Evaluation of Service user Experiences

within Mental Health Services in Leicestershire County, Rutland and Leicester City

May 2012

SUCRAN
AUDITS
RESEARCH

Service User and Carer Research Audit Network

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Without these people this research could not have happened.

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Introduction

This report sets out the results of an audit of a research project that was designed, delivered and evaluated by service users and carers in 2009.

The original work entitled “Service User Experience of Mental Health Provision in Leicester and Leicestershire and Rutland” was commissioned by the Leicester City and Leicestershire County Primary Care Trusts, and undertaken by the Service User and Carer Research Audit Network (SUCRAN). In addition the report draws upon evidence gathered from the 2011 Audit of the Mental Health Charter (SUCRAN 2011) and attempts to provide a strong evidence base from these 3 studies.

Background

The 2009 study developed from questions and concerns raised by service users and carers, 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 in receipt of services, with the aim of celebrating good practice, and identifying areas where it could be improved. The aspiration that the outcomes of the research would improve the experience of people using services through changed practice, required the need to build in an audit against the original findings.

This audit mirrors many of the questions from the original report and in addition, attempts to ascertain a more accurate geographical location from where perceptions have been gathered.

SUCRAN and De Montfort University (DMU) worked closely to generate the original study and develop a suitable audit tool. 25 Research Interviewers were employed by DMU all of whom have a background as a user or carer of someone with mental health issues.

SUCRAN not only shaped and validated the questions, undertook interviews, analysed the results and will disseminate 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, Psychology and Interpreting services together with ethical approval from local and national committees ensured the best interests of *all* participants and research interviewers were observed.

Research Methods

Both the original 2009 study and this audit against the findings aspire to change practice and are therefore considered within the umbrella of Action Research

.

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 v19 (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 of the original and this report.

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 original questionnaire 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.

The original question set was used as the basis to design the audit tool which was undertaken by a number of Task and Finish groups from SUCRAN.

The outputs from these groups were peer reviewed 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 and De Montfort University)

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 and risk assessments, processing queries and communicating with participating services about the study. In addition materials to promote and advertise the project were generated by the SUCRAN.

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 Consultant Psychologist from Psychology Services Leicester 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.

However, psychological 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 policies for liability and indemnity insurance.

A member of the Welfare Rights Service joined SUCRAN for the duration of the project, providing advice and on-going 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 in the original work and 111 in the audit, across those receiving services from statutory voluntary and independent services throughout Leicester and Leicestershire and Rutland. A further 123 interviews were held to review the Charter for Mental Health (2008). 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 information sheet 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 information sheet 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 participants 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 an information sheet about how to access further mental health support if participants should wish, from services such as Focusline.

All interviewers ensured that participants read the participant information sheet. The participant information sheet made clear that participation was voluntary, that withdrawal from the process at any time was appropriate, and that participation would not affect the care in any way. All participants were asked to read and sign the consent form before the interview commenced. 173 and 111 Consent forms were fully completed respectfully.

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 v19. 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 18 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 1 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 SUCRAN over a number of meetings to consider interpretations and observations which are included at the foot of each question.

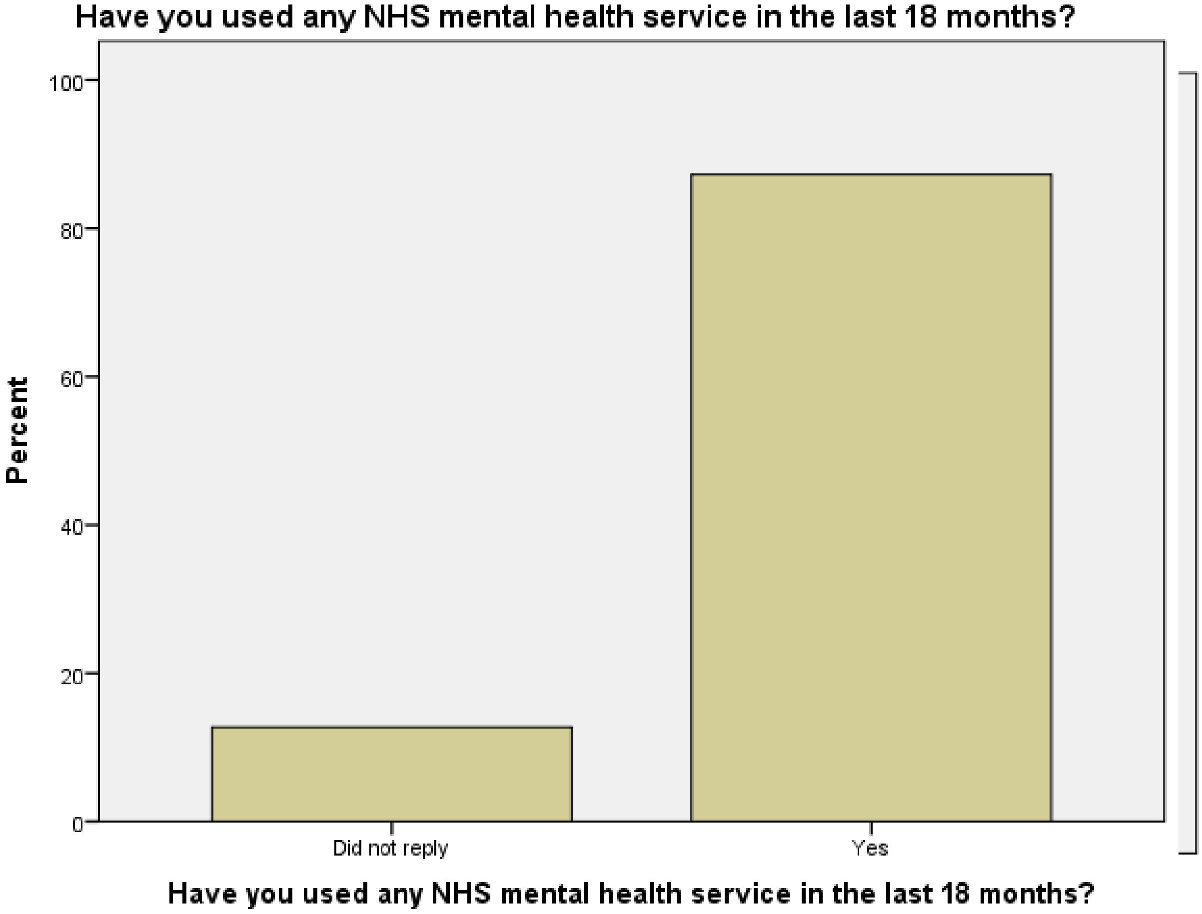
Qualitative Data Analysis

The qualitative data extracted verbatim from questions 17, 21 and 32 together with additional notes and explanations discussed during individual interviews. This was initially placed in a database and some analysis was attempted using NVivo 9. 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.

Q1

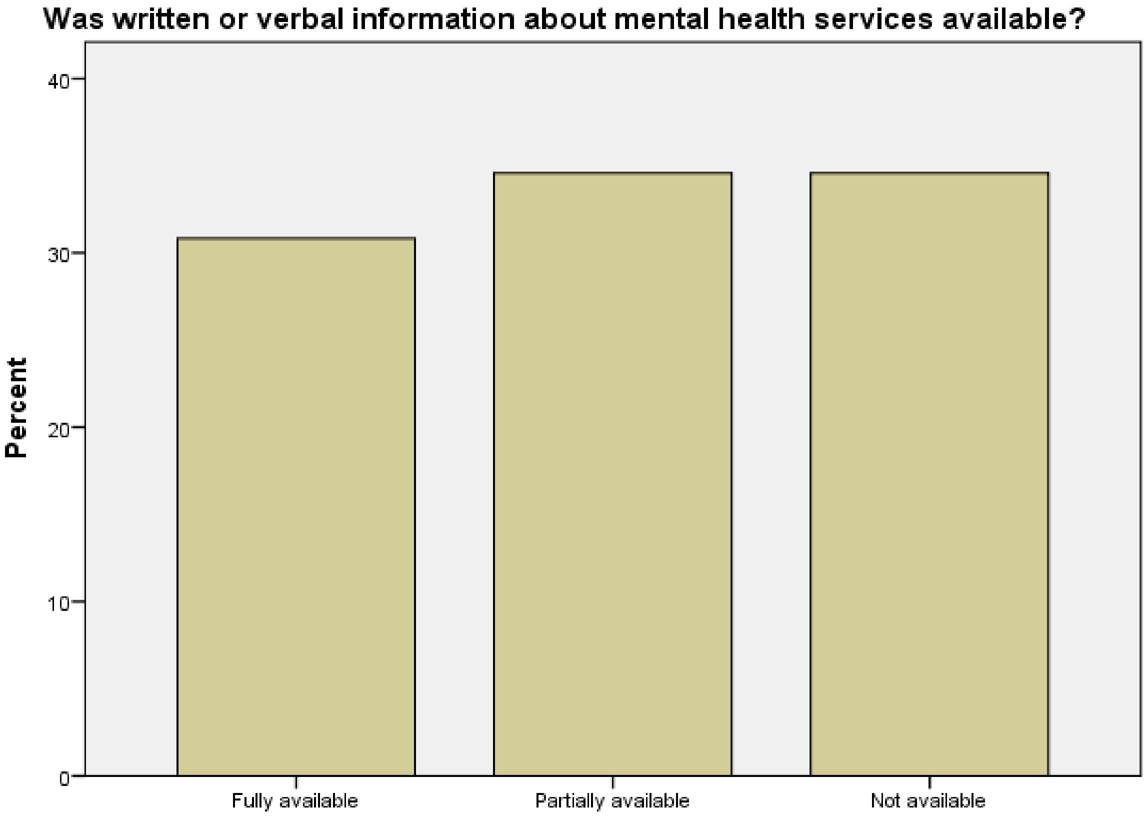


	Frequency	Valid Percent
Did not reply	14	12.7
Yes	96	87.3
Total	110	100.0

There is an assumption that the 13% (n= 14) that did not reply to this question are in receipt of services, considering that they were interviewed within a health setting and did not answer “no”.

These statistics are similar to the 2009 Study which reveals that 95% (n = 162) of participants identified that they had used Mental Health services within the last 18 months, with. 5% (n = 9) answering “no”. and again participants were interviewed within a setting for people with Mental Health problems, and were in fact users of that service.

Q2

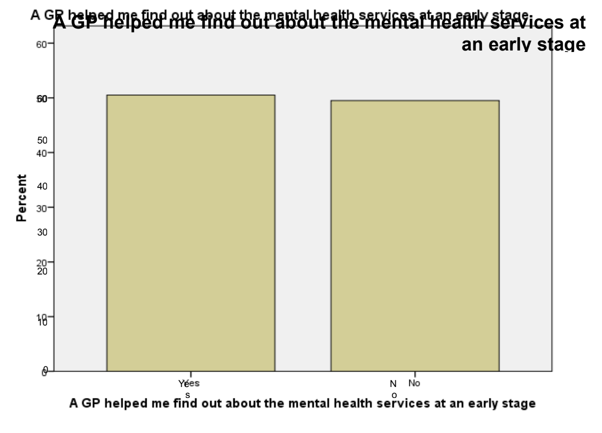
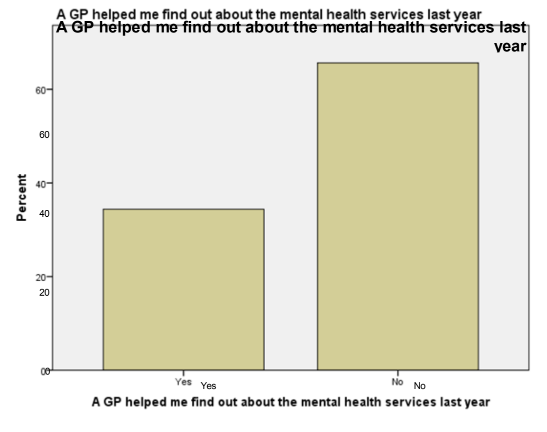


Was written or verbal information about mental health services available?

