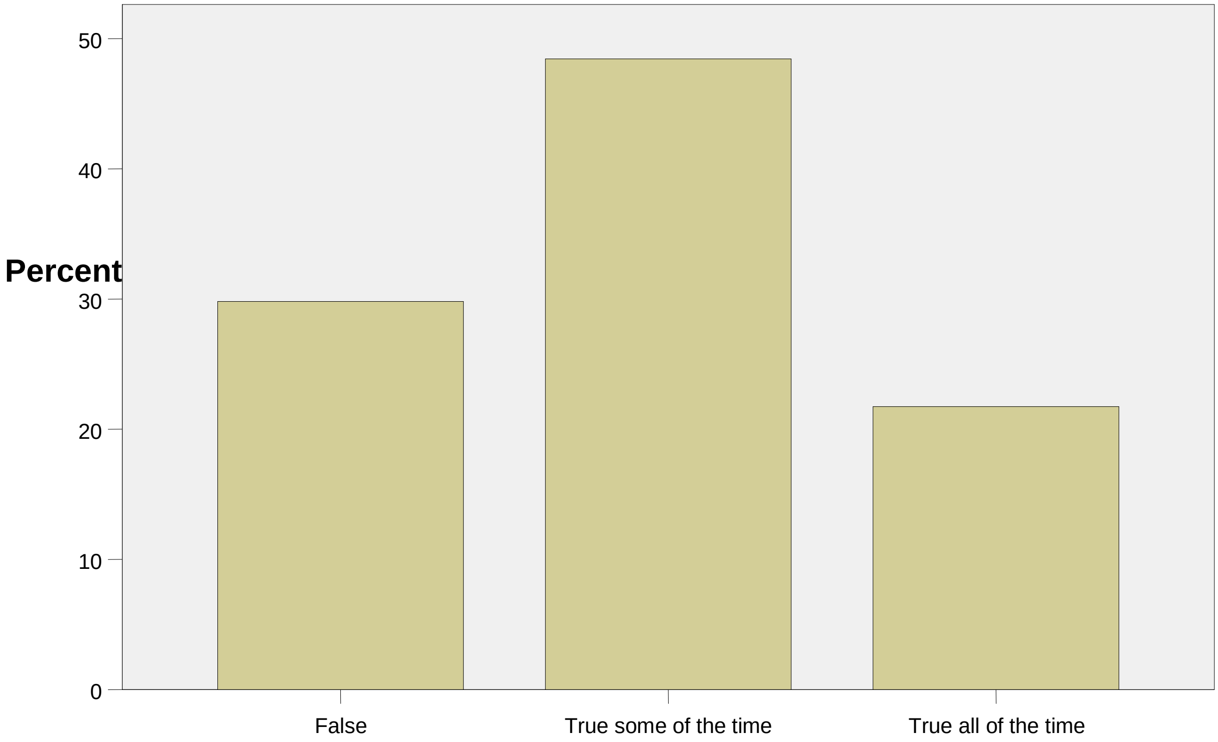
71.3% of respondents (N=114) expressed the opinion that staff feel service users are attention seeking. The Service User Audit Group feel that seeking attention is a natural phenomena, however if for example a patient asked for information that had not been given they may well be left with the feeling that they have done something wrong, and be classed as attention seeking.

Question 26p Staff feel that Service Users can’t make their own decisions

Answered 161 (93.1%)
Missing Answers 12 (6.9%)

	Frequency	Percent
False	48	29.8
True some of the time	78	48.4
True all of the time	35	21.7

Staff feel that Service Users can't make their own decisions



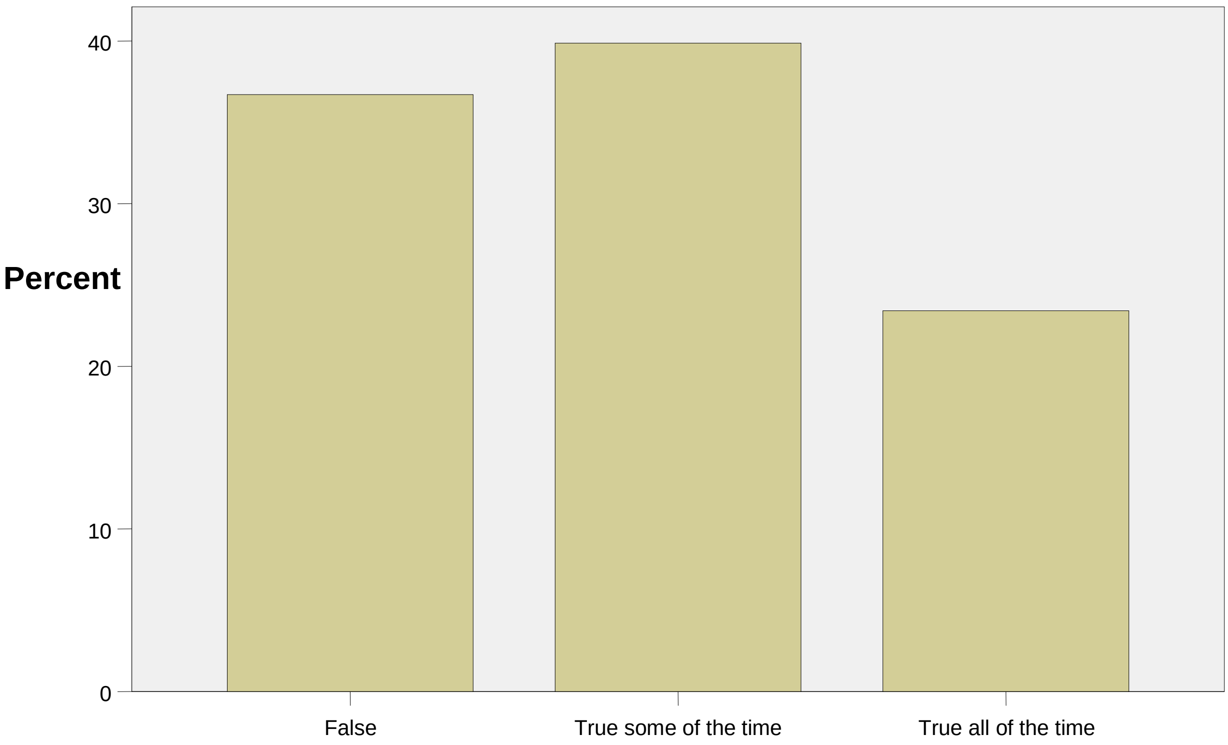
The perception that staff feel service users can’t make their own decisions was expressed by 70.1% of respondents (N=113). Informed decision making will be improved with better information, knowledge and the opportunity to discuss things like medication.

Question 26q Staff feel that Service Users are the best judge of their symptoms

Answered 158 (91.3%)
Missing Answers 15 (8.7%)

	Frequency	Percent
False	58	36.7
True some of the time	63	39.9
True all of the time	37	23.4

Staff feel that Service Users are the best judge of their symptoms



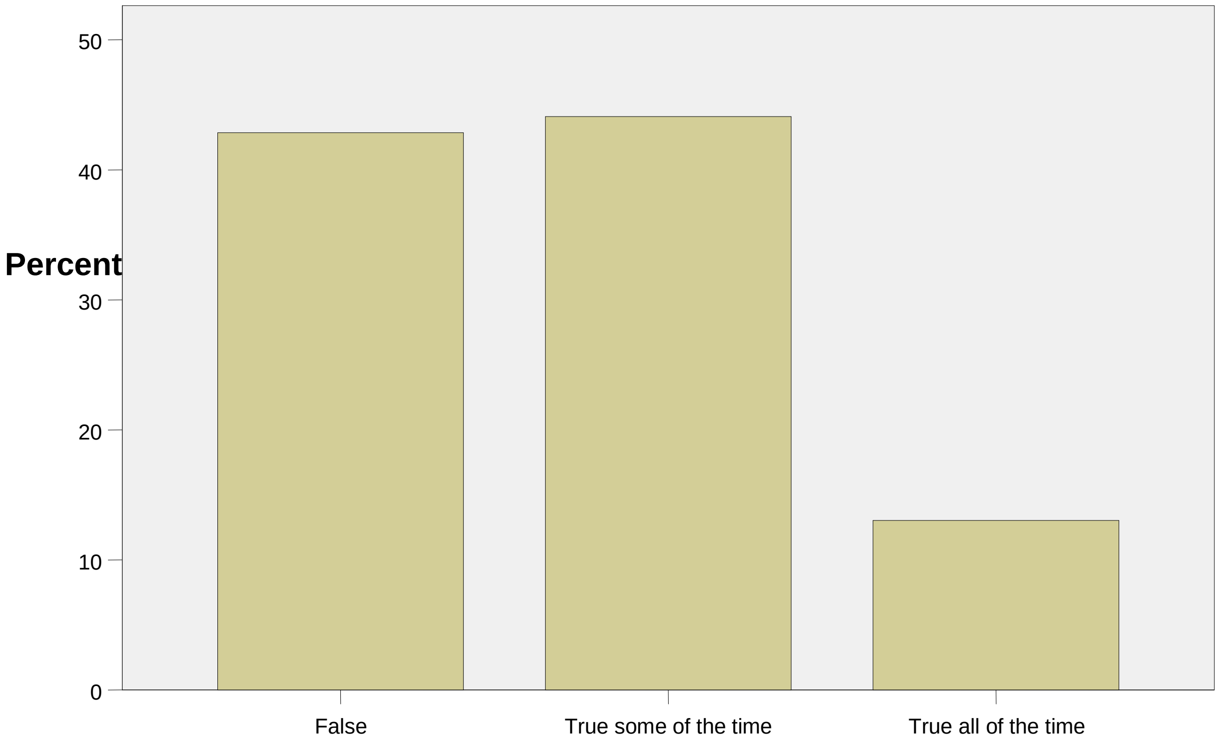
63.3% of respondents (N=100) expressed the opinion that staff feel service users are the best judge of their symptoms.

Question 26r Staff feel that Service Users are a nuisance

Answered 161 (93.1%)
Missing Answers 12 (6.9%)

	Frequency	Percent
False	69	42.9
True some of the time	71	44.1
True all of the time	21	13

Staff feel that Service Users are a nuisance



57.1% of respondents (N=92) expressed the opinion that staff feel service users are a nuisance.

The Service User Audit Group feel this may emanate from the feelings of patients that ordinary requests are perceived as demanding by staff.

Question 26s Staff patronise Service Users

Answered 160 (92.5%)
Missing Answers 13(7.5%)

	Frequency	Percent
False	66	41.3
True some of the time	67	41.9
True all of the time	27	16.9

Staff patronise Service Users

58.8% of respondents (N=94) expressed the opinion that staff patronise service users. Although this represents the experience of respondents the Service User Audit Group feel the vulnerability of being an in- patient for example may lead to the mis interpretation of simple instruction or routine (as previously mentioned).

Question 27 To what extent are the following statements accurate on a scale of 1 to 3 where one = false and three = true all of the time

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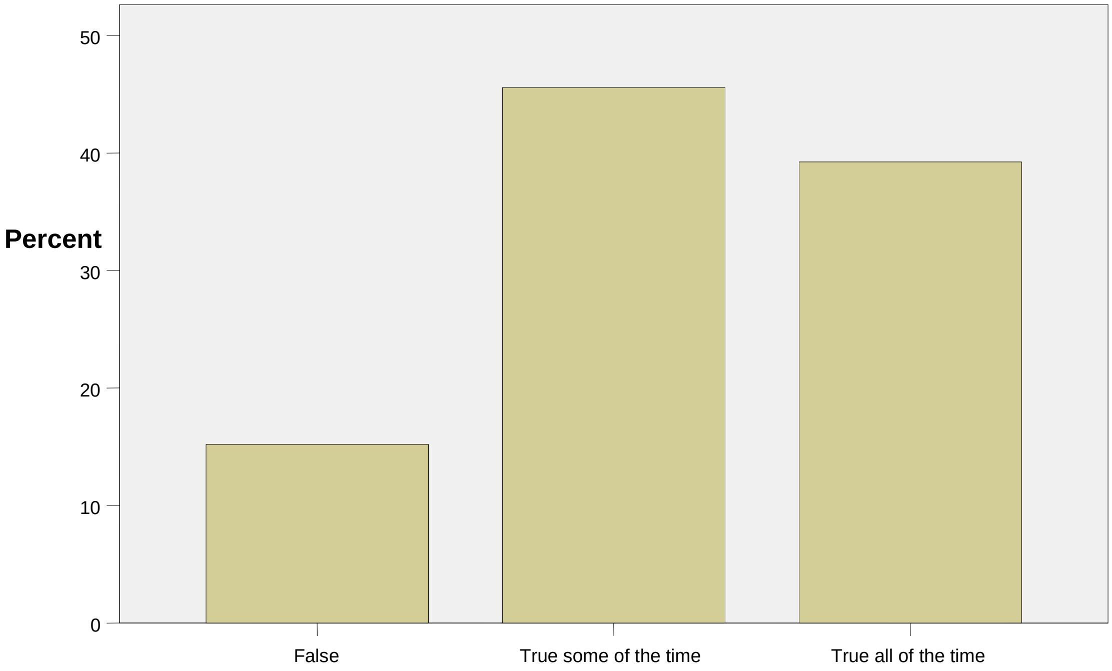
Question 27a Mental Health Service Users are treated like individuals

Answered 158 (91.3%)
Missing Answers 15 (8.7%)

	Frequency	Percent
False	24	15.2
True some of the time	72	45.6
True all of the time	62	39.2

Mental health service users are treated like individuals



84.8% (N=134) of respondents felt that mental Health Service users are treated like individuals some or all of the time. The Service User Audit Group feel this is a positive outcome and to some extent contradicts answers given in questions26m,n,o,p,q,r and s.