		Frequency	Valid Percent
Valid	Fully available	33	30.8
	Partially available	37	34.6
	Not available	37	34.6
	Total	107	100.0
Missing	System	3	
Total		110	

The combined total of participants who identified that information was only partially or not available, constitutes 69% (n = 74) of the 107 participants who answered this question during their interview. This suggests that more needs to be done by provider organisations to ensure a better understanding of services available for both users and their carers. An interesting factor relates to the lack of verbal information, and a consequent question must explore the communication skills of professionals working in this sector.

A Comparison with 2009 Study reveals that the availability of information has suffered, where 60% of participants indicated that information was either not available (N=46) or only partly available (N =55). This 9% fall in the perceived availability of information comes despite the alert that providing information is a very important aspect of empowering service users and carers. Additional cross calculations were performed that established no significant differences between ethnicity, age, gender and length of contact with services, were influential in these results.

Question 3b a1			**Question 3b b1**		
A GP helped me find out about the mental health services at an early stage Answered 99 Missing Answers 11			**The GP helped me find out about mental Health Services in the last year** Answered 96 Missing Answers 14		
	Frequency	Percent		Frequency	Percent
Yes	50	50.5	Yes	33	34
No	49	49.5	No	63	65
					

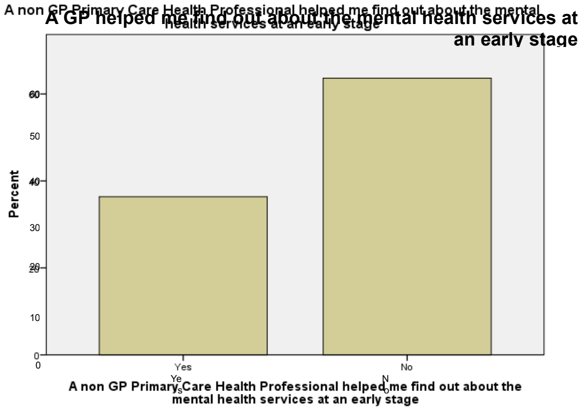
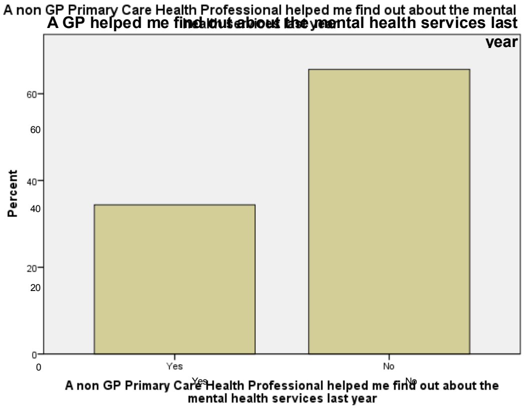
General Practitioners play a key role in the explanation of and signposting to services as their pivotal role within Primary Care. The Analysis Team Were surprised that of the 99 participants who responded only 50% had been helped by their GP.

Comparing these results to the 2009 study demonstrates little change over time as just under half of participants received help from their GP.

To reiterate the 2009 observations, General Practitioners are the cornerstone of primary care and it should be reasonably expected that this group of professionals are the primary source of information and signposting for people at an early stage of their contact with Mental Health Services.

It is suggested 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.

As with the 2009 study there was a fall of support offered by GPs in the last year, which is attributed to the majority of participants being in receipt of services for more than one year.

Question 3b 2			**Question 3b b2**		
A non GP Primary Health Professional helped me find out about the mental health services at an early stage Answered 99 Missing Answers 11			**A non GP Primary Health Professional helped me find out about the mental health services in the last year** Answered 96 Missing Answers 14		
	Frequency	Percent		Frequency	Percent
Yes	36	50.5	Yes	33	34
No	63	49.5	No	63	65
					

Primary Health Care Professionals other than GPs continue to play a part in the help needed to find out about services at an early stage of a person’s contact.

In comparison to the 2009 study, Non GP primary health professionals appear to be providing more help, as there is a notable rise from 19% to a little over 50% in the early stages, and a rise of 13% in help provided within the last year.

It is assumed that a non GP Primary Health Professional is any other professional worker other than a GP.

<table>
<tr><td colspan="3">**Question 3b 3**</td><td colspan="3">**Question 3b b3**</td></tr>
<tr><td colspan="3">**A Mental Health Nurse helped me find out about mental health services at an early stage**
Answered 99
Missing Answers 11</td><td colspan="3">**A Mental Health Nurse helped me find out about mental health services in the last year**
Answered 96
Missing Answers 14</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>35</td><td>35</td><td>Yes</td><td>26</td><td>27</td></tr>
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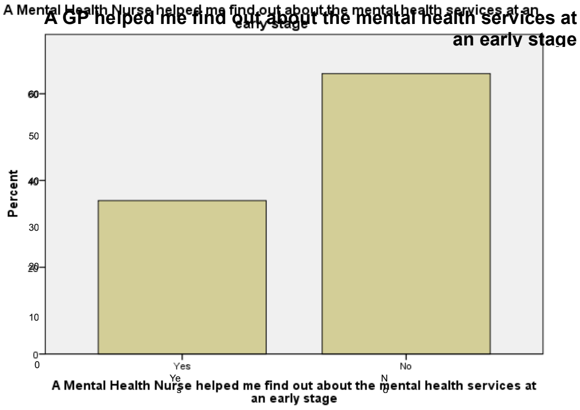
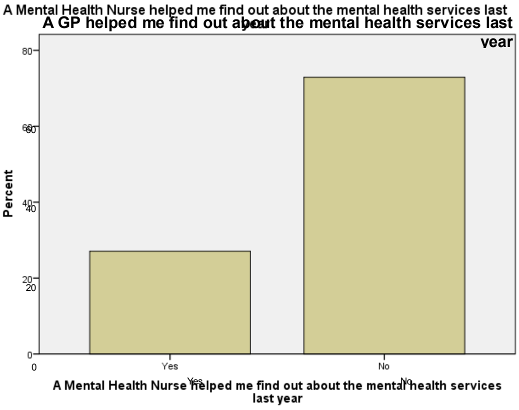
<tr><td colspan="3">
</td><td colspan="3">
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</table>

In comparison to the 2009 study the results for this question are broadly the same. The 2009 study suggested that 31.1 % (N= 46) of participants 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 3b 4</td><td colspan="3">Question 3b b4</td></tr>
<tr><td colspan="3">A Voluntary Sector Professional helped me find out about mental health services at an early stage
Answered 99
Missing Answers 11</td><td colspan="3">A Voluntary Sector Professional helped me find out about mental health services in the last year
Answered 96
Missing Answers 14</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
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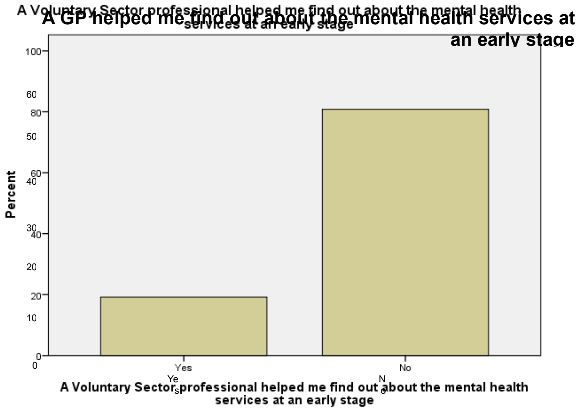
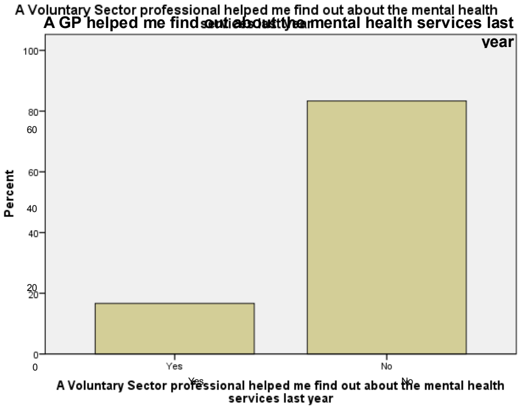
<tr><td>No</td><td>80</td><td>81</td><td>No</td><td>80</td><td>83</td></tr>
<tr><td colspan="3">
</td><td colspan="3">
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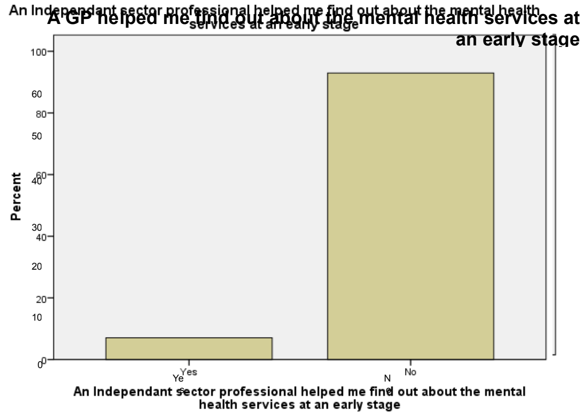
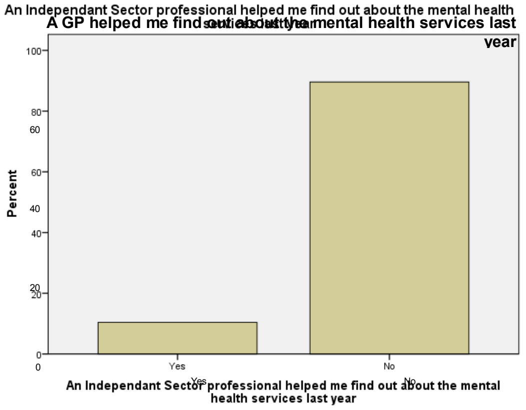
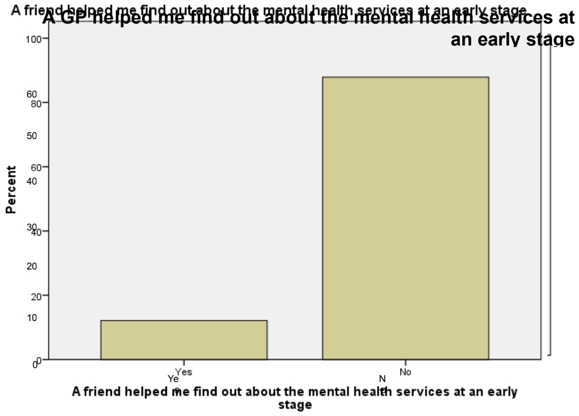
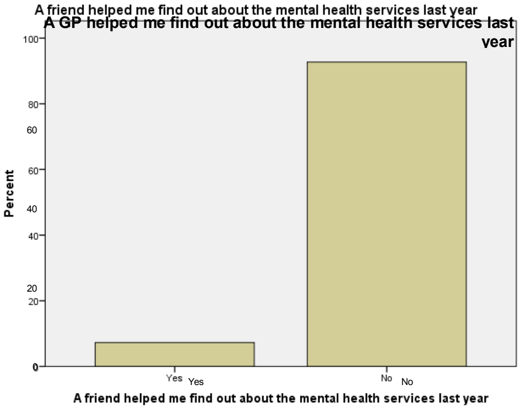
The percentage of help received by the Voluntary Sector has increased by 8% in the early stages and by 5% in the last year when comparing these results to the outcomes from the 2009 study.

<table>
<tr><td colspan="3">Question 3b 5</td><td colspan="3">Question 3b b5</td></tr>
<tr><td colspan="3">An Independent Sector Professional helped me find out about mental health services at an early stage
Answered 99
Missing Answers 11</td><td colspan="3">An Independent Sector Professional helped me find out about mental health services in the last year
Answered 96
Missing Answers 14</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>7</td><td>7</td><td>Yes</td><td>10</td><td>10</td></tr>
<tr><td>No</td><td>92</td><td>93</td><td>No</td><td>86</td><td>90</td></tr>
<tr><td colspan="3"> </td><td colspan="3"> </td></tr>
</table>

Feedback evidence from Research Interviewers suggested that participants were not able to differentiate between voluntary and independent sector providers, however slight increases were observed in the percentage of participants who had been helped 2% in the early stages and 6% within the last year.

3b6

<table>
<tr><td colspan="3">Question 3b 6</td><td colspan="3">Question 3b b6</td></tr>
<tr><td colspan="3">A friend helped me find out about mental health services at an early stage
Answered 99
Missing Answers 11</td><td colspan="3">A friend helped me find out about mental health services in the last year
Answered 96
Missing Answers 14</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>12</td><td>12</td><td>Yes</td><td>7</td><td>7</td></tr>
<tr><td>No</td><td>87</td><td>88</td><td>No</td><td>89</td><td>92</td></tr>
<tr><td colspan="3">
</td><td colspan="3">
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It appears that the role of friends may be playing a marginally less significant part when comparing results from the 2009 study. This role has reduced by 6% in the early stages and 11% in the last year.

As in the 2009 study, these results are influenced by the fact that in some cases the carer was a family member or friend.

<table>
<tr><td colspan="3">Question 3b 7</td><td colspan="3">Question 3b b7</td></tr>
<tr><td colspan="3">A family member helped me find out about mental health services at an early stage
Answered 99
Missing Answers 11</td><td colspan="3">A family member helped me find out about mental health services in the last year
Answered 96
Missing Answers 14</td></tr>
<tr><td></td><td>Frequency</td><td>Percent</td><td></td><td>Frequency</td><td>Percent</td></tr>
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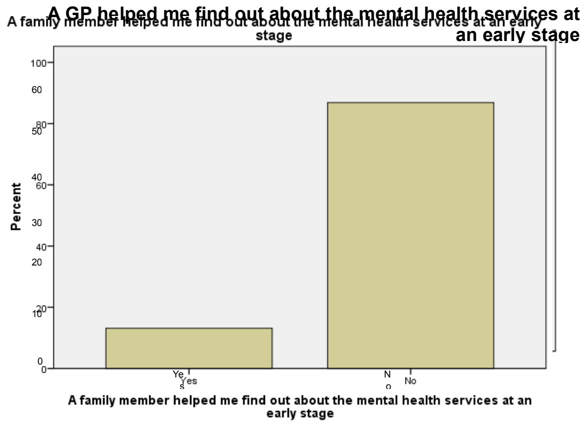
<tr><td>No</td><td>87</td><td>88</td><td>No</td><td>90</td><td>94</td></tr>
<tr><td colspan="3"> </td><td colspan="3"> </td></tr>
</table>

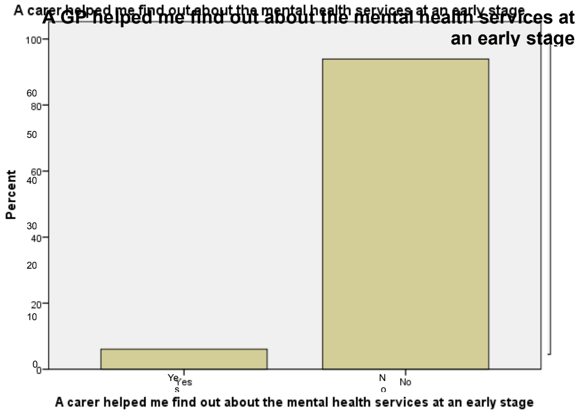
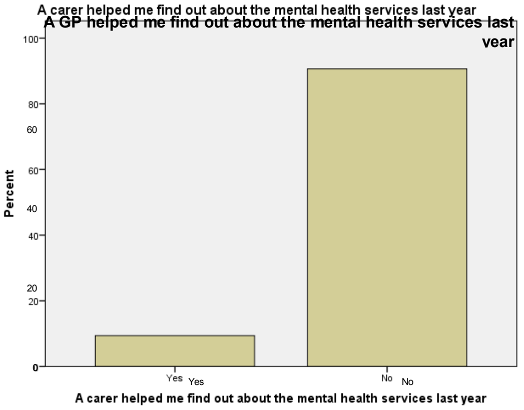
When comparing these outcomes to the 2009 study we observe that the role family members play in helping find out about services has reduced by 19% in the early stages and 15% within the last year.

This is an interesting set of outcomes considering a key objective of the Mental Health Charter (2008) is the recognition, respect and support the role of carers, family and friends. THE audit (SUCRAN (2011) identified a worrying quarter of participants stating “not at all”, that is, participants felt there was no recognition or respect of familial support. Furthermore, when asked about staff assistance in building or rebuilding positive relationships with friends and family “not at all” responses rose to 27%.

It is widely recognised in policy documentation (HMSO (1995), DH (1999a), DH (1999b) DH (2001), DH (2010), Banks (1998) Banks Roberts (2000)), that the family often becomes a central component of care for a person recovering from an episode of mental ill health and the acknowledgement of the powerful impact that family and significant others can have on health should be a consideration for all care providers. Historically this has been overlooked and undersupported.by organisations. The support offered by family and friends has been considered a cheap means of augmenting care provision particularly for people with longstanding disorders. Family members and friends are in a position to make significant contributions to the care of a person with a mental health problem although it is recognized that not everyone had supportive family or friends they could rely on, or are not in a position to ask their friends or family for help. It should also be noted that events and life experiences within the family may influence a family member's susceptibility to illness or the relapse of a chronic disease. In other words, conditions in the family, such as stress and social support, increase or decrease the likelihood that family members will become ill themselves (Doherty and Campbell, 1990).

There are more than 5 million carers in England and Wales, more than a million of whom care for more than 50 hours a week RCP (2004) and it is suggested that providing education, support, and therapy for families of people with mental health problems prevents relapse of the service user and results in cost savings of 19 to 27 percent; the increased costs of family support are offset by decreased use of mental health services (COFO, 1992).

In summary, families play a critical role in the health and treatment of their members, a play an important role in recovery and should be provided with the highest quality information to enable informed family based decision making.

Question 3b 8			**Question 3b b8**		
A carer helped me find out about mental health services at an early stage Answered 99 Missing Answers 11			**A carer helped me find out about mental health services in the last year** Answered 96 Missing Answers 14		
	Frequency	Percent		Frequency	Percent
Yes	6	6	Yes	9	9
No	94	90	No	87	91
					

Only 6% (N = 6) of carers were acknowledged as helping find out about mental Health Services at an early stage compared to 9.5 % (N= 14)in the 2009 study. These results are influenced by the fact that in some cases the carer was a family member or friend.

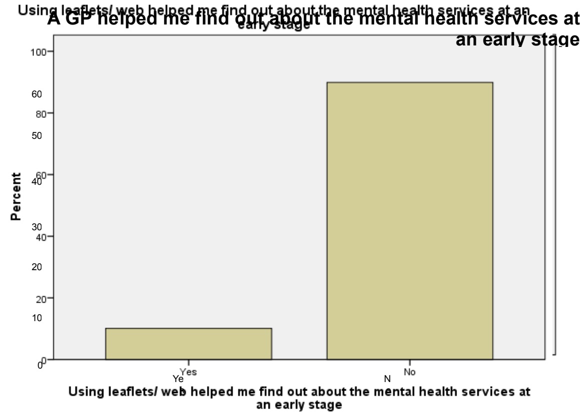
And within the last year only 9% (n = 9) were helped by a carer. (10.8% (n= 16) in the 2009 study. (See 3b7 analysis)

Question 3b 9

Using leaflets / web helped me find out about mental health services at an early stage

Answered 99
Missing Answers 11

	Frequency	Percent
Yes	10	10
No	89	90

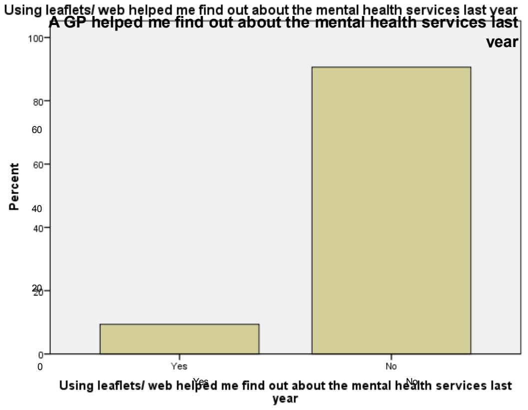


Question 3b b9

Using leaflets / web helped me find out about mental health services in the last year

Answered 96
Missing Answers 14

	Frequency	Percent
Yes	9	9
No	87	91

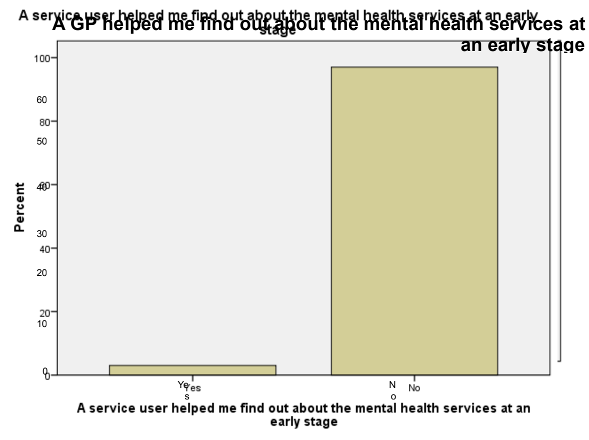
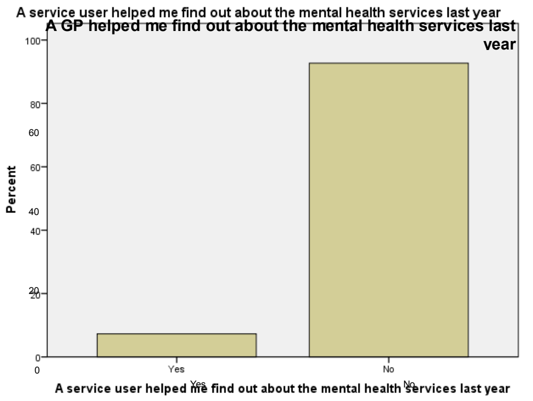


Surprisingly gathering information from the internet and information leaflets remains at a fairly low level seeing a small increase from 5% in the early stages and a 3% increase in the last year when compared to the 2009 study.

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.

<table>
<tr><td colspan="3">Question 3b 10</td><td colspan="3">Question 3b b10</td></tr>
<tr><td colspan="3">A service user helped me find out about mental health services at an early stage
Answered 99
Missing Answers 11</td><td colspan="3">A service user helped me find out about mental health services in the last year
Answered 96
Missing Answers 14</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>3</td><td>7</td><td>Yes</td><td>7</td><td>7</td></tr>
<tr><td>No</td><td>96</td><td>97</td><td>No</td><td>89</td><td>93</td></tr>
<tr><td colspan="3">
</td><td colspan="3">
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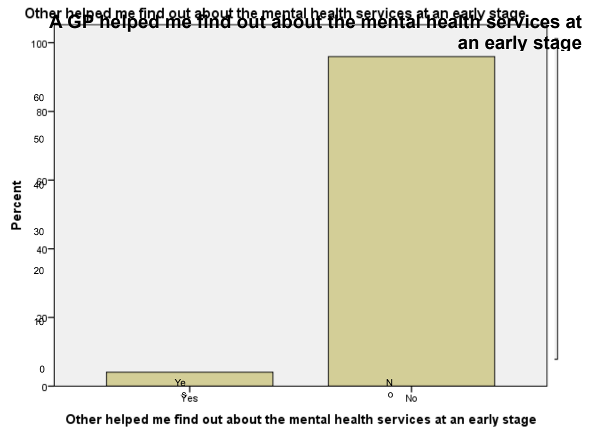
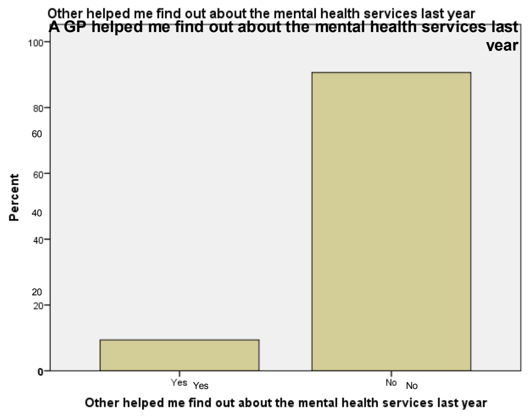
</table>

Help from other service users in the early stages of treatment remains at a fairly low level seeing a small increase by 2% in the early stages and a 6% reduction in the last year when compared to the 2009 study.