Question 27 b

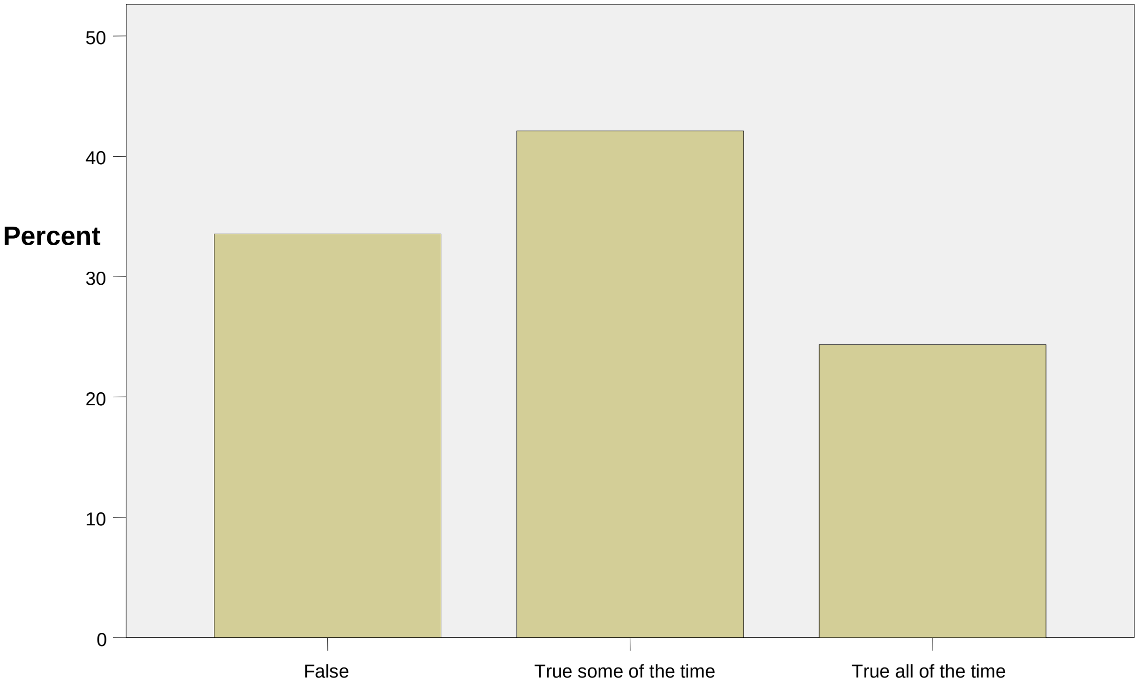
Mental Health Service Users are treated like customers

Answered 152 (87.9%)

Missing Answers 21 (12.1%)

	Frequency	Percent
False	51	33.6
True some of the time	64	42.1
True all of the time	37	24.3

Mental Health Service Users are treated like customers

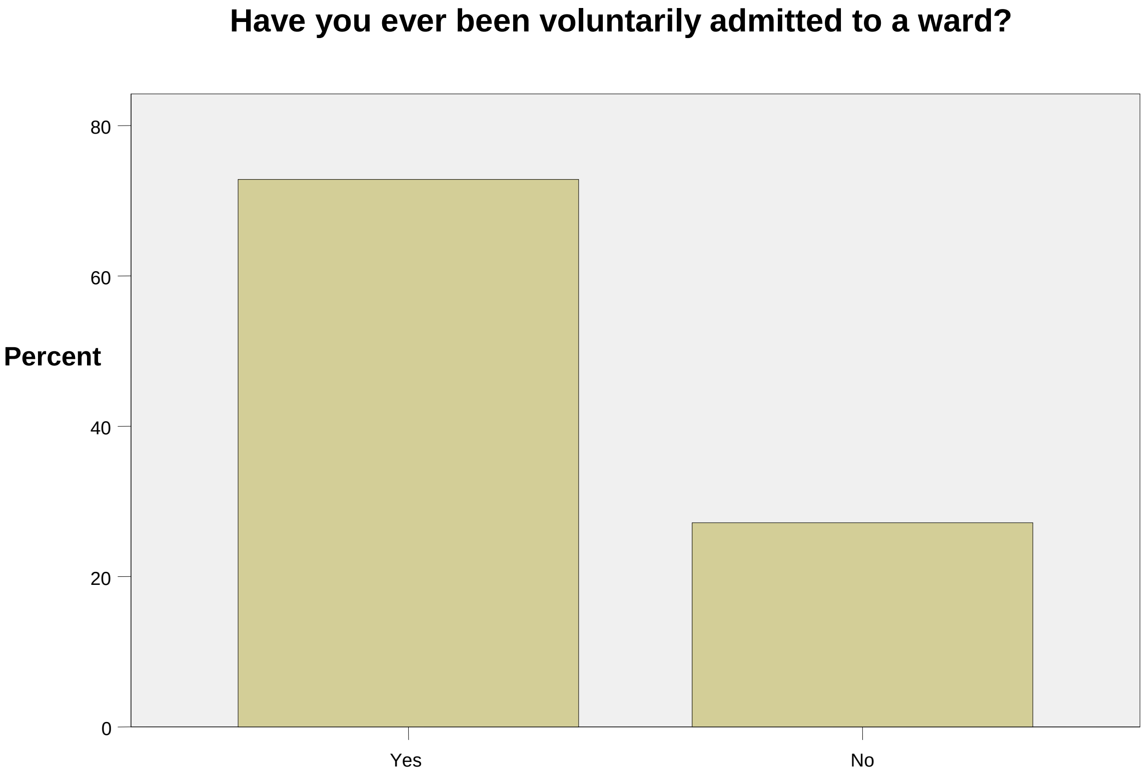


66.4% (N=101) of respondents suggested that Mental Health Service Users are treated like customers some or all of the time. It is recognised that detained patients may never feel they are being treated like customers.

Question 28
Have you ever been voluntarily admitted to a ward?

Answered 162 (93.6%)
Missing Answers 11 (6.4%)

	Frequency	Percent
Yes	118	68.2
No	44	25.4



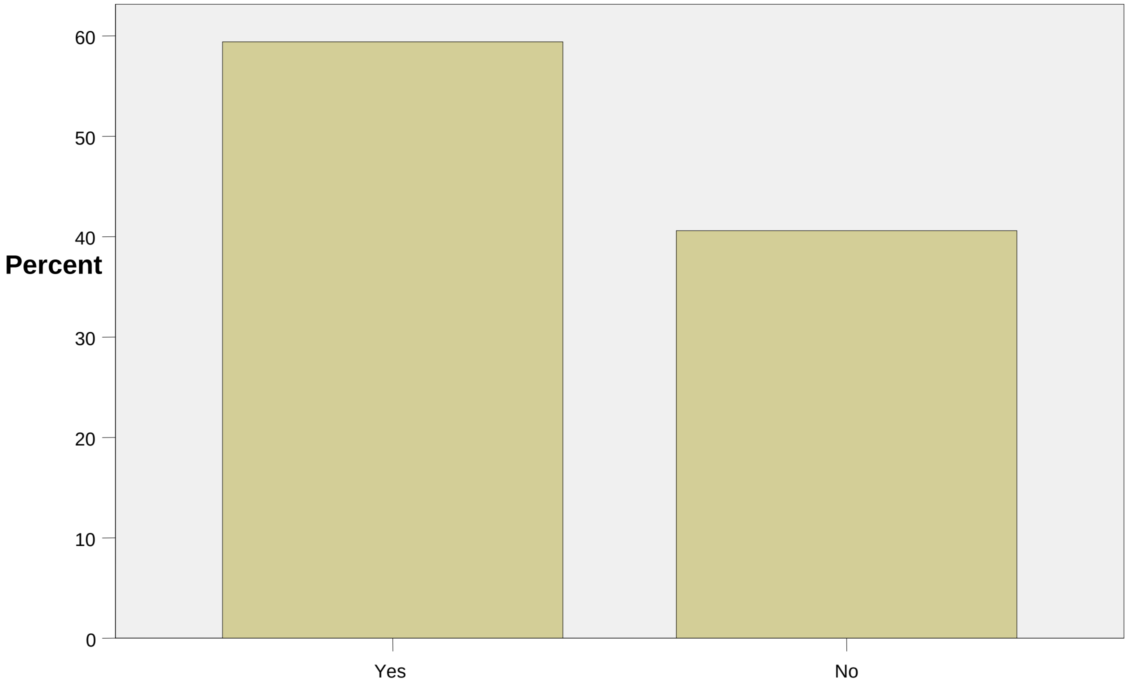
78.2% (N=118) of respondents had been admitted voluntarily to a ward

Question 29
While you were a voluntary patient, were you allowed to leave the ward?

Answered 133 (76.9%)
Missing Answers 40(23.1%)

	Frequency	Percent
Yes	79	59.4
No	54	40.6

While you were a voluntary patient, were you allowed to leave the ward?



59.4% (N=79) of respondents suggested that they were allowed to leave the ward. Interestingly 40.6 % (N=54) of respondents identified that they were not. Qualitative responses indicated that being allowed to leave the ward varied depending on the staff that were on duty and the ward itself. There appears to be no clear policy regarding voluntary patients' movements when they have been admitted.

Question 30
Is there anything else you would like to tell us about leaving the ward whilst being a voluntary patient?

This answer required a qualitative response and selected verbatim quotations are listed below:

- Couldn't leave because of possible self harm
- Allowed to go on leave – back for meal times No problem with it
- Worried about being turned out too soon
- At the moment I am not allowed to leave the ward. I feel frustrated. Yesterday re assessed again. Not happy about this but why understand why later
- At the beginning the nurses and psychiatrist checks to see if you are OK to leave the ward
- Dr ignored me for 3 days then I had a seizure, vomiting and hypothermia and was left for 13 days and then they could section me
- Has to be assessed before leaving ward
- As long as I am allowed to leave the ward and go about my business I don't mind being under the section. As long as the section is fare.
- Want to be able to leave the ward for longer than half an hour.
- On a section 17 should allow me to leave the ward after a week for longer time.
- If I left the ward and the staff didn't want me to leave the ward as I was a danger to myself they would try and section me
- Not allowed to leave initially. Was frustrated but accepted it was for my own safety
- Accompanied by a nurse for a period
- Was not allowed to go out
- There was a smoke room to go in
- Able to leave the ward escorted
- Give you freedom. Trust is important
- Don't agree with time restrictions need a break when needed
- Important to get to day service but sometimes no staff to accompany
- Felt unsafe outside the ward

- Escorted for smoking.
- Access to fresh air not always possible
- Best interest to stay on the ward
- Anti smoking. Nothing happens on the ward but not allowed to leave
- No set self small goals.
- Sectioned due to self harm allowed to stay on unit
- Wanted to travel but knew would be sectioned
- I believe and understand that this is for my own safety and I am quite happy about this position
- Nothing to add. Satisfied I can leave the ward
- I found it frustrating. I could not even go for a walk. I feel it affected my recovery.
- When you try to leave the ward I was put on a section. I was unhappy about this.
- Quite happy to be on a ward for 2 weeks. I was too ill to go out
- Staff very supportive in making first decision on leaving the ward
- Although voluntary I am on a detox but am not allowed to leave the ward.
- Would like to use recreational facilities. Nothing to do on the ward. No exercise available.
- Allowed to leave for a cigarette and wandered down to the shop. Feel they trust me.

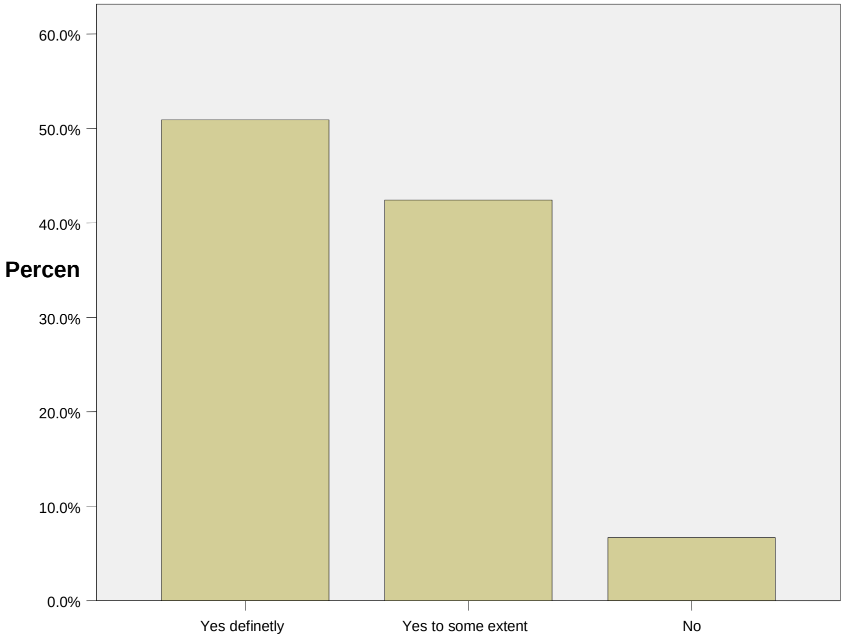
These responses are mixed with a number being satisgied and understanding why restrictions have been imposed. Concern should be highlighted for those who feel “there is nothing to do” yet have restricted access to fresh air.

Thinking about the staff from the services you currently access:
The answers in this section may contain some ambiguity as research interviewers reported that respondents in some cases were answering from the perspective of their total experience rather than their current experience. In addition it has not been possible during this piece of work to identify particular wards, day centres or clinical service from which there responses emanated. It will therefore be difficult to target specific areas or staff, where improvements could be made.