Question 3b 11			**Question 3b b11**		
Other helped me find out about mental health services at an early stage Answered 99 Missing Answers 11			**A service user helped me find out about mental health services in the last year** Answered 96 Missing Answers 14		
	Frequency	Percent		Frequency	Percent
Yes	4	4	Yes	9	9
No	95	96	No	87	91
					

Other information (not specified), assisted 9% in the early stages and 14 %, of participants in the last year of the 2009 study which are comparable outcomes to this current audit.

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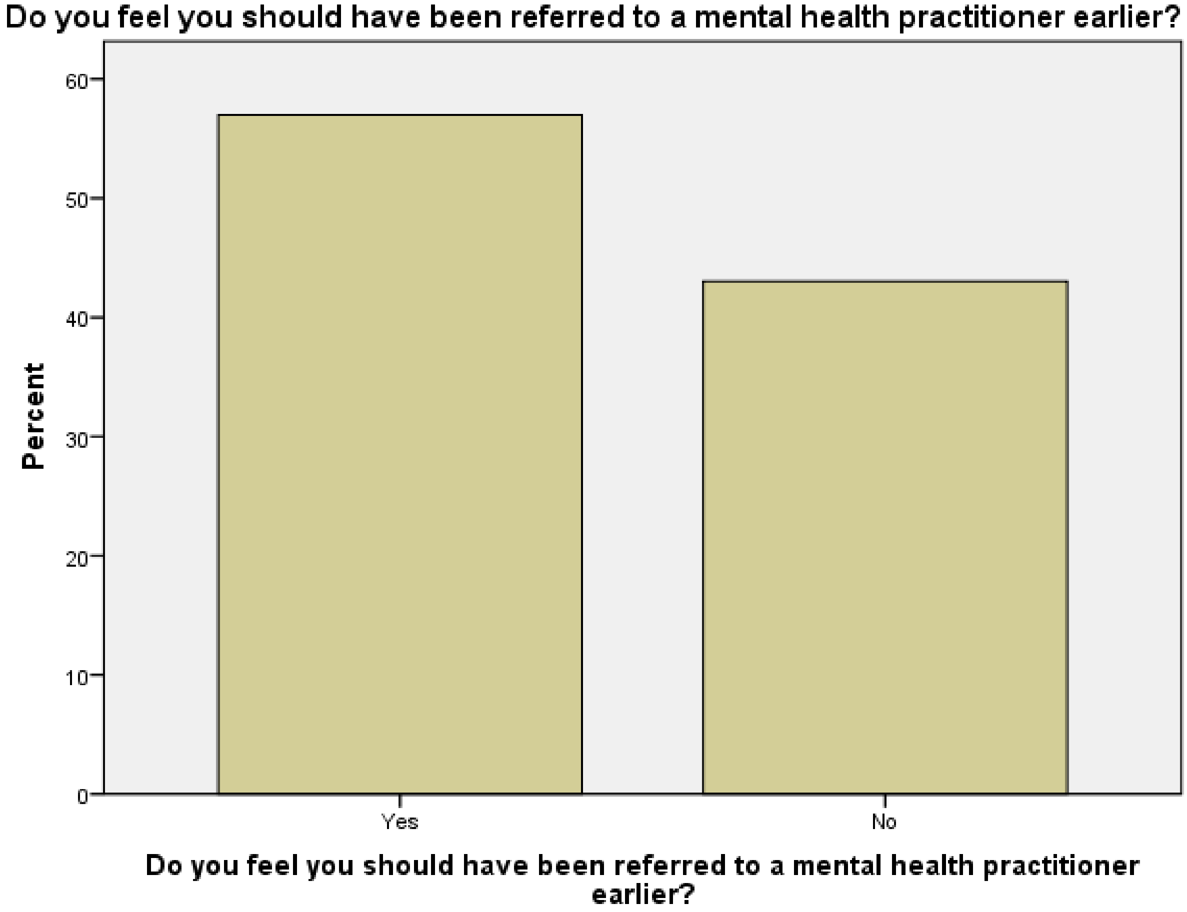
It is clear however that the provision of information and signposting could be improved. Statutory, voluntary and independent sectors all need relevant contemporary information with which to signpost service users and their carers.

As stressed in the 2009 study 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.

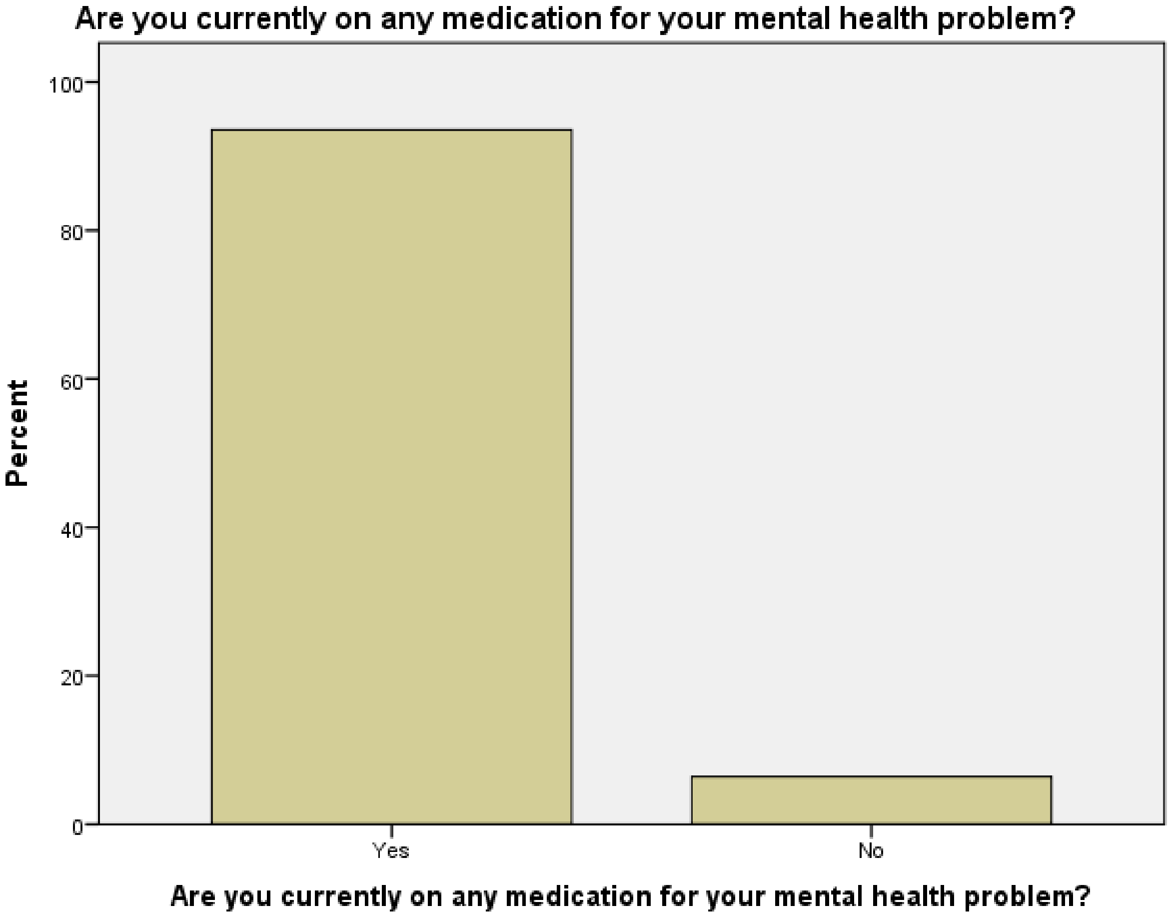
Q4



		Frequency	Valid Percent
Valid	Yes	49	57.0
	No	37	43.0
	Total	86	100.0
Missing	System	24	
Total		110	

A comparison between the 2009 study and this audit reveals broadly similar outcomes in that 61 % of participants (N= 100), felt they should have been referred earlier in 2009 and 57% of participants (N= 49), felt they should have been referred earlier in this audit. Responses to this question may be seen as justification for the instigation and development of early intervention services. The SUCRAN suggest that a primary care should provide easier access to secondary and in patient provision, developing a self- referral process where appropriate.

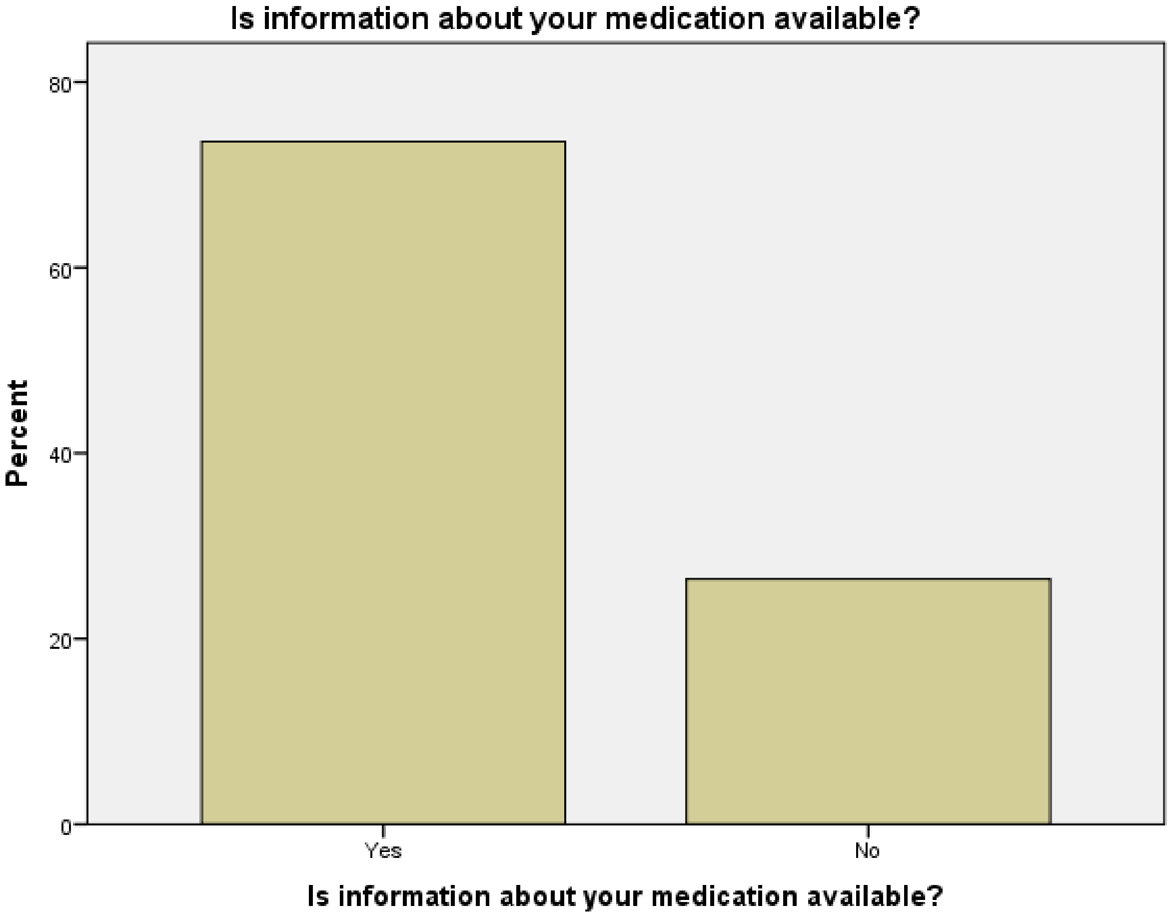
Q5



		Frequency	Valid Percent
Valid	Yes	102	93.6
	No	7	6.4
	Total	109	100.0
Missing	System	1	
Total		110	

92% of participants (N= 158) in 2009 and 93% of participants in this audit 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.

Q6

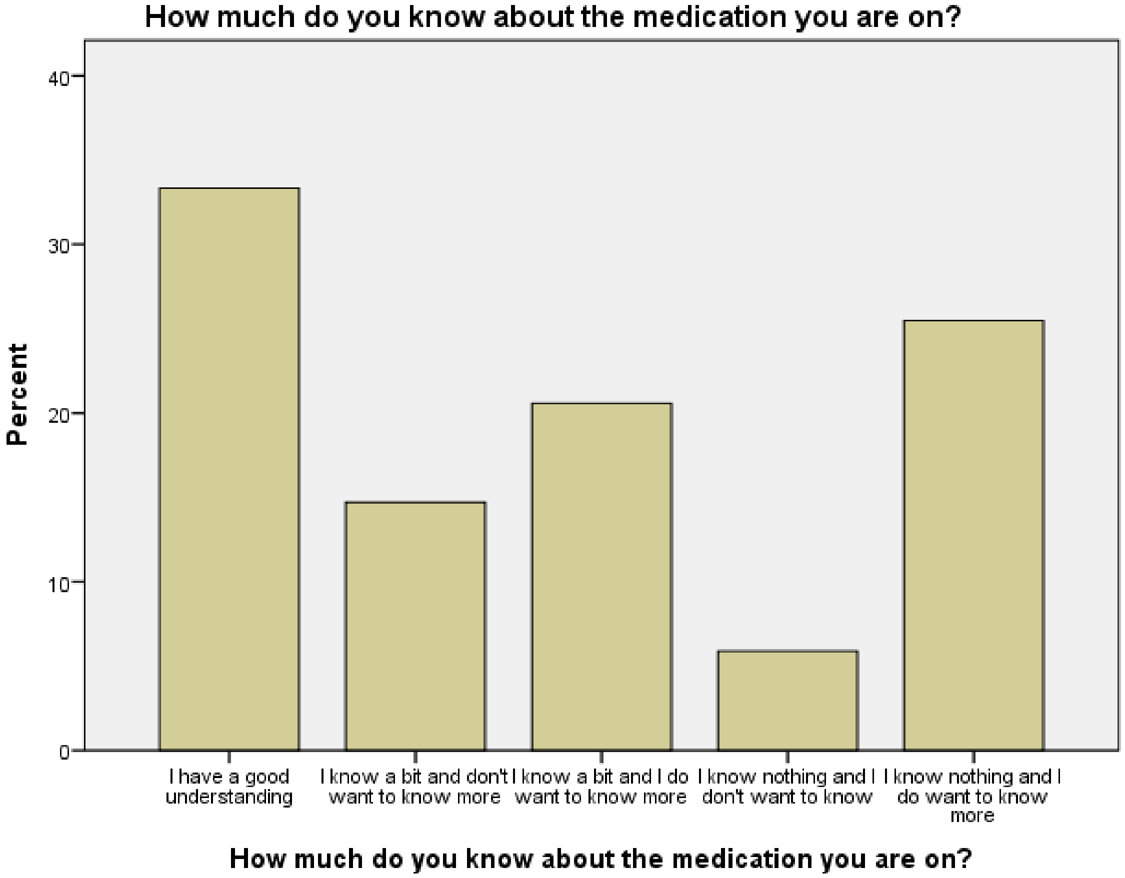


		Frequency	Valid Percent
Valid	Yes	78	73.6
	No	28	26.4
	Total	106	100.0
Missing	System	4	
Total		110	

Information about medication was available to 74% (n = 78) of participants compared to 74.9% (N= 125) of participants in the 2009 study.

However the lack of progress in availing information about this cornerstone of policy is an issue of concern. It is unacceptable for 26% of service users to feel that information was not available. 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, and despite the majority of participants having access to information about medication the following table in question 7 indicates that the information failed to instil a clear understanding.

Q7



		Frequency	Valid Percent
Valid	I have a good understanding	34	33.3
	I know a bit and don't want to know more	15	14.7
	I know a bit and I do want to know more	21	20.6
	I know nothing and I don't want to know	6	5.9
	I know nothing and I do want to know more	26	25.5
	Total	102	100.0
Missing	System	8	
Total		110	

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 participants, this question identified that 33% of participants had a good understanding of the medication they were taking.

However 32% (n= 32) identified that they knew nothing about the medication they had been prescribed. 41% of participants (n=47) wanted to know more. Compared to the 2009 study where 35.3% (N= 81) of participants wanted to know more.

This indicates that prescribers 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.

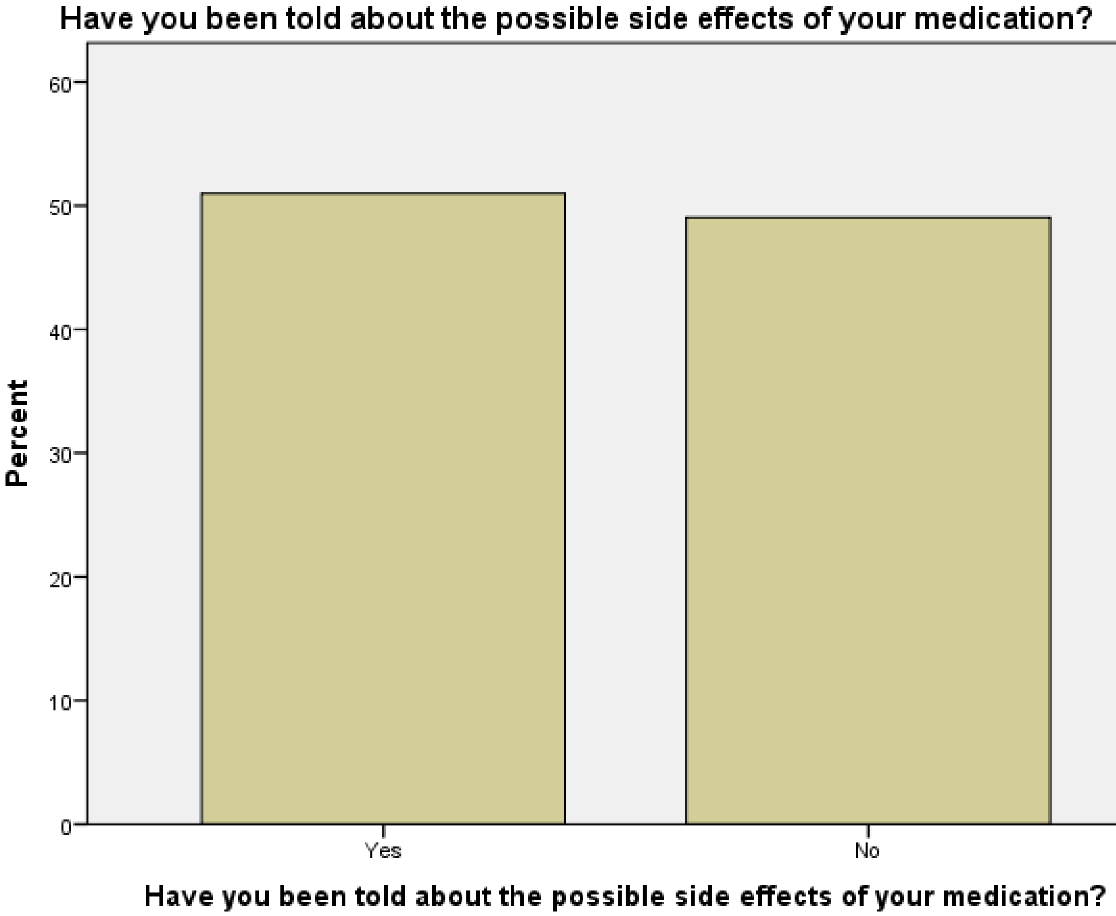
SUCRAN continue to promote the idea that increased levels of understanding will lead to patients making an informed choice, greater empowerment and ultimately better adherence and concordance to any medication regime.

The balance to these figures identifies 69% (n =70) of participants as having either a good understanding or some knowledge (81.1% (n= 133) in 2009). Only 33% (n= 34) of the total participants felt they have a good understanding.

SUCRAN recommend an increased number of medication groups based within inpatient, outpatient and other settings (the involvement centre for example). 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 on-going updates relating to side effects, indications, contra indications and jointly monitor the effects upon the individual.

It is unfortunate that between 2009 and the present very little progress has been made on this issue.

Q8

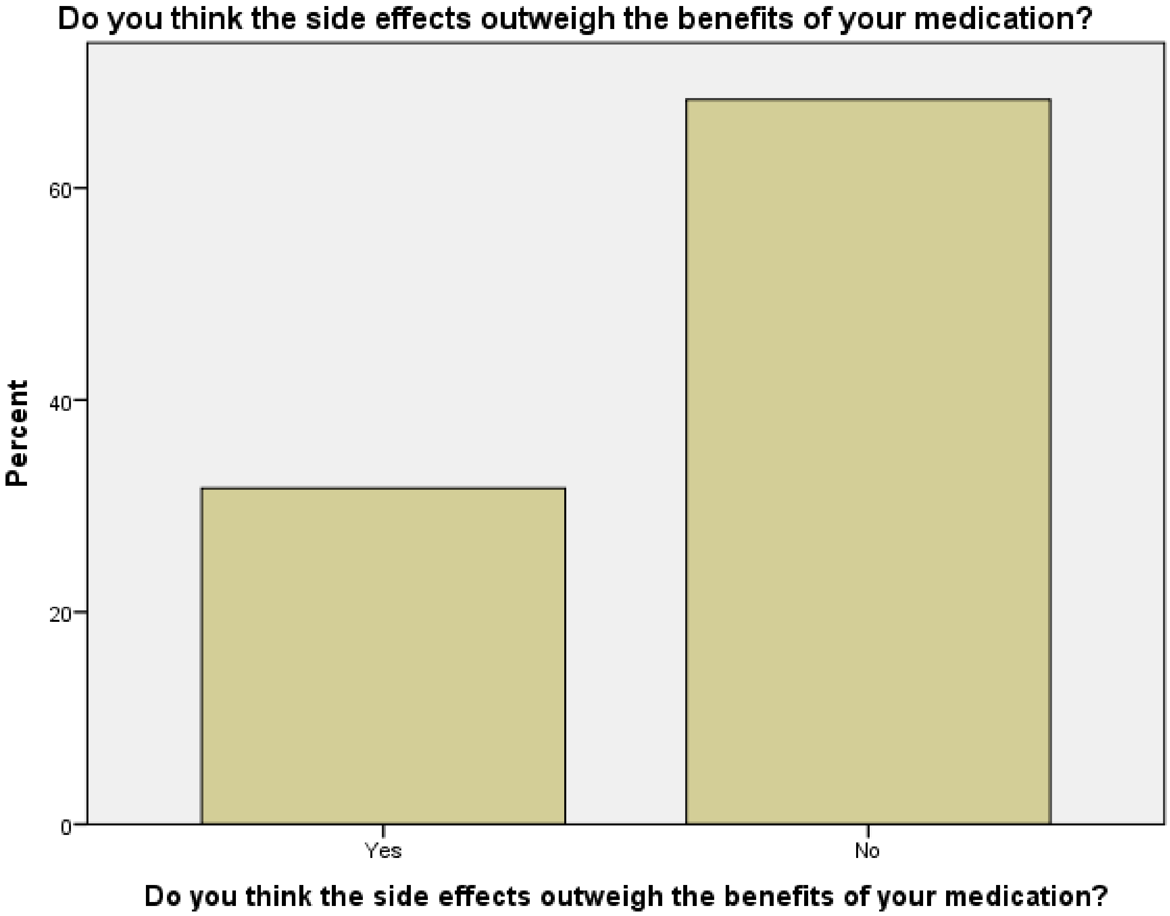


		Frequency	Valid Percent
Valid	Yes	53	51.0
	No	51	49.0
	Total	104	100.0
Missing	System	6	
Total		110	

Little progress has been made in the disclosure of medication side effects as 49% of participants (n = 51), had not been told of them. (53.1% (N= 85) in 2009)

This should represent a significant concern to prescribers, managers and all providers of care. The responsibility for providing information about side effects should rest firmly with the prescriber (Doctor or Nurse Prescriber), however SUCRAN 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 is 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.