Question 31
Staff in the services they currently access, listen carefully to me

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
Yes definitely	84	50.9
Yes to some extent	70	42.4
No	11	6.7

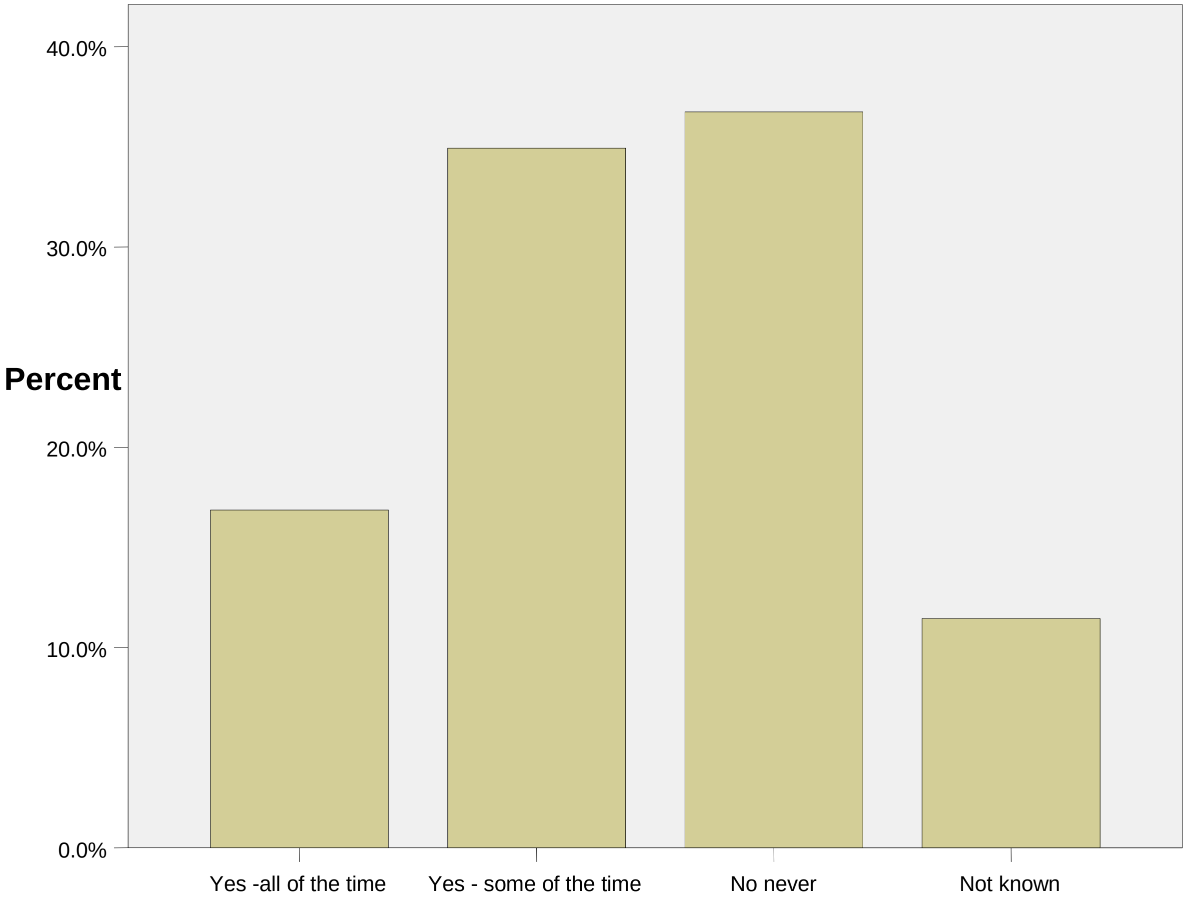


93.3% (N=154) of respondents identified that staff at in the services they currently access, listen carefully either some or all of the time. The Service User Audit Group feel this is an excellent result for providers of Mental Health Services.

Question 32
Have these staff ever mis-represented what you had said?

Answered 166 (96%)
Missing Answers 7 (4%)

	Frequency	Percent
Yes or all of the time	28	16.9
Yes some of the time	58	34.9
No never	61	36.7
Not known	19	11.4

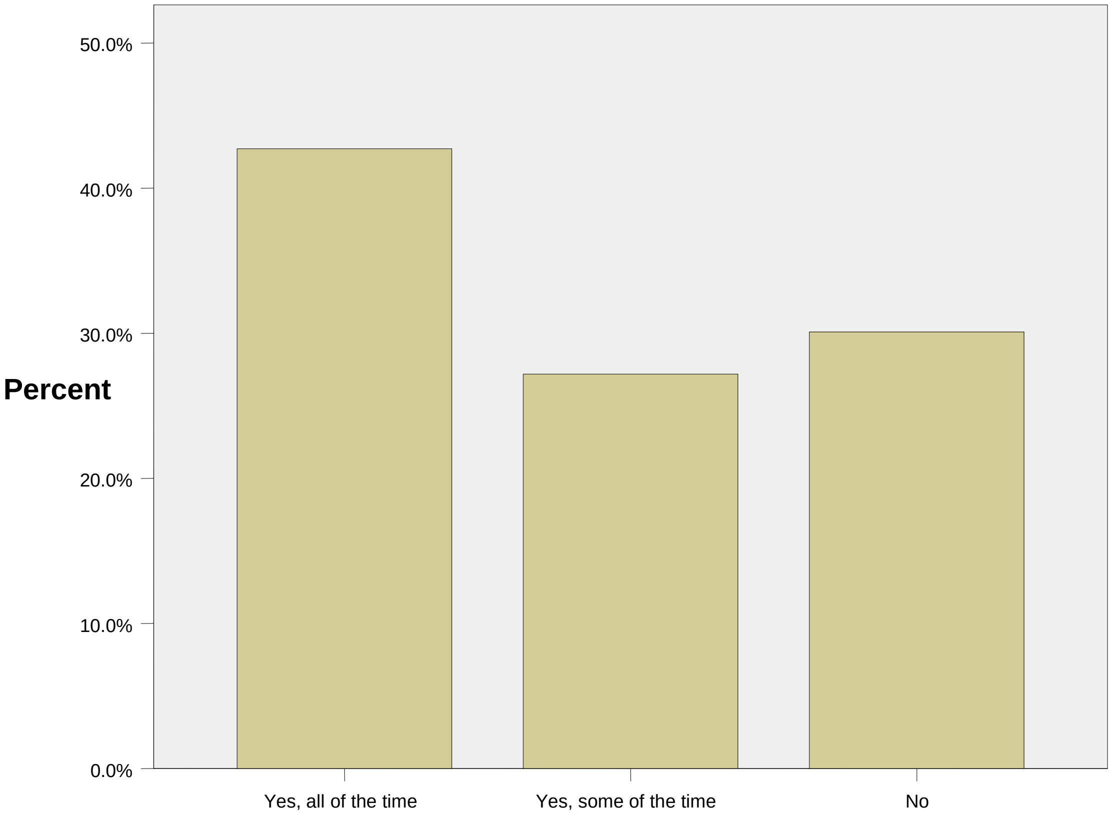


51.8% (N=86) of respondents indicated that within the service they currently access, staff have mis-represented what they have said either some or all of the time.
The Service User Audit Group consider that misrepresentation either real or perceived, is an issue for concern.

Question 33
Did you feel able to challenge these Misrepresentations?

Answered 103 (59.5%)
Missing Answers 70 (40.5%)

	Frequency	Percent
Yes or all of the time	44	42.7
Yes some of the time	28	27.2
No never	31	30.1



69.9% (N=72) of respondents felt that they could challenge misrepresentations either some or all of the time. This is an encouraging result and indicates that patients receiving services feel, in the main, sufficiently empowered to challenge misrepresentation by staff.

Question 34

Do you want to tell us anything else about being mis represented by staff?

This answer required a qualitative response and selected verbatim quotations are listed below:

Sometimes when you are honest about problems, can be held against you by staff i.e. privileges can be taken off you

Once I was shouting at my son and the staff misrepresented this as emotional abuse. Staff knew I was irritable because of medication

Its annoying when passed onto different Consultants

Did not feel threatened

Misunderstanding between me and the nurse and psychiatrist. Communication confusing

I feel threatened by the drugs and the action they take

Some staff thought I was gay. Nothing that has really affected me

Vulnerable when first admitted and cannot speak up for yourself and you are all out of control

Ive told them about certain people. They said I am imagining it

Being physically disabled no support with bath, bedroom or hygene. Place not made for handicapped

Staff can say anything and you havn’t the right to reply

Still being told to stay after 28 days (section 2)

Unable to challenge as staff are not 100% accurate or reliable

Crisis team should provide continuity. Link to liase when sectioned

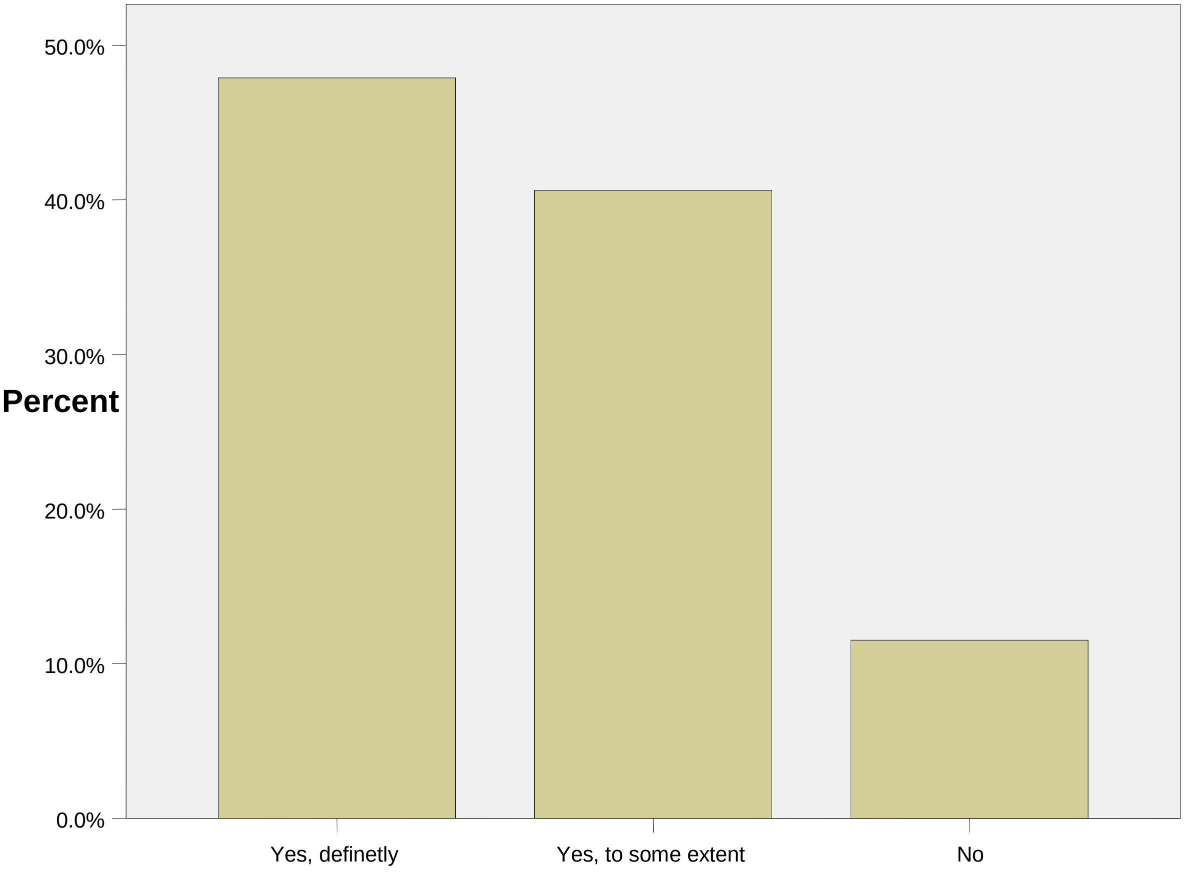
Feel staff are limited by what they can do- system fails- communication breakdown between staff

Complained of a dirty toilet. Complained to a member of staff and was told to clean it myself.

Question 35
Do you have trust and confidence in the staff the services you currently access?

Answered 165 (95.4%)
Missing Answers 8(4.6%)

	Frequency	Percent
Yes definitely	79	47.9
Yes to some extent	67	40.6
No	19	11.5

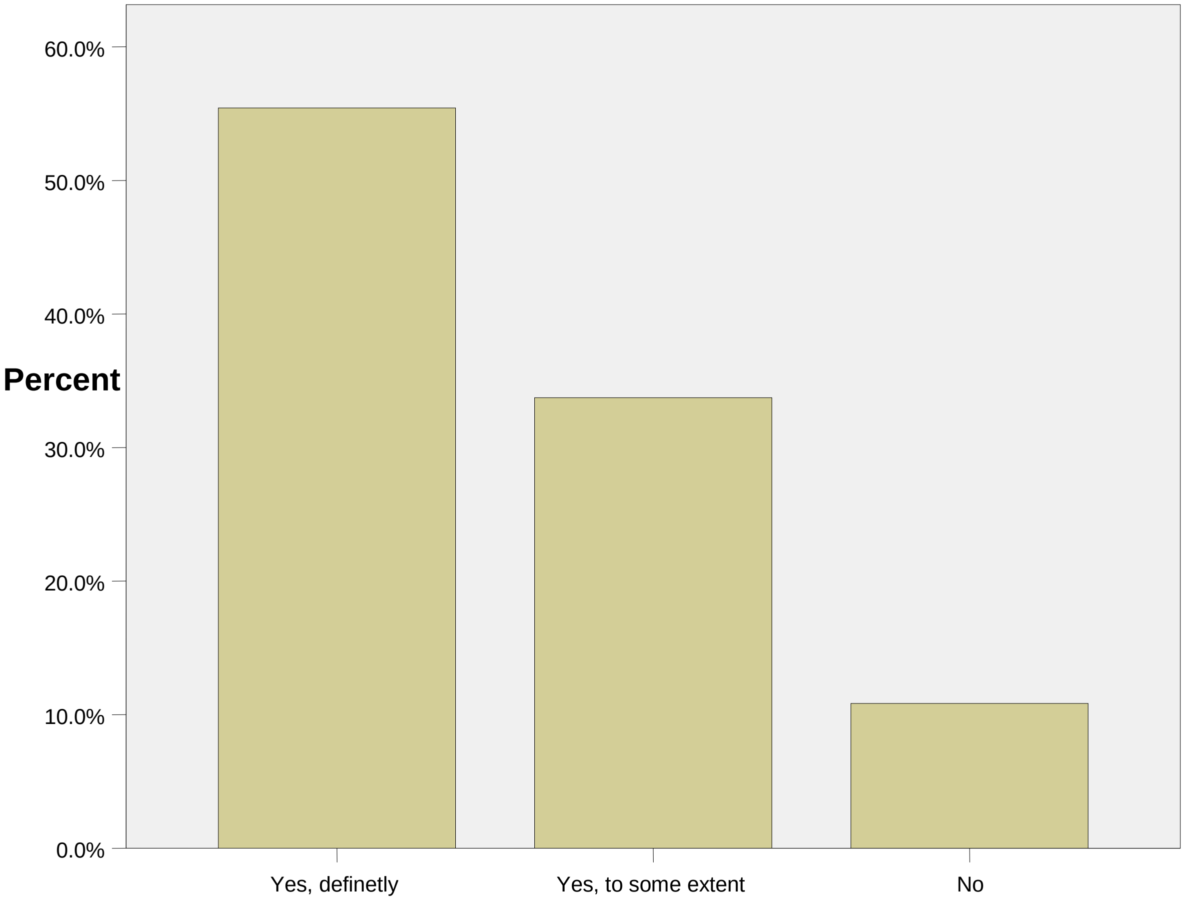


88.5 per cent (N=146) of respondents considered that they have trust and confidence in the staff who were providing services that they currently access. Again this is an encouraging result, and an endorsement of the regard in which patients hold staff.