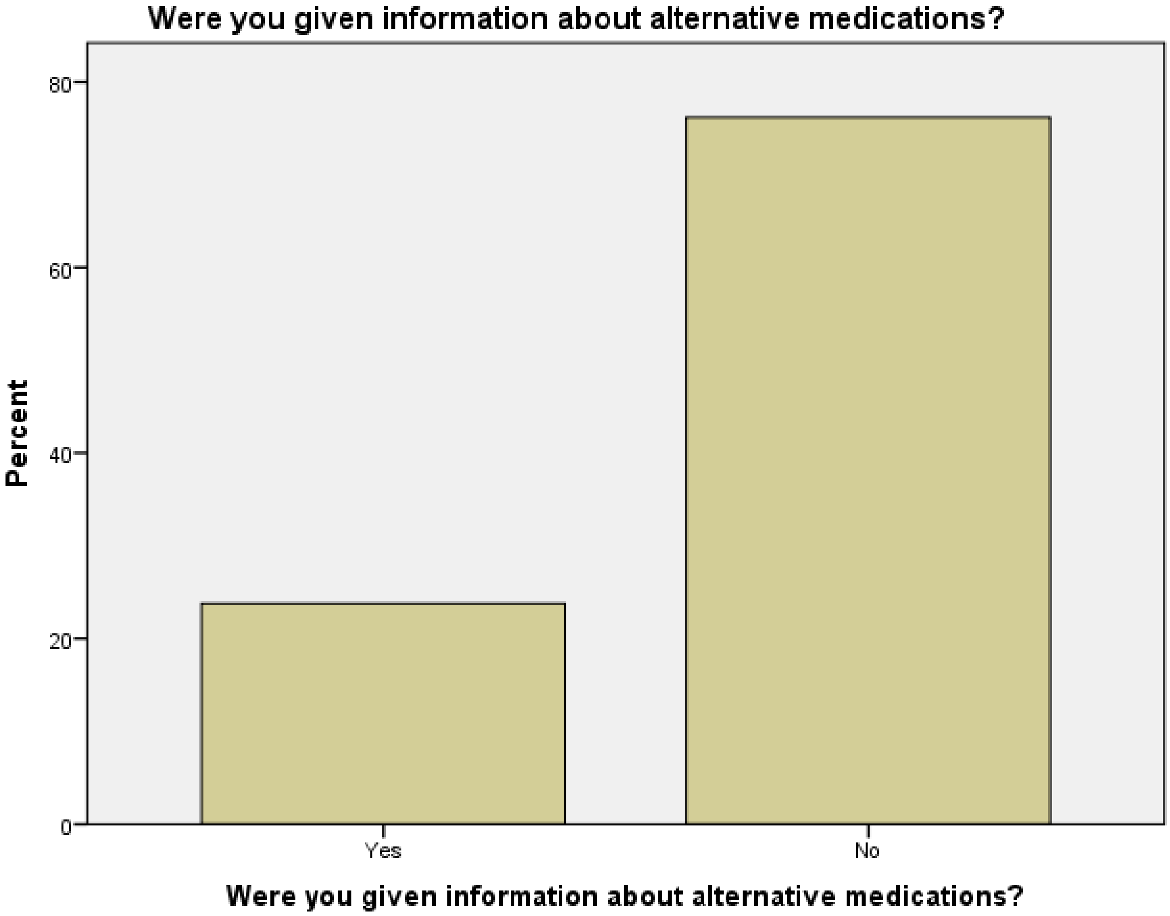
Q9



		Frequency	Valid Percent
Valid	Yes	32	31.7
	No	69	68.3
	Total	101	100.0
Missing	System	9	
Total		110	

Following analysis, the results for this question are not considered to be valid due to Research Interviewers alerting the analysis team that many participants did not understand the question and seemed to give false positives in their answers. No further analysis has been carried out but the raw data has been retained within the report for transparency.

Q10

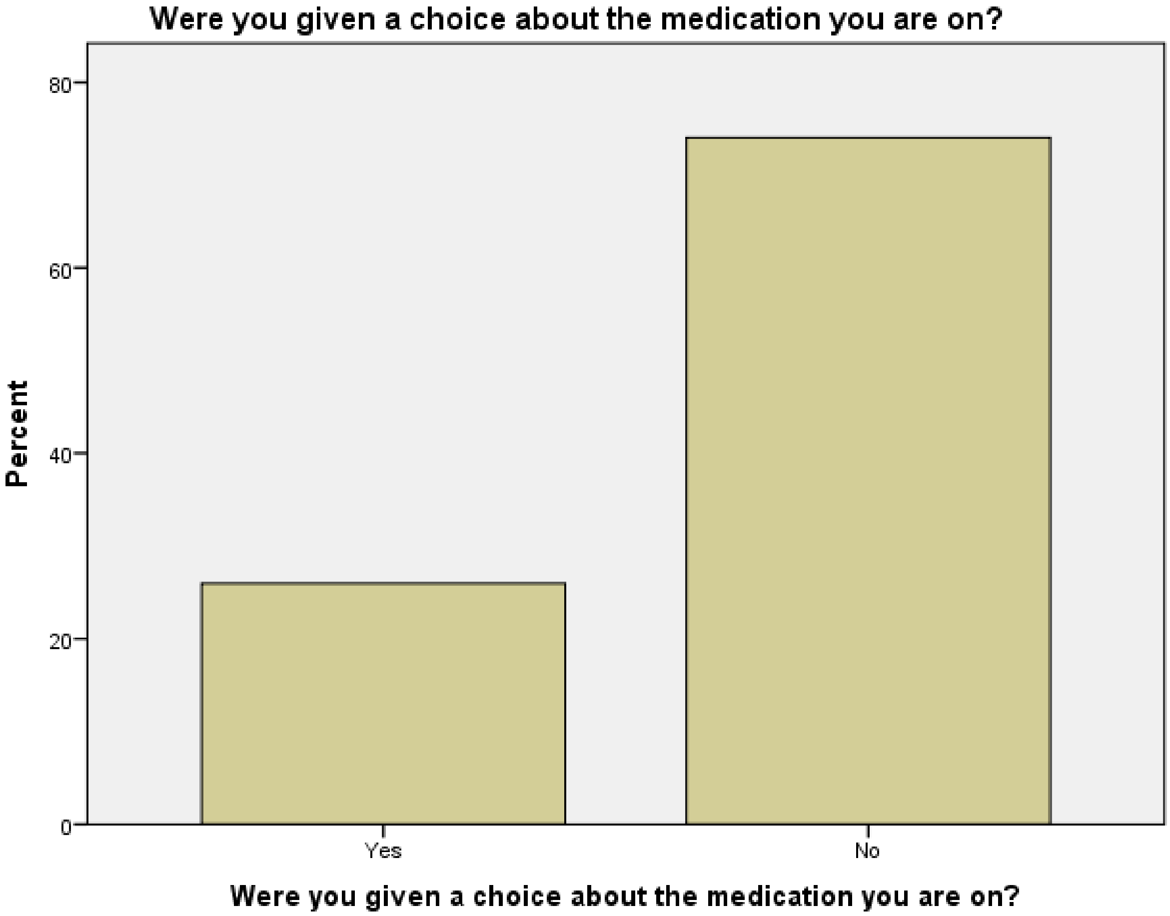


		Frequency	Valid Percent
Valid	Yes	25	23.8
	No	80	76.2
	Total	105	100.0
Missing	System	5	
Total		110	

It appears that the opportunity to be offered an alternative medication has reduced with 76% of participants (n = 80) not offered any information about alternative medications. This compares to 69.1% (N= 114) of participants in the 2009 study.

This response rate correlates directly with the answers for question 11 which relate to choice. SUCRAN wish to see the issue of choice addressed as a matter of priority

Q11



		Frequency	Valid Percent
Valid	Yes	27	26.0
	No	77	74.0
	Total	104	100.0
Missing	System	6	
Total		110	

74% of participants (n = 77) declared they were not given any choice compared to 71.2 % (N= 116) in the 2009 study, and represents no significant movement in establishing a key principle of the Mental Health Charter (2008) which established an aspiration to "Give people the information they need to make their own decisions and choices"

SUCRAN 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. Providing good quality, accessible information is a critical factor that ensures people who use services are able to make informed decisions, “Once you make a decision, the universe conspires to make it happen.” Emerson (1870). Empowered choices lead to decisions and behaviour that are a practical expression of that choice, and choice is an important element for service users to feel empowered and fulfilled. Dooher (2003).

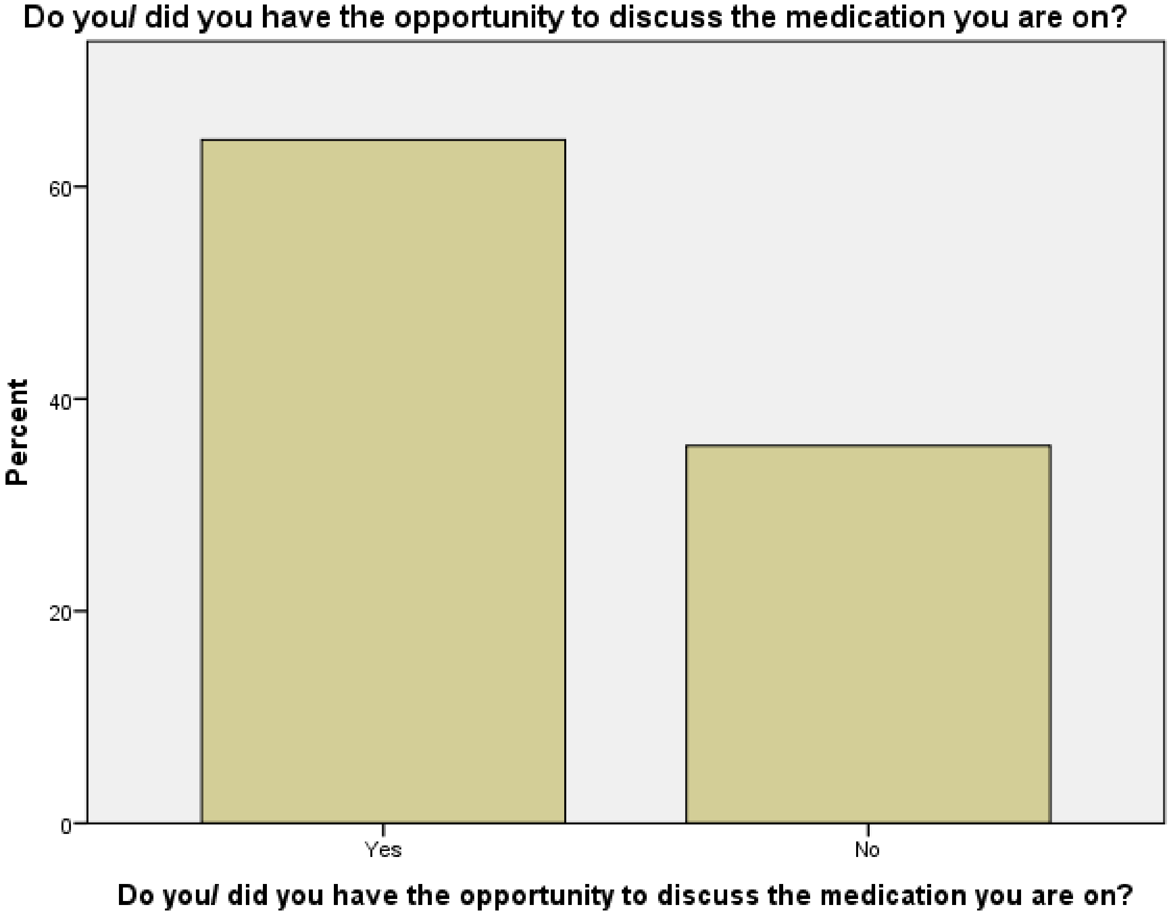
Whilst choices may be constrained by both economic and health factors, the information that explains the options should be honest, explicit and accessible. Information should provide a rationale for the rationing of services as well as those which are available.