Question 36
Do these staff treat you with respect and dignity?

Answered 166 (96%)
Missing Answers 7 (4%)

	Frequency	Percent
Yes definitely	92	55.4
Yes to some extent	56	33.7
No	18	10.8

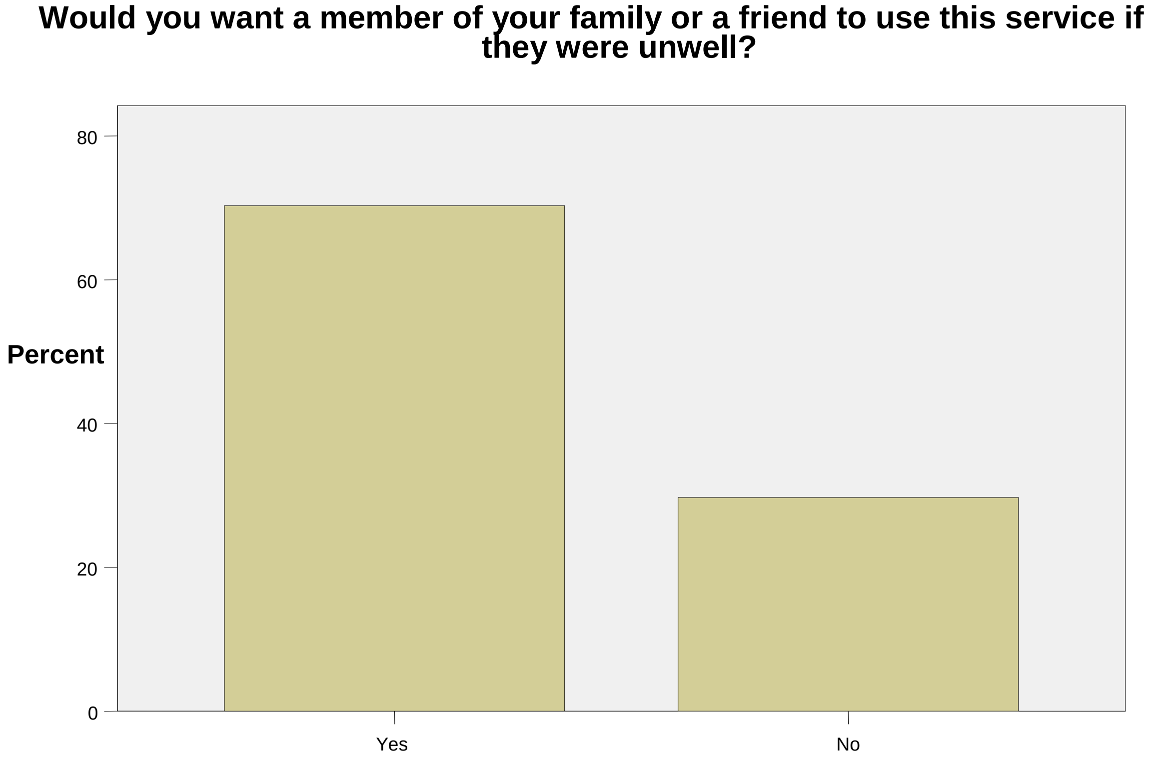


89.1 per cent (N=148) of respondents indicated that they definitely or to some extent felt that staff treated them with respect and dignity.
Although this result is encouraging the remainder of patients who feel they are not treated with dignity and respect will be adversely affected by this situation. Research interviewers reported that some of the responses related to one staff member rather than the hall staff team and cited personality conflicts with particular individual members of staff.

Question 37
Would you want a member of your family or a friend to use this service if they were unwell?

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
Yes	116	70.3
No	49	29.7



70.3% (N=116) of respondents would wish you member of the family to use this service if they were unwell, however only significant proportion, 29.9% (N=49), stated that they would not recommend the service.

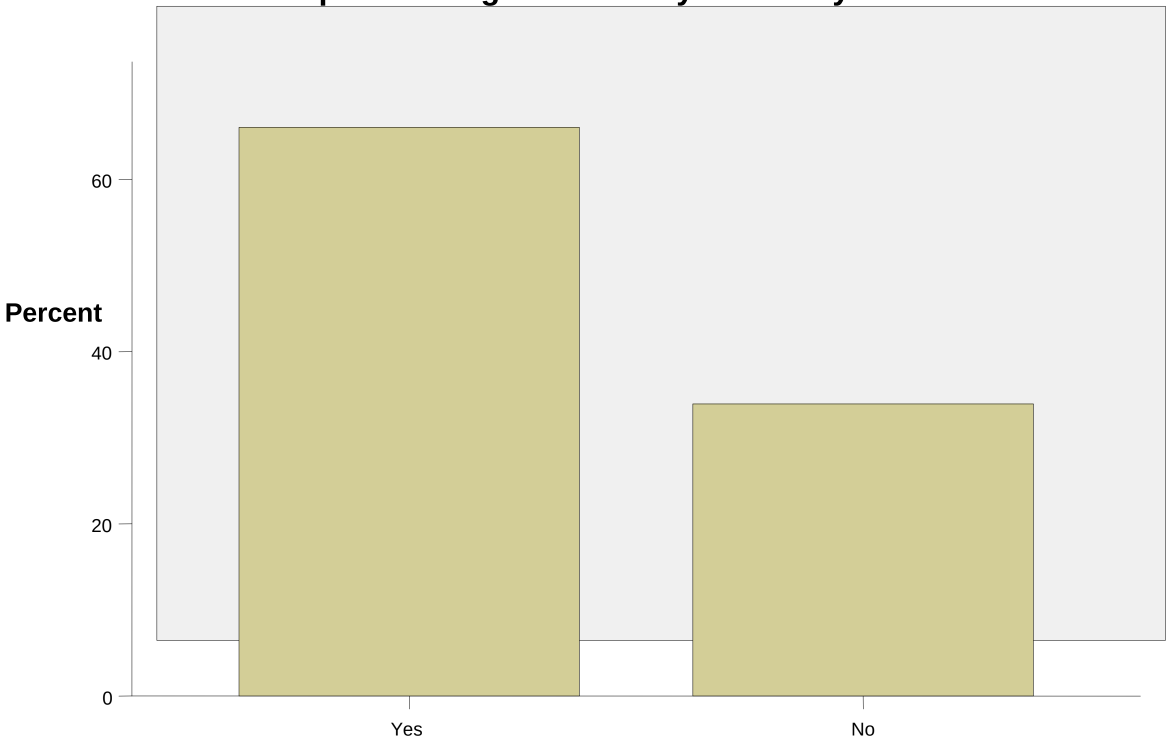
Question 38

Do staff spend enough time with you when you need them?

Answered 165 (95.4%)

Missing Answers 8 (4.6%)

	Frequency	Percent
Yes	109	66.1
No	56	33.9



Do staff spend enough time with you when you need them?

66.1 per cent (N=109) of respondents suggested that staff did spend enough time with them however respondents recognized that staff shortages reduced their expectations. It was suggested in the qualitative responses that staff do make the effort to spend time with them but suggested that the system was at fault not the staff. Qualitative results suggested that service users considered staff to be doing the “best they could under the circumstances”.

Question 39
Do you have any ideas about how staff could make themselves more available?

This answer required a qualitative response and selected verbatim quotations are listed below:

- More staff
- More nurses on wards
- More staff needed on wards to talk to patients
- Always generally busy
- Have more sympathy with me
- Financial restrains has effect on the care. More staffing levels
- Staffing levels too low per shift. Named nurse may not be around all the time. Not enough qualified staff
- There should be more staff available but I cant think of any ideas of how to alleviate this
- Allocate themselves to 1 person and sit and talk to them all day
- Allocate half an hour per person per week to discuss issues
- More staff
- Can see CPN monthly. Says always available but when needed wasn't available
- Too much paperwork. Too few staff. Need more staff
- Have more of them
- More Staff
- Less paperwork. More interactive. Treat you as a person not a number
- Daily time slot with key nurse or other nurse
- More staff for the service. One staff for 8 or 9 service users
- Should have emergency consultant appointments
- A telephone helpline should be set up
- Less Paperwork . Too few staff
- Need 24 hour care –nothing
- More staff on the ward
- Get more staff on the wards
- By stopping being pompus
- Staff should ask patient about needs rather than patient have to wait to ask
- Staff need to make more time or increase staff levels
- Specified time to speak to staff
- More staff
- More staff. Should slow down and take more time
- Don't know named nurse
- No named nurse or key worker
- More staff/ auxiliaries at meal times
- Not sitting in their office behind their desk
- To make an effort to speak or have a proper conversation at least once a day
- More off an appointment. Time for me to talk and more regular would help me feel more progressive
- Staff always seem to be in the office. Available once a day at least
- Feel staff could mingle more with patients.

- I have regular one to one with my named nurse. Not found availability a problem.
- Find ways available within half an hour
- Occasional meetings for the whole ward to meet staff for discussions.
- If needs to have extra staff a standby member should be available to step in and give individual urgent care
- The opportunity to make an appointment to see someone about something at amicable time.
- Staff should give me more advice on how to cope when I get out of hospital
- By having more staff on duty all the time
- Feel staff are not always available. A slot twice per week where service users can approach staff
- Depends on how busy they are

These quotations demonstrate a clear indication that the quantity and availability of staff correlate perfectly from a service users perspective, however it is recognised that the question design may have influenced responses.

Question 40

Are there any other issues around staff attitudes and communication that you want to tell us about?

This answer required a qualitative response and selected verbatim quotations are listed below:

- Staff Here are Good
- Staff notice if down in the dumps
- Staff should be more in touch with what makes that person a person
- Some staff nurses and consultants talk to me as a kid. More understanding from them
- Have a pool table
- Meal choices are not there. Internet and wireless laptop
- Wrong attitude - way they talk to me in a superior way
- On Wednesday ward rounds decisions not communicated very well. Given to you on a sheet before lunch, should be discussed with everybody after lunch. Named nurse can make decisions verbally but no proof of these decisions if challenged later by someone else. Should always be written down so no ambiguity
- Generally very helpful. Do make you understand about your illness. Would be good if more information about new medications on the market
- Sometimes they speak softly and then we seem to be aggressive as we are talking louder than them
- Mixed ward Religious staff and not religious staff. Some religious staff treat the none religious patients badly
- I bought stereo system, cannot use headphones. One staff member allowed it another staff member stopped this is inconsistent, making up rules as they go along. No redress
- Most excellent but one CPN has a them and us attitude
- Seem not to be kept informed and don’t know what is happening. Also making errors. Sent to hospital on wrong day for leg injury. Had to go back on another day
- Helpful
- Found it good overall
- Information sometimes too technical it could be simplified