Offering service users the “freedom to choose” does not however equate to offering them more power, although the availability of information enables a better understanding of the range of available or un- available options.

Given that the freedom to choose brings with it both the risks and responsibility for making that choice, there is strong evidence to support the enablement of service users in this respect, with approximately 84% of participants identifying that they were “allowed” to make mistakes. (SUCRAN 2011).

This is a disappointing result.

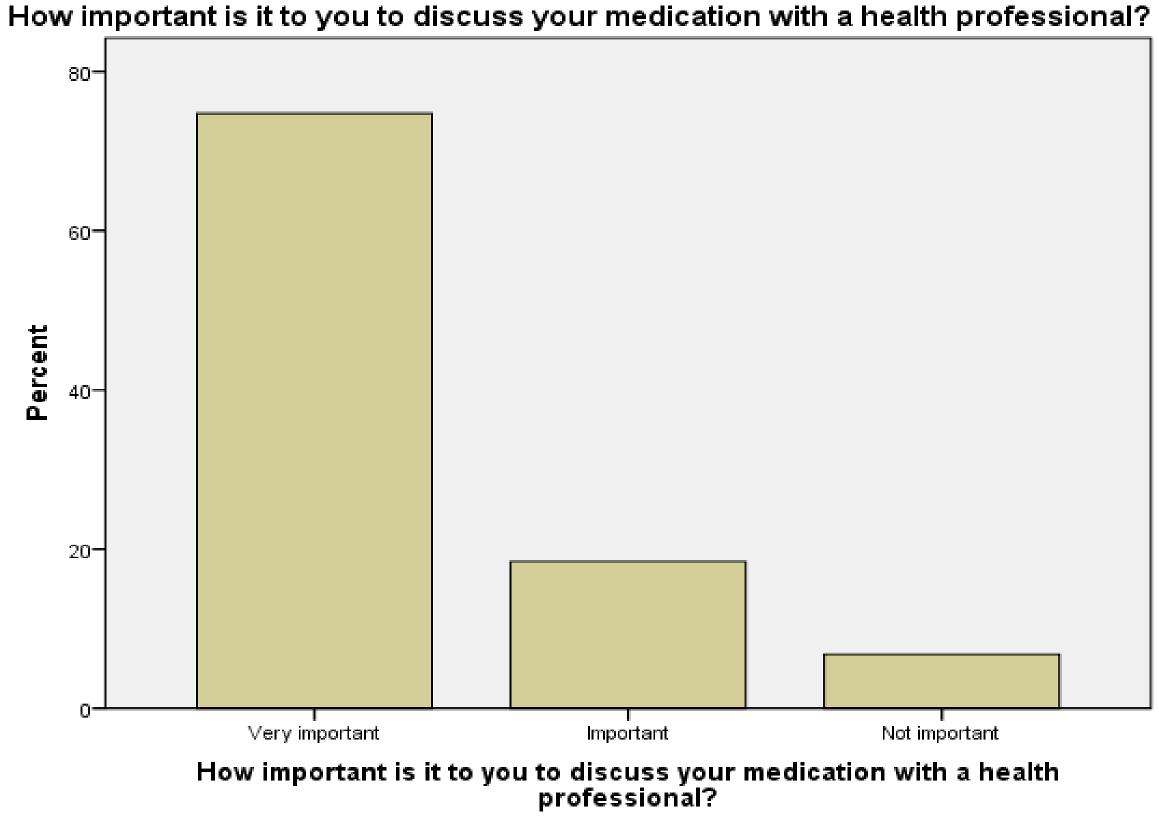
Q12



		Frequency	Valid Percent
Valid	Yes	67	64.4
	No	37	35.6
	Total	104	100.0
Missing	System	6	
Total		110	

The opportunity to discuss medication was given to 64% 9n = 67) compared with 57.9% (N= 95) in 2009. However, 36% (n = 37) felt they had no opportunity to discuss their medication. These results indicate that the opportunity to discuss medication did not involve alternatives or choices for some of those participants. This implies that the discussion may have been one way, because a significant proportion of participants had already highlighted a lack of information, discussion and choice. SUCRAN suggest that these factors undermine feelings of empowerment and the opportunity for concordance within both participants, and the broader patient population. This outcome must be addressed as a matter of priority.

Q13



		Frequency	Valid Percent
Valid	Very important	77	74.8
	Important	19	18.4
	Not important	7	6.8
	Total	103	100.0
Missing	System	8	
Total		111	

The majority of participants, 75% (n = 77) felt that discussion of the medication was either important for very important. (89.2%, n= 148 in 2009)

This result demonstrates the disparity between the wishes of the person receiving treatment and the service they are receiving. SUCRAN 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.

Q14 How often would you like to discuss your medication with a health professional?

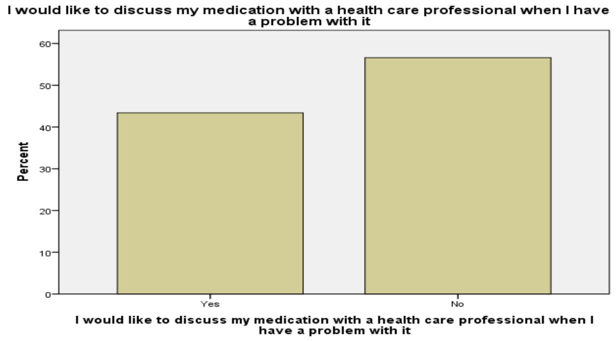
Q14a

		Frequency	Valid Percent
Valid	Yes	68	64.2
	No	38	35.8
	Total	106	100.0
Missing	System	5	
Total		111	

Q14b

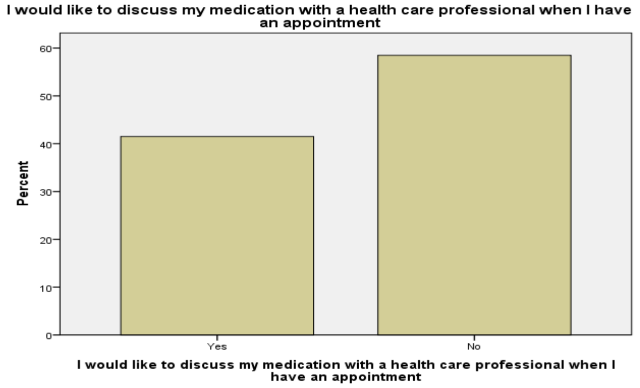
		Frequency	Valid Percent
Valid	Yes	36	34.0
	No	70	66.0
	Total	106	100.0
Missing	System	5	
Total		111	

Q14c



		Frequency	Valid Percent
Valid	Yes	46	43.4
	No	60	56.6
	Total	106	100.0
Missing	System	5	
Total		111	

Q14d



		Frequency	Valid Percent
Valid	Yes	44	41.5
	No	62	58.5
	Total	106	100.0
Missing	System	5	
Total		111	

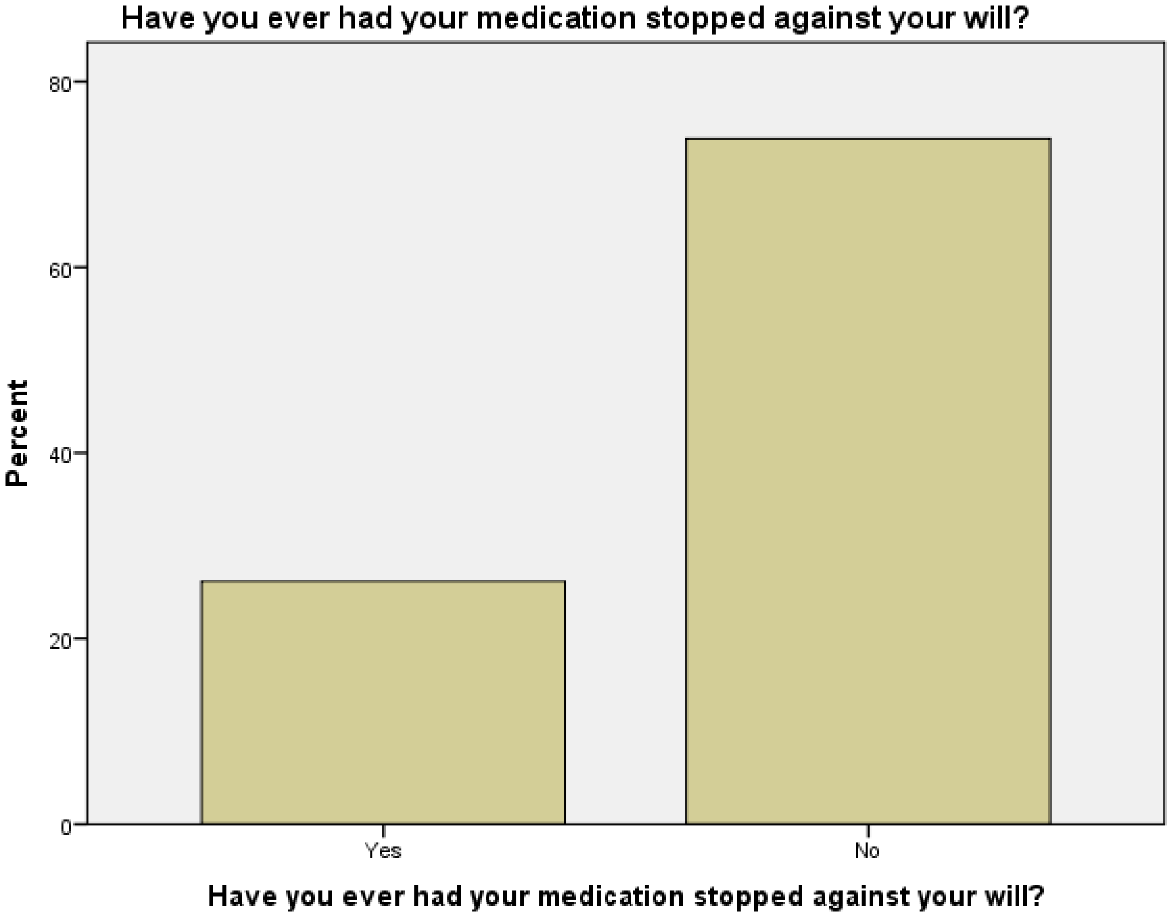
Whenever I like was preferred by 64 % (n = 68) of participants followed by “when I have a problem with it” as 43% (n = 46) respondents chose a positive response.

Q15

		Frequency	Valid Percent
Valid	I decided to reduce/ stop medication	43	50.0
	I and a health professional decided to reduce/ stop	24	27.9
	My health professional decided to reduce/ stop	19	22.1
	Total	86	100.0
Missing	System	25	
Total		111	

As with the 2009 study responses to this question were comparatively poor with 25 participants not responding (39.9 % n=69 in 2009). Of those who did respond, 50% (n= 43) had decided to reduce or stopped taking medication alone, whilst 28% 9 (n = 24) stopped in collaboration with a health professional (19.2% s (n= 20) in 2009). SUCRAN consider 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..

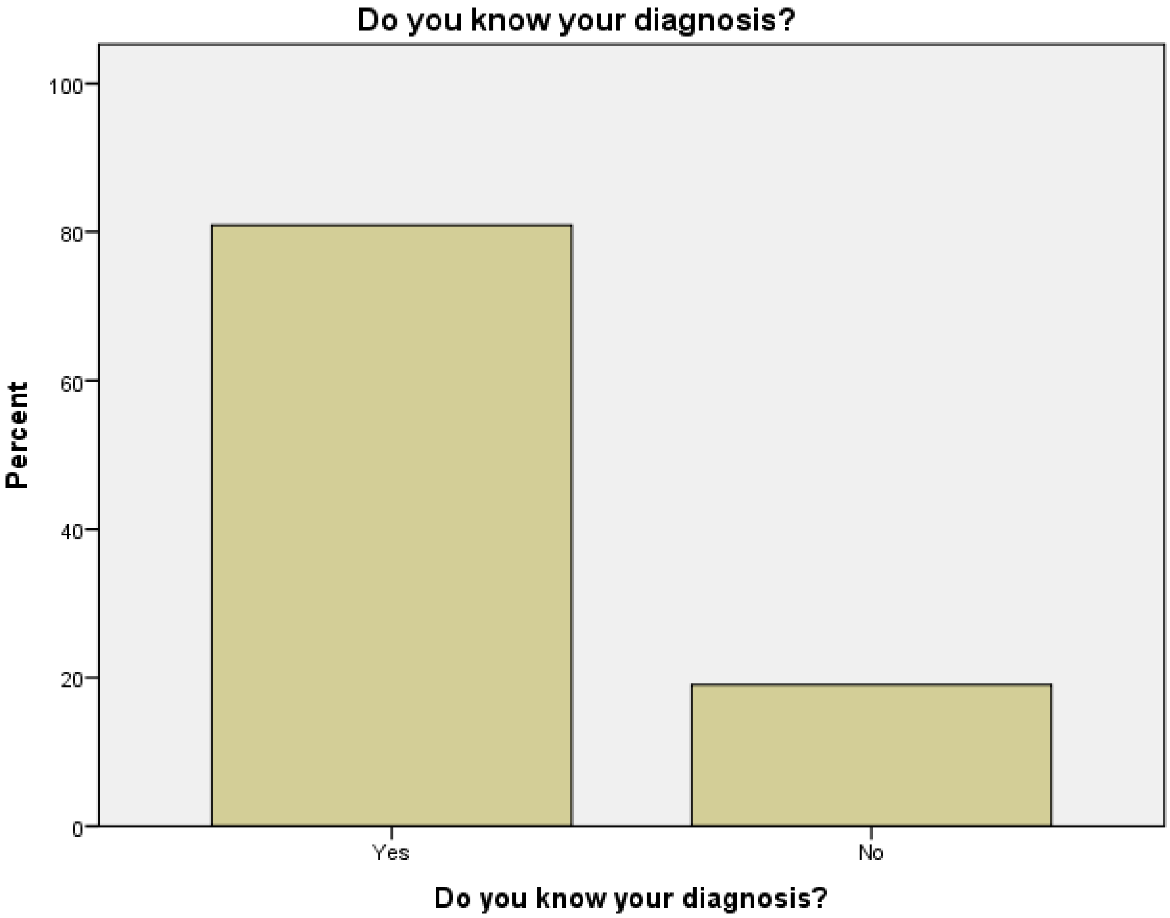
Q16



		Frequency	Valid Percent
Valid	Yes	28	26.2
	No	79	73.8
	Total	107	100.0
Missing	System	4	
Total		111	

The majority of participants (73% n = 79) had never had medication stopped against their will, which is very similar to the outcomes of the 2009 study. We assume that 26% (n = 28) disagreed with the decision to stop medication

Q17

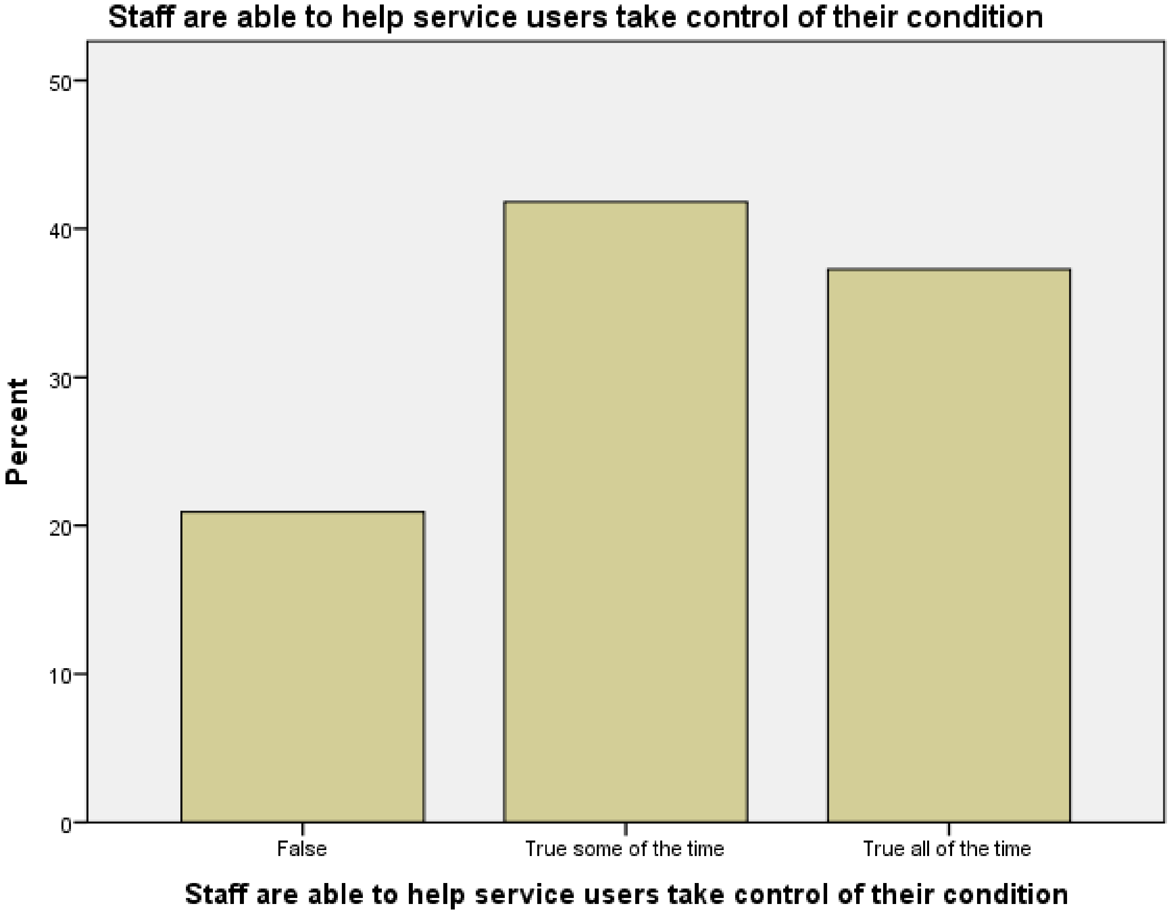


		Frequency	Valid Percent
Valid	Yes	85	81.0
	No	20	19.0
	Total	105	100.0
Missing	System	6	
Total		111	

81% of participants (n = 85) knew their diagnosis however of more concern is that 19% did not (n = 20).

In 2009 77% (n = 132) indicated that they knew their diagnosis, and 21.4% (n = 36) of participants did not. SUCRAN feel that the proportion of participants 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.

Q18a



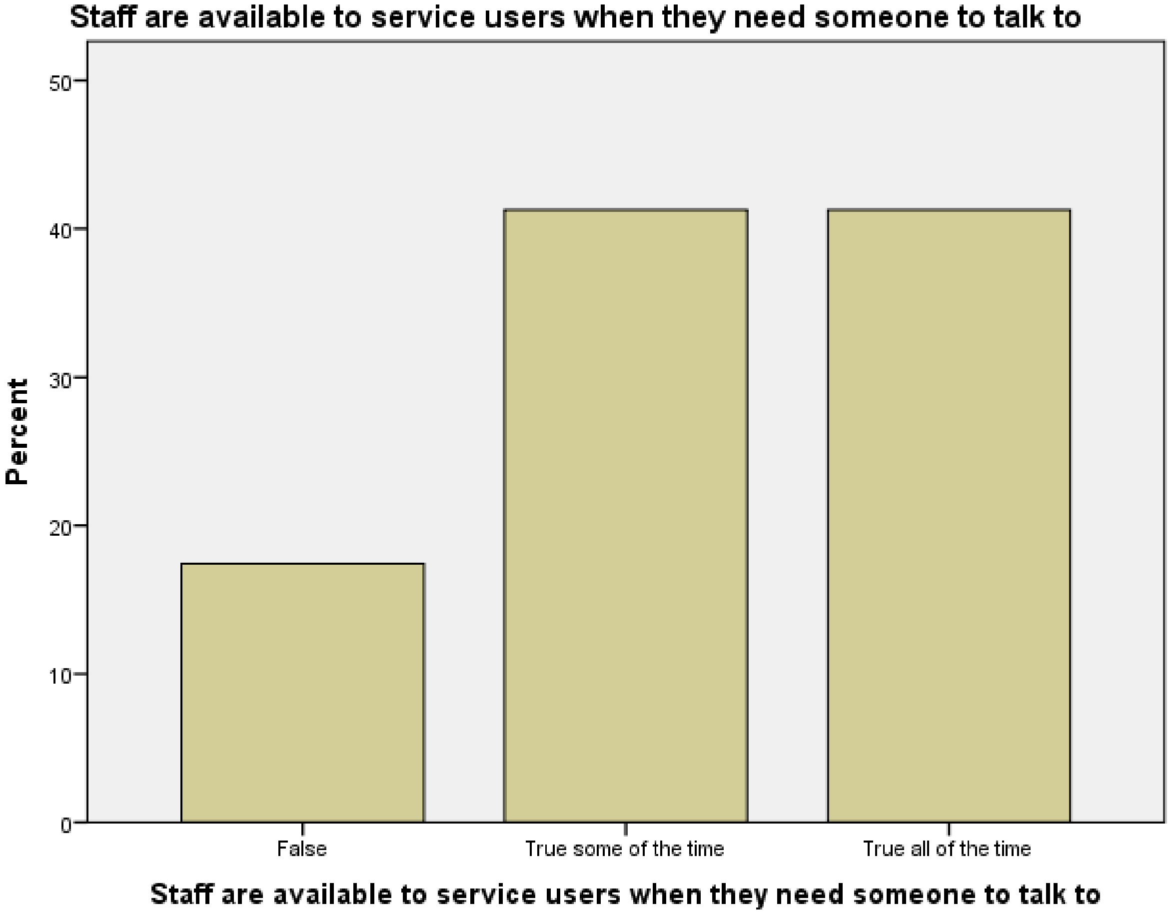
		Frequency	Valid Percent
Valid	False	23	20.9
	True some of the time	46	41.8
	True all of the time	41	37.3
	Total	110	100.0
Missing	System	1	
Total		111	

The percentage of participants who felt that staff were able to help them take control of their condition being true some, or all of the time was 79% (n = 87), compared with 85.3% (n= 140) in 2009. SUCRAN commends service providers for their efforts in enabling staff to instil this perception within participants.

The Audit of the Mental Health Charter (SUCRAN 2011) explored the aspiration that staff are guided by the individual's views about what they need and what helps them and proposed that "the ability to recognise and respect the contribution that people make to their own care and wellbeing is an important element of the partnership between professional care giver and the recipient of that care. 76% of participants had been asked about treatment options and in addition this was broken down into education, employment, relationships, finance and physical health. Results showed that assistance in these areas is inconsistent across all services and may well relate to the knowledge and confidence of staff who are providing the advice.

In particular positive support in rebuilding relationships