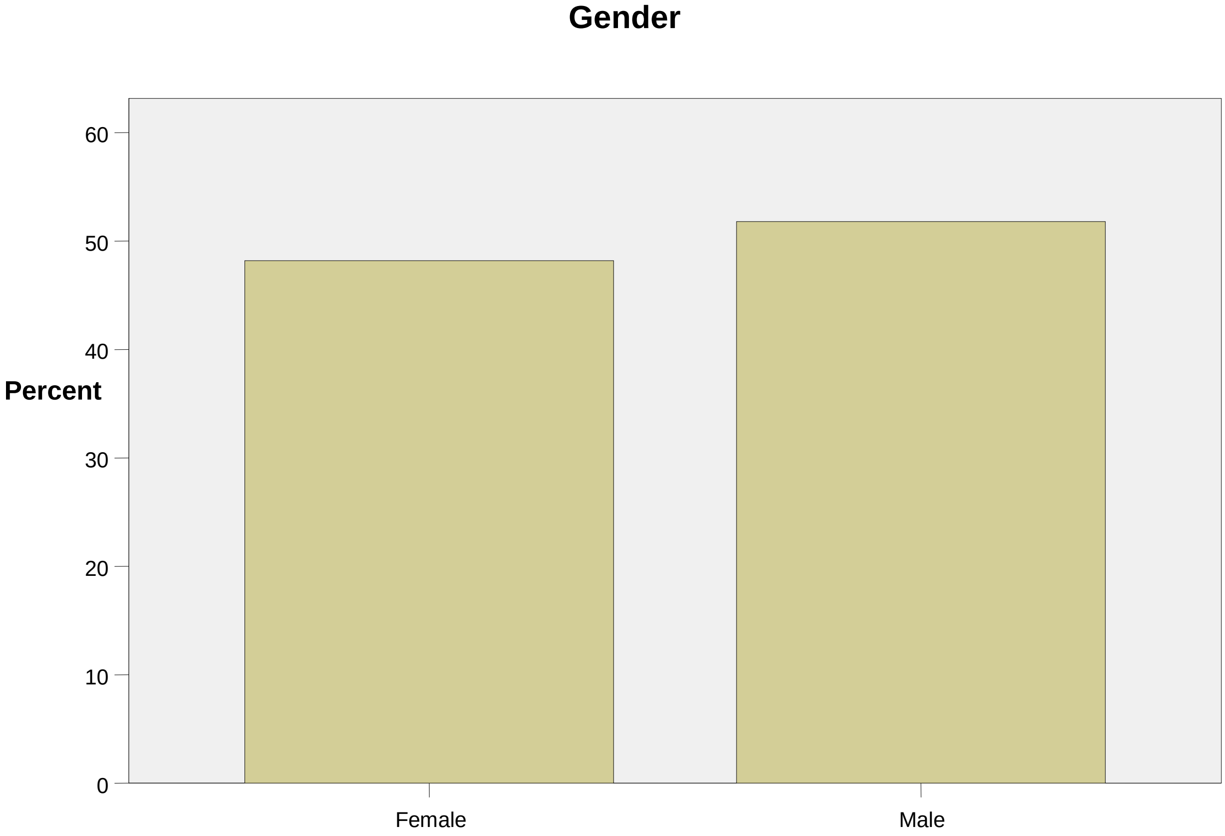
- Staff are excellent
- Service user forum to be facilitator – Partnership of equals
- Staff laughing and joking at you

The comment about the ambiguity of the named nurse making decisions verbally without being written down highlights the need for good quality notekeeping.

Question 41 Gender

Answered 166 (96%)
Missing Answers 7 (4%)

	Frequency	Percent
Male	80	48.2
Female	86	51.8



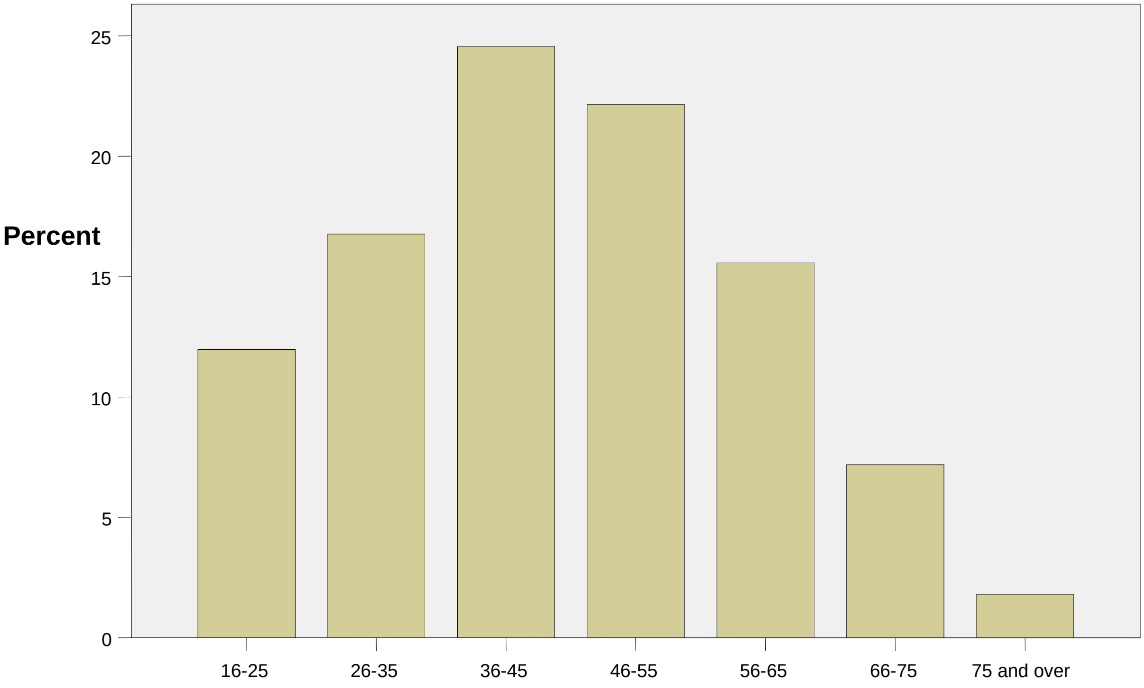
The research was able to almost meet its target of an equal representation from each gender. Of those who responded in the question and 48.2% (N=80) were female and 51.8% (N=86) were male.

Question 42
In which of these age categories are you?

Answered 167(96.5%)
Missing Answers 6 (3.5%)

	Frequency	Percent
16 -25	20	12
26 -35	28	16.8
36 – 45	41	24.6
46 – 55	37	22.2
56 – 65	26	15.6
66 – 75	12	7.2
75 and over	3	1.8

Age in years



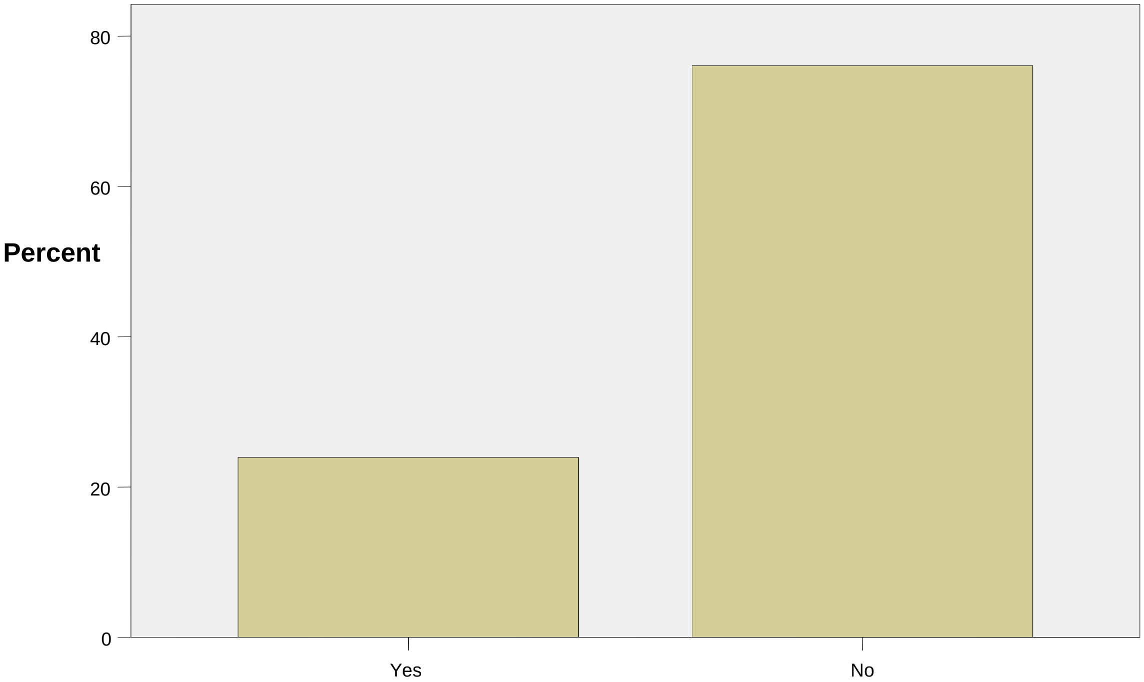
The distribution of respondent’s age appears normal with the majority falling in the 36 to 45 years bracket and this meets the target set at the outset of the project.

Question 43
Do you consider yourself to be from an ethnic minority?

Answered 163(94.2%)
Missing Answers 10 (5.8%)

	Frequency	Percent
Yes	39	23.9
No	124	76.1

Do you consider yourself to be from an ethnic minority?

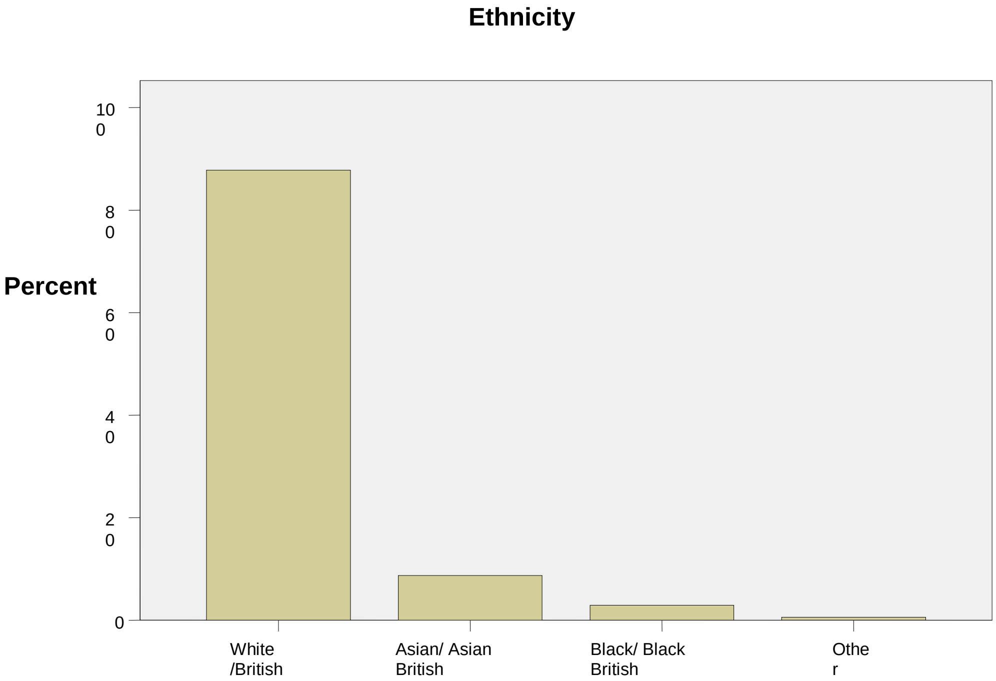


Of those respondents who answered this question 23.9% (N=39) considered themselves to be from an ethnic minority while 76.1% (N=124) considered themselves not. However anecdotal evidence from the research interviewers, would suggest that considering oneself from an ethnic minority has no relationship necessarily to culture or colour.

Question 44
Ethnicity

Answered 172(98.3%)
Missing Answers 3 (1.7%)

	Frequency	Percent
White	151	87.8
Asian/Asian British	15	8.7
Black/Black British	5	2.9
Other	1	0.6



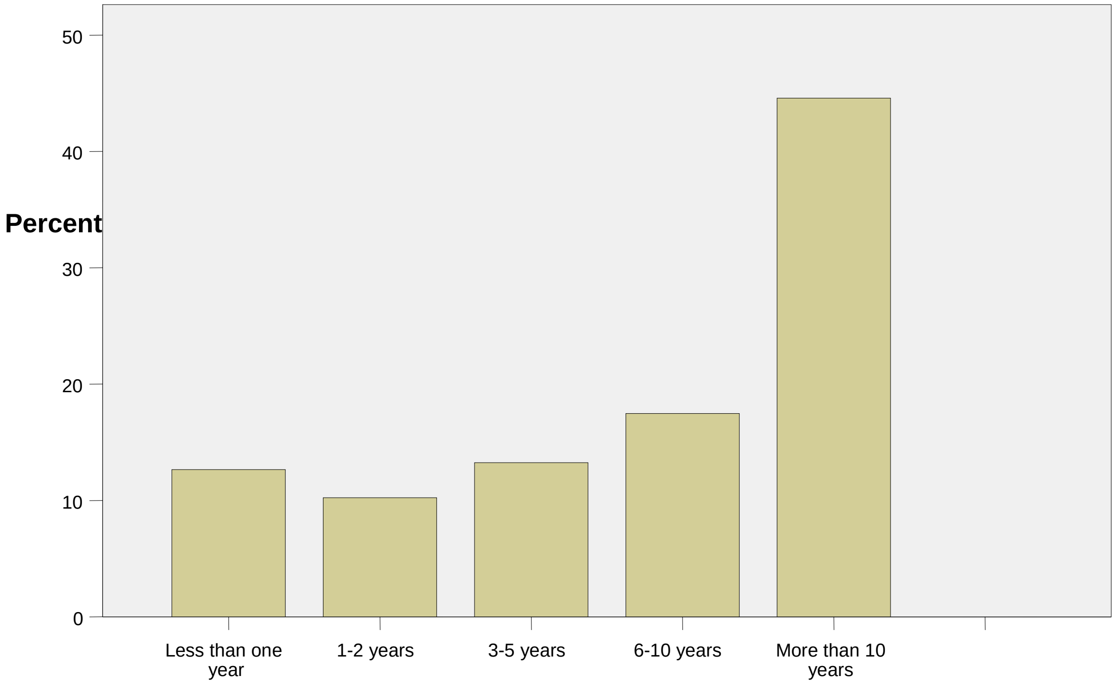
The project failed to reach its targets in sampling a proportionate representation of the ethnic mix within the population despite having a full range of interpreting services on offer. This failure may be for the following reasons:
Refusal to participate from one of the primary organisations providing specific support to black people
The ethnic mix of patients in general services does not reflect the broader population.
People from an ethnic origin other than white were reluctant to participate.
Some of those who described themselves as British may be considered within other categorisations to be from an alternative ethnic origin

Question 45
How long have you been in contact with mental Health Services?

Answered 166(96%)
Missing Answers 7(4%)

	Frequency	Percent
Less than one year	21	12.7
1-2 years	17	10.2
3-5 years	22	13.3
6-10 years	29	17.5
More than 10 years	74	44.6

How long have you been in contact with mental health services?



The majority of respondents 44.6 % (N=74) had been in contact with mental Health Services for more than 10 years.

Question 46

What do you consider to be your Mental Health issues?

This answer required a qualitative response and selected verbatim quotations which identify the individuals interpretation of their diagnosis are listed below:

- Things are very confusing
- Life Stress
- Depression Anxiety
- Diagnose with slight schizophrenia endogenous depression. Took a few years for accurate diagnosis
- Depression
- Do not know
- Confusion. Stress have has flashbacks of images
- Depression and anxiety
- Alcoholic
- Chemical balance in brain triggered by family stress
- Suffer from anorexia and depression
- Bipolar disorder Depression Anxiety
- Psychosis can lead to schizophrenia and depression
- Bullying and abuse and cowardice
- They think psychosis which I don't believe. Said I was schizophrenic but changed their mind later
- Initially feeling slightly depressed and wrongly diagnosed as paranoid
- schizophrenia by a discredited consultant psychiatrist.(Name removed by researcher). Problems with medication and treatments that followed suit resulted in a classification of wrong diagnosis and treatment
- Keep kneeling on floor. Nails in peoples feet. Holes in my hands. Then I feel loved. People on my back. They make me feel loved. Cutting brings back people. I want them back. Friend on ward is Michelle.
- Racing thoughts
- Schizophrenia but less of a problem. Foundation life issues for the future
- Depression
- Bipolar disorder. Wrongly diagnosed on some occasions only when admitted to hospital
- I don't get the help I need
- Paranoid Schizophrenia and Aspergers Syndrome
- Schizoid Affective disorder
- Depression and Autism
- Depression Anxiety Suicide attempt Self harm and stress
- BiPolar
- Schizophrenia
- Depression insomnia Compulsive disorder
- Schizophrenic and depression and agrophobia anxiety
- Depression Panic attacks
- Has wondered about bi polar on the basis of ups and downs
- Compulsive disorder
- Depression

- Depresion Anxiety and Panic attacks
- Borderline personality disorder
- Depression paranoia hallucinations
- Don’t know
- Alcohol and depression
- Better treatment more access to therapeutic activities
- Acute Depression Anxiety
- Ill sick started with physical problems but confused about transfer to Mental Health unit
- Domestic marital problems
- Mood swings No physical aggression just verbal
- Go into panic. Self harm . Hear voices. Cushings syndrome
- Compulsive disorder illness
- Depression Bipolar
- Drink…. need more counselling
- Manic depression. Not taken seriously when highAnxiety stresss drugs and sexual abuse. ADHD
- Severe depression, anxiety panic attacks. In fear of the real world particularly going out
- Acute Depression Anxiety
- Severe depression
- Depression
- Depression Suicidal tendencies
- Paranoid schizophrenia
- Depression
- Alcoholism and depression
- Bi polar disorder
- Alcohol dependant due to job loss led to depression and alcohol
- Depression. The medication has improved condition. Had bouts of paranoia and stayed indoors. Now more outgoing
- I suffer from depression anxiety and alcohol problems. Fits with diagnosis made by doctors.
- I hear voices. Nice voices. Talk about cars. Take tablets to calm me down
- No mental health issues
- Eating disorder

The responses represent a spectrum of interpretation of symptoms. It is clear that many service users utilize the diagnosis ascribed to them, rather than explaining the symptoms.

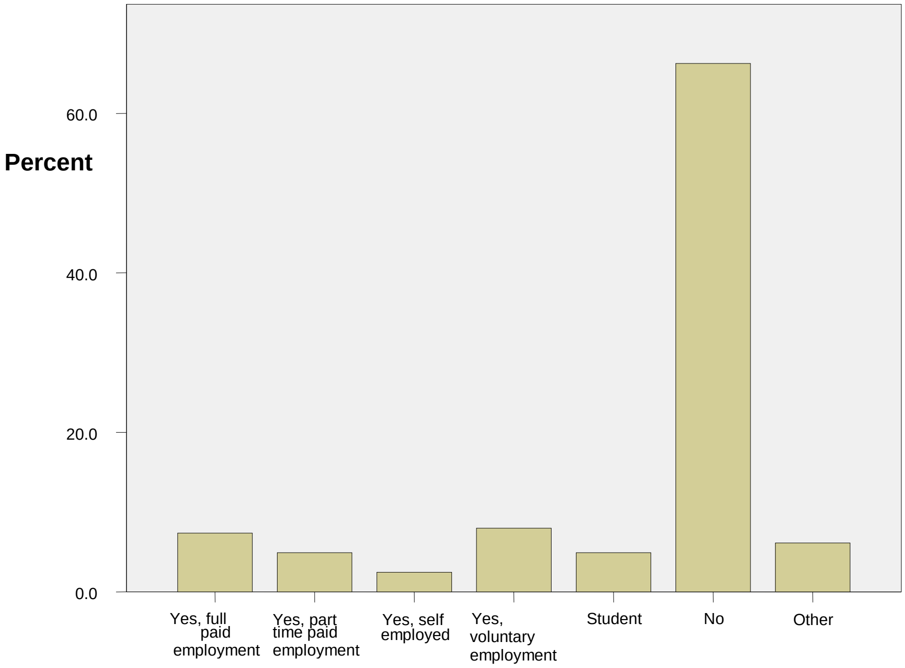
Question 47

Are you in employment now?

Answered 163(94.2%)
Missing Answers 10(5.8%)

	Frequency	Percent
Yes fulltime paid employment	12	7.4
Yes part time paid employment	8	4.9
Yes self employed	4	2.5
He has unpaid in employment/voluntary	13	8
Students	8	4.9
No	108	66.3
Other	10	6.1

Are you in employment now?

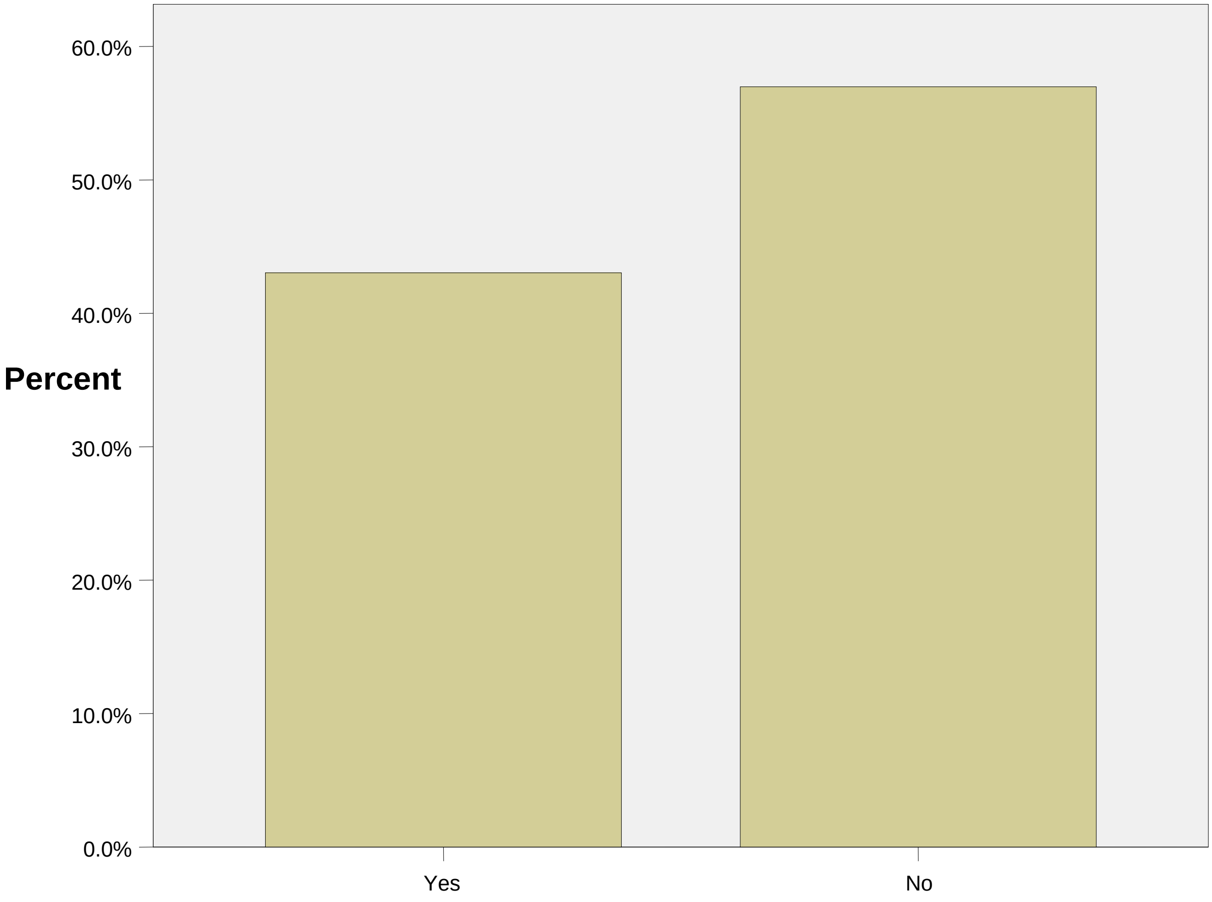


66.3% (N=108) of respondents stated that they were not in fulltime employment at the time of the interview. Those benefiting from fulltime paid employment amounted to only7.4% (N=12). The Service User Audit Group acknowledges research that conclusively proves the relationship between good mental health and employment. It is suggested that service providers strive to incorporate the skills for seeking meaningful employment into recovery plans.

Question 48
Have you ever lost your job because of mental health problems?

Answered 165(95.4%)
Missing Answers 8(4.6%)

	Frequency	Percent
Yes	71	43
No	94	57



In 43 per cent (N=71) of respondents stated that they had lost your job because of their mental health problems.

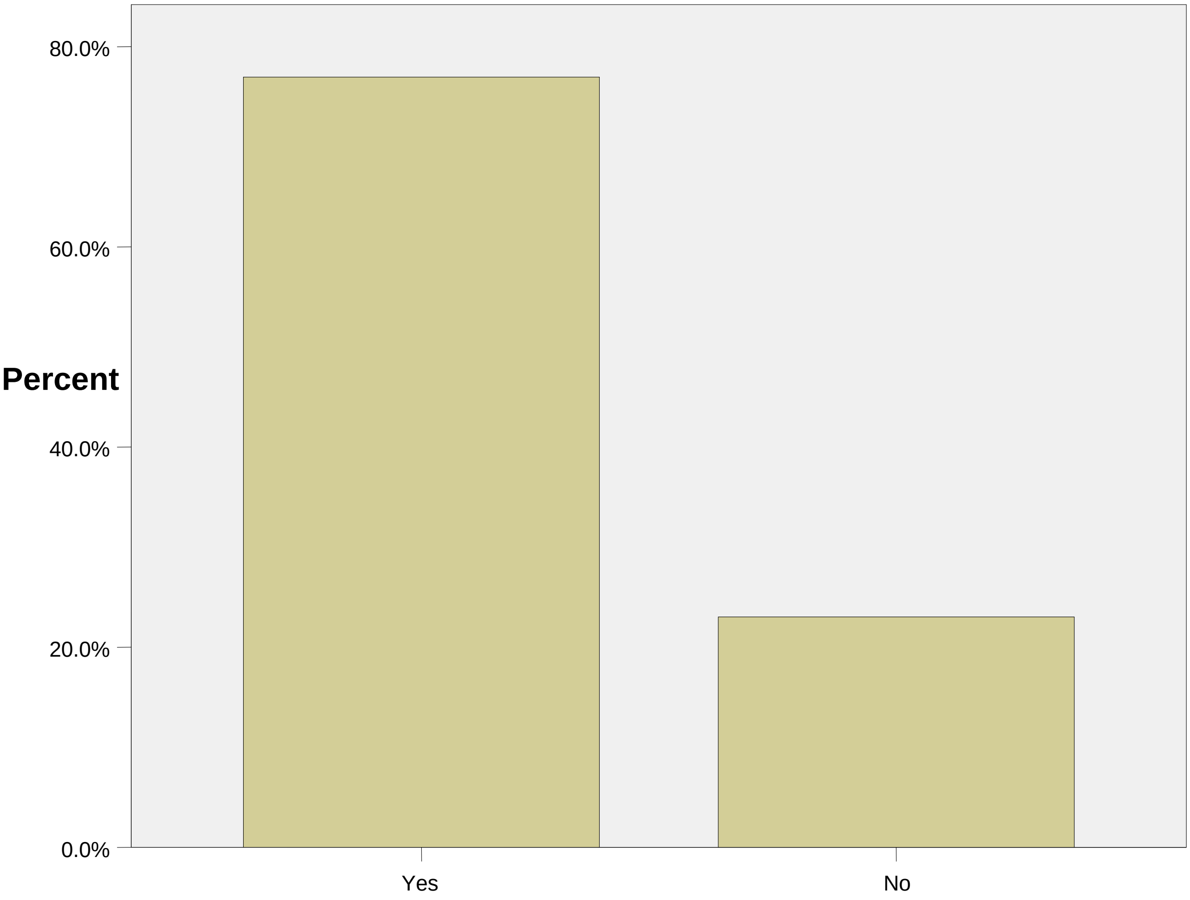
Question 49

Which mental Health Services have you used in the last 18 months?

49a NHS the out patients

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
Yes	127	77
No	38	23

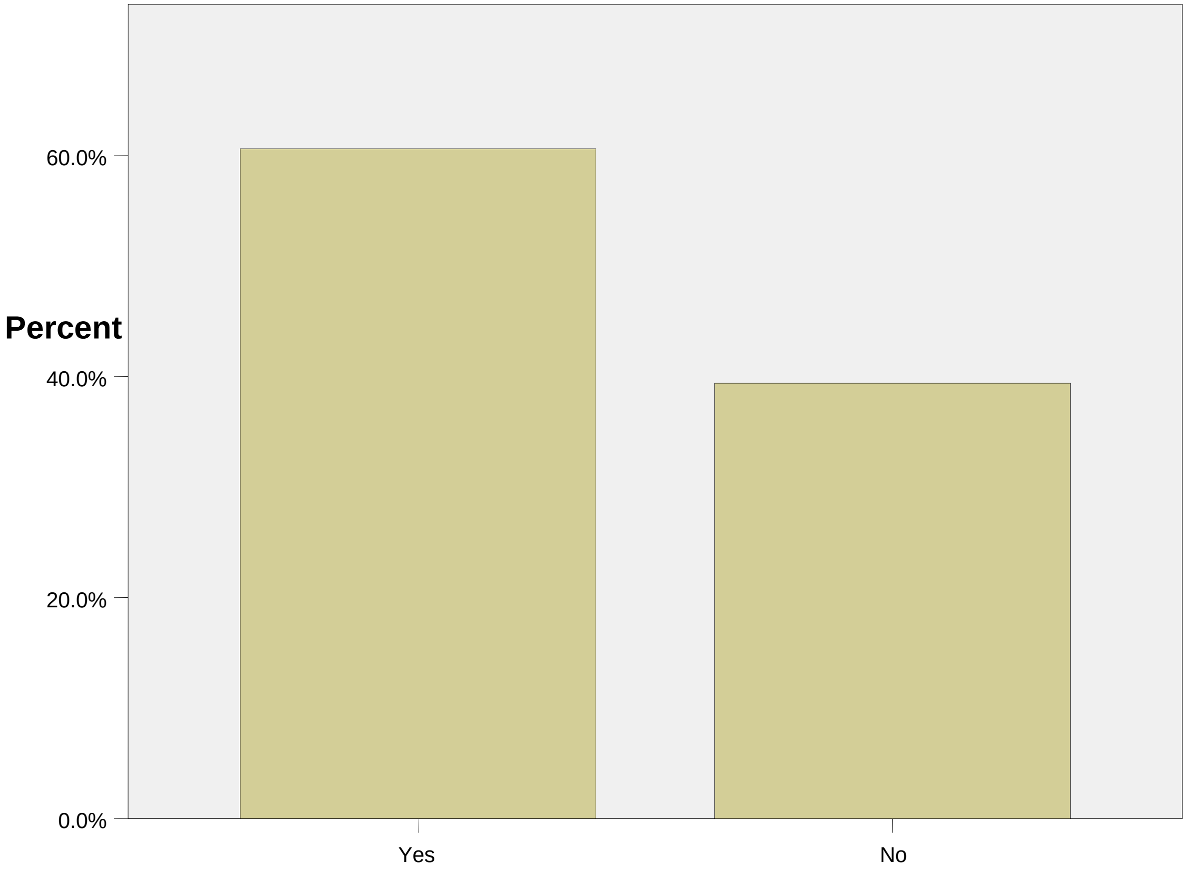


77 % (N=127) of respondents had used NHS outpatient services.

49b NHS in patients – ward\Mental Health Services

Answered 165 (95.4%)
Missing Answers 8 (4.6%)

	Frequency	Percent
Yes	100	60.6
No	65	39.4

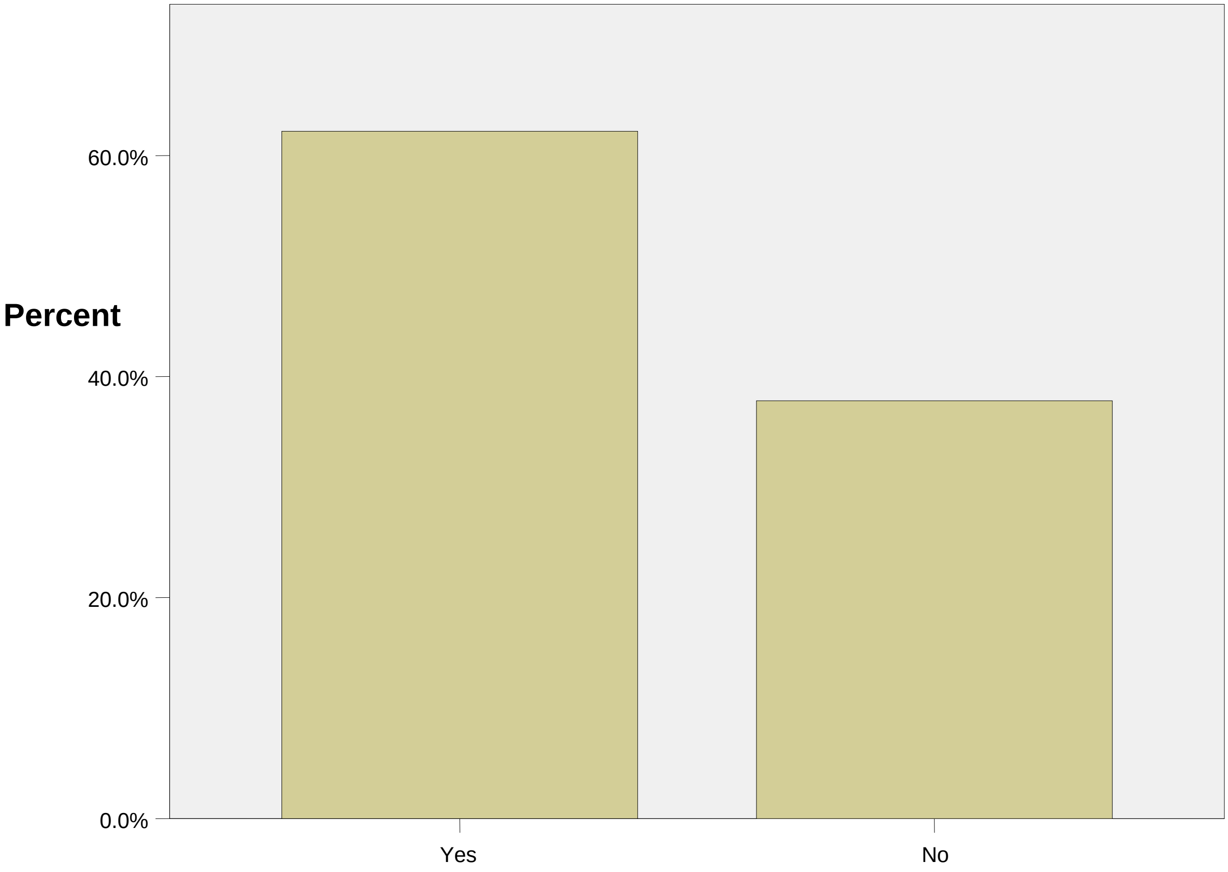


60.6 % (N=100) of respondents had used the NHS in patient services.

Question 49c Community Mental Health Services for example CRS, CMHT, crisis resolution

Answered 164(94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
Yes	102	62.2
No	62	37.8

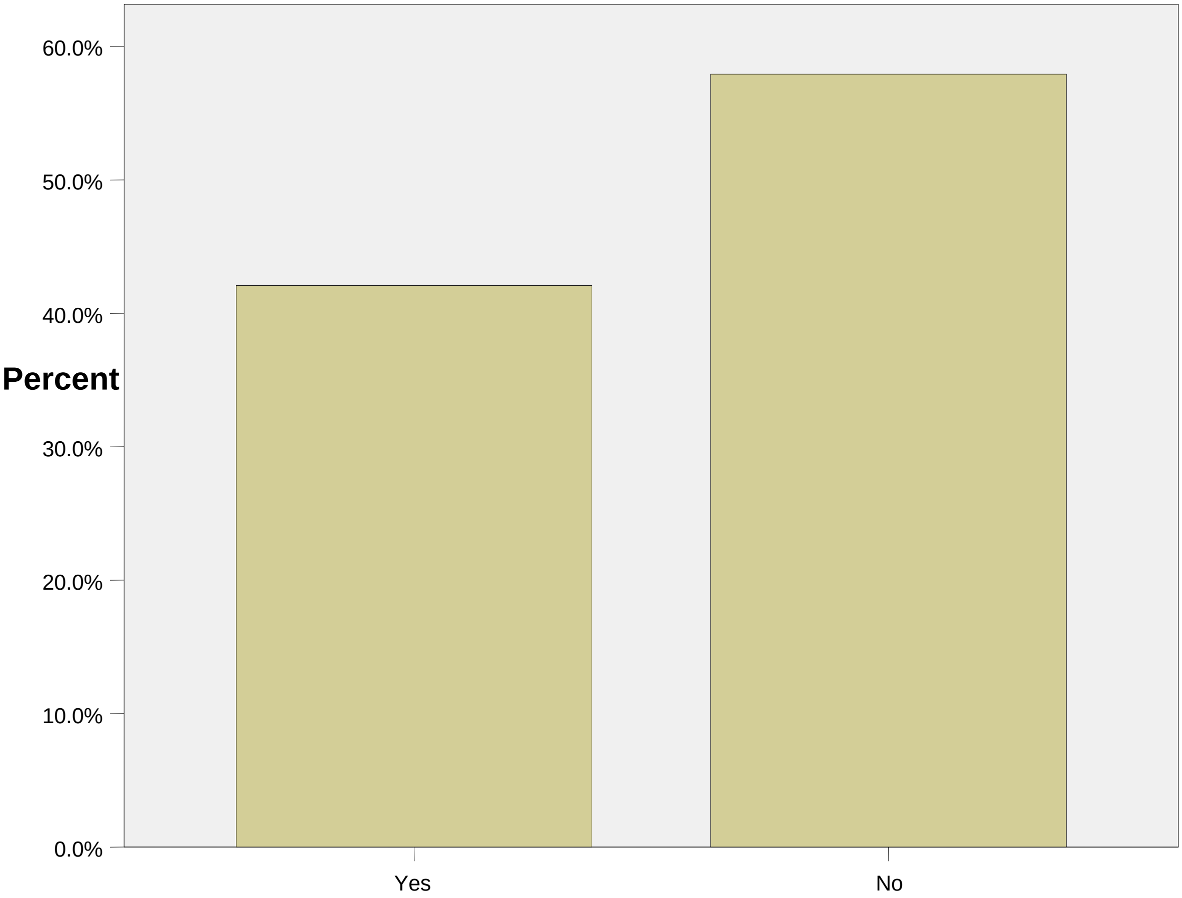


62.2% (N=102) had used NHS Community Mental Health Services.

Question 49d Social Services / Mental Health Services

Answered 164(94.8%)
Missing Answers 9 (5.2%)

	Frequency	Percent
Yes	69	42.1
No	95	57.9

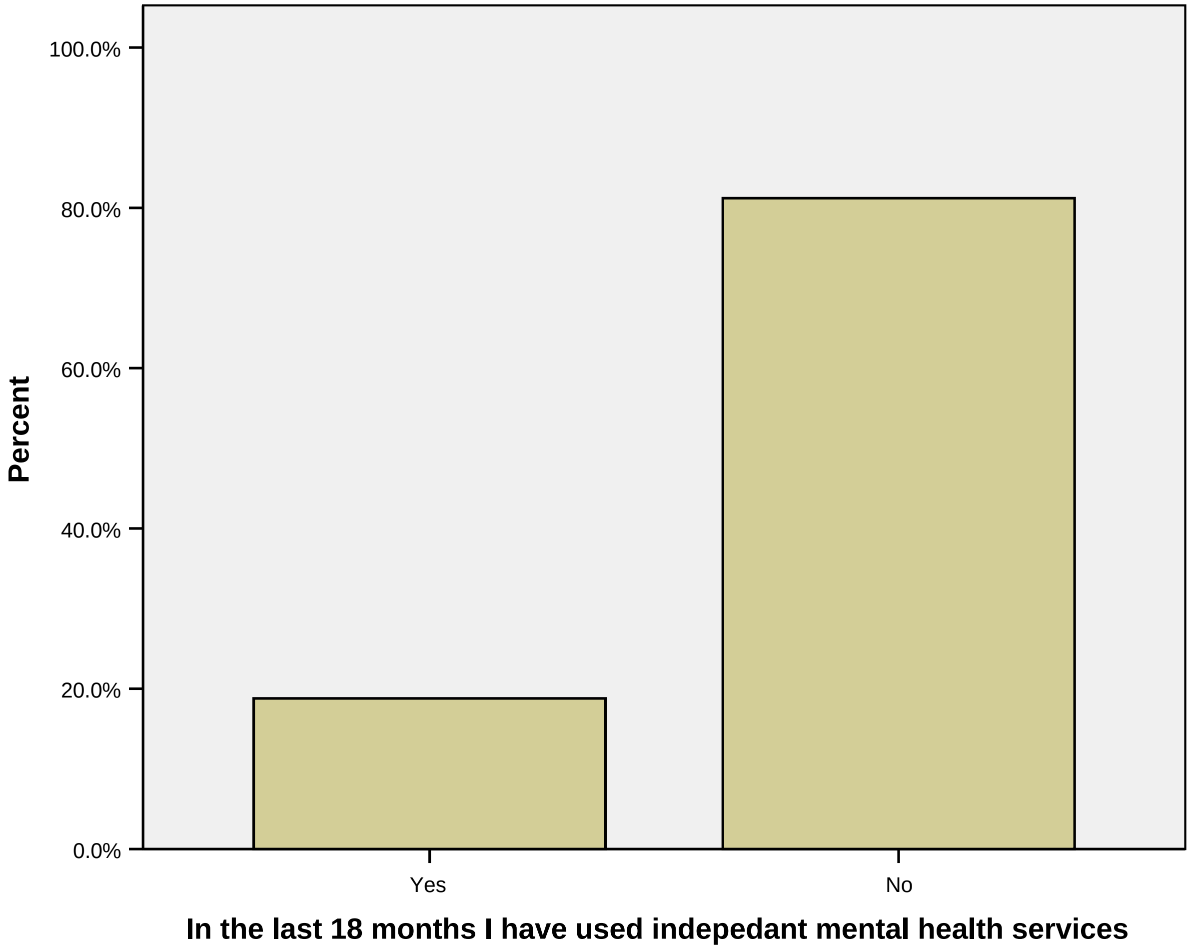


42.1% (N=69) had used social services mental Health Services

Question 49e Independent Mental Health Services

Answered 165(95.4%)
Missing Answers 8 (4.6%)

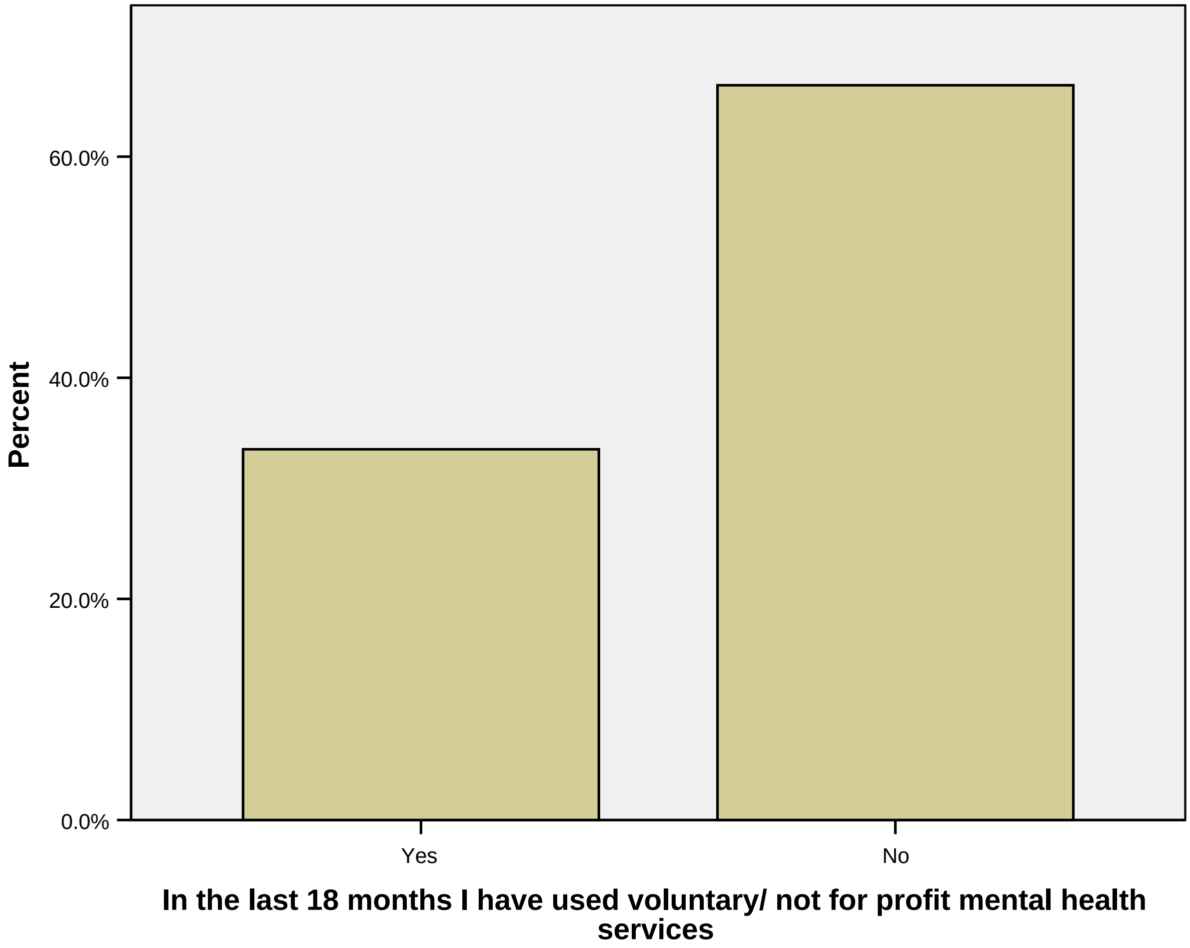
	Frequency	Percent
Yes	31	18.8
No	134	81.2



18.8% (N=31) had used the independent sector mental Health Services.

Question 49F Voluntary/not for profit mental Health Services

Answered 164 (94.8%)
Missing Answers 9 (5.2%)



	Frequency	Percent
Yes	55	33.5
No	109	66.5

33.5% (N=55) had used voluntary/not for profit Mental Health Services

Conclusions

This research has achieved many successful outcomes in terms of the process of design, the methods used for gathering data, and the analysis of that data.

The Service User Audit Group were instrumental in the selection of interviewers and for steering this project towards the achievement of its aims which will largely rely on the response of provider organisations to the results and consequent action plans.

The Service User Audit Group hope this work can contribute to a shift in the culture of mental health service providers towards service user centred care, moving away from a culture which has been perceived as focussing upon staff needs as a primary goal.

The full participation of the local service user movement has added value to every element of this work, and at the very least enabled a step towards recovery for the people that have been involved. It is envisaged that the outcomes of this work will be considered and further analysed by providers, who may wish to provide feedback for staff about their performance, and the results together with feedback, will be a change agent in areas that need it, and a welcome congratulation in the areas which have been well evaluated.

Without doubt the information gathered from the 173 respondents represents a cross section of those who have accessed the service in the last 18 months, and the design of the research (questions from service users and interviews by service users), has enabled a far higher response rate and more detailed answers than a postal survey for example. The Project target aimed for 100 respondents which was clearly exceeded. The data may be considered to be of the highest quality, in that, information was gathered face to face by peers, and as such, obviated possible negative effects of bias created by the “professional versus patient” divide.

This peer status of the interviewers, may have positively influenced the numbers of respondents opting into the study, and consequently enhanced the richness by increasing the number and volume of answers. Anecdotal evidence gathered from Research Interviewers suggested that throughout the whole process, participants felt less intimidated than if the interviewer was a professional, and the method of face to face interviews worked very well.

What Has Been Learned?

The full participation of interviewers in the project has been reported as generating feelings of empowerment, and acquision of new skills and subsequent increases in confidence and experience, have promoted the process of recovery for those concerned.

As a pilot project the SUAG wished to research the service users' "total experience" throughout their illness, however the task was eventually considered to be too big for the resources available. The questions generated by the working group, amounted to a second questionnaire, which was held in abeyance until required.

Overall the questions were well phrased and easily understood, although we can identify a number questions which caused some confusion and so, did not produce conclusive outcomes or results which were as reliable as they could have been.

The assumption (based upon practise sessions) estimated that interviews would last approximately 20 minutes with a hesitant participant. However the majority of interviews took at least 35 minutes with some needing up to one hour to complete. An interview briefing pack and training events should be considered an essential element of preparation for future studies.

The block of questions considered in question 26, produced some statistically significant results which can be used with confidence as a reliable satisfaction monitor. The 16 questions (reduced from 19 as the further 3 added no additional value) may be used a simple stand alone set, to ascertain satisfaction with any Mental Health service being received. This set of questions is totally robust and may have a commercial value.

1. Staff are available to help service users take control of their condition
2. Staff are friendly and approachable
3. Staff treat service users as their equals
4. Staff respect the rights of service users
5. Staff and service users work together to aid recovery
6. Staff feel that service users don't know what they want
7. Staff feel that service users don't know what they need
8. Staff feel that service users should do as they are told
9. Staff feel that service users should be seen and not heard
10. Staff do not feel able to question orders given to them by senior staff
11. Staff treat the label diagnosis and not the person
12. Staff feel that service users are manipulative
13. Staff feel that service users are attention seeking
14. Staff feel that service users can't make their own decisions
15. Staff feel that service users are a nuisance
16. Staff patronise service users

Table 1

Providers of Mental Health services received a good deal of positive acknowledgement particularly related to respondents' feelings of trust and confidence in the staff who provide care, and being listened to, and treated with respect and dignity. Service users felt listened to, and these feelings reflected in their willingness to recommend the providers to friends and family. However there was some perception of being misrepresented but this was countered by respondents’ confidence in their ability to challenge those misrepresentations, and leads to a conclusion that in the main, service users have some degree of self efficacy and have been empwowered.

Where providers have fallen below expectations largely relates to choice and opportunity to discuss medication. The results make clear the dissatisfaction with information and alternative options with regard to medication. At the same time, the vast majority continue to take prescribed medication, but this must be seen as existing within a milieu of compliance rather than concordance.

Although the spectrum of participants from black and ethnic minority backgrounds did not meet the projects initial aspiration those who were interviewed presented no significant difference in perception than their white counterparts and rigorous testing of results revealed that one’s ethnicity, gender and age plays no part in either positive or negative perceptions of the service received. This is a very welcome result for all providers.

The demographic responses relating to employment, whilst not suprising, perhaps reflect employers’ reticence to engage people who have a history of mental health problems. Those who felt they had lost employment as a direct result of their Mental Health problem indicate a level of intolerance within the workplace.

Research Limitations and Shortcomings

The Service User Audit Group have been particularly aware that bias can occur when interpreting research that produces unexpected results that are not statistically significant (Hewitt et al 2008), and understand that as co designers it is critical for the credibility of the work that neutrality and objectivity are maintained. The Group acknowledge that in designing the questions they invested a degree of both emotion and intellectual capital, and a hope that responses would provide conclusive evidence for each question that was asked.

Where those conclusive responses were not achieved, care was taken to sustain objectivity within the context of questions that obtained insignificant results would be trimmed from future evaluations rather than succumbing to interpretive bias.

It is rather disappointing that the qualitative responses failed to generate sufficient narrative to utilize some of the software we hoped to use, however as stand alone comments the Service User Audit Group felt they were a powerful set of contributions.

The hours that some of the Research Interviewers were able to contribute to the project were inhibited by the Benefit System, which in turn limited the hourly rate which could be offered for involvement in the project.

The Project Lead was able to donate scholarly activity time to the project (which became effectively a no cost element to the project), and was a distinct advantage for the overall cost of the work, but a distinct disadvantage, in enabling a concentrated dedicated block of time for the study, due to competing priorities. This factor impacted on every stage of the project and slowed it down. In addition, whilst the extended consultation at every level was fully participative and wholly empowering for all concerned, it slowed the project completion down.

The attribution of results to specific areas, which separate those from the County and those from the City would have been beneficial. SUAG recognise that if change indicators arise from the analysis, more specific coding will be required in the future. In addition it is understood that service providers will want to know how their own service is viewed. A method will be devised for future work, through which, questions that better identify details such as, clinical area, department or ward for example, will be developed. These would be mindful of the need to protect interviewee anonymity and questions will be phrased to extrapolate specific experiences rather than generalised answers.

Some of the Likert scale questions required significant manipulation (reversing polartity and re coding) to unravel meaningful results. Future questions will be standardised so the scale of answers (e.g. negative to positive) is consistent.

The benefits, advantages and applications of the research

The benefits, advantages and applications of this type of research can be represented by some of the adjectives used by those involved in the project:

Replicatable

Emancipatory

Evo and revo lutionary

Untainted by professional agendas

Credible

Value for money

Worthwhile

Recommendations

The Service User Audit Group recommends the following in terms of the research process:

- The process of future research and audit design involves people who are caring for, have used, or are using Mental Health services. This should take place under the umbrella of organisations such as the Peoples Forum and Open Assembly@Genesis.

- Research Interviewers are employed and appropriately remunerated to carry out data collection, analysis and dissemination of research and audit.

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- CRB checks for all prospective Research Interviewers must be in place prior to undertaking any contact with other Service Users and services.

- Research Interviewers are enabled to engage with statutory services as credible peers, with managerial support and authorisation to conduct activities associated with the project. Wearing of an official badge to enable professional workers recognise the legitimacy of the Interviewers is important and enables participants to identify names should there be a need for redress.

- Research Interviewers are trained and prepared for their role appropriately

- Research Interviewers are supported practically and psychologically. Involvement of Welfare Rights services and availability of a psychologist or therapist for the duration of any project will enhance beneficence and ensure non malificence for Interviewers.

- Any future project acknowledges the need for independent academic support to ensure research governance is of the highest quality. Peoples Forum and Open Assembly@Genesis and the Service User Audit Group have developed an excellent working relationship with De Montfort University (who have a Research Assessment Exercise (RAE 2008) rating of 4* World Leading Research) and recommend that this is developed further.

- Participating organisations have full knowledge of future projects in good time and managerial support

- The Service User Audit Group becomes the principal coordinators including administration and budget holding for User and Carer focussed research and monitoring in Leicestershire.

- Recruit train and develop a larger pool of Research Interviewers to ensure future projects are able to complete within a short time scale.

- Services which participate in future projects are given an opportunity to contribute to the pool of research questions.

- The Service User Audit Group recommends initial meetings with senior clinicians and managers, letters and information sheets to be distributed at least two weeks prior to any contact. The use of posters that set out the schedule and aspirations of the project together with clear contact details.

The Service User Audit Group recommends the following in terms of the change:

- Service providers must consider the availability, quality and accessibility of information about what their service does, and how it goes about its business, for prospective users and carers. This will enable informed choices and better understanding of policy and procedure prior to any formal engagement or admission

- Service providers must consider the positive impact information about medication has on the people who take it and endeavour to improve opportunities to find out and become informed

- Service providers must consider improvements in the choice and alternatives to medication

- Service providers must improve access to staff for one to one discussions about care

- Service providers must maintain their focus upon Service Users and Carers as customers, ensuring equity in the planning delivery and evaluation of care.

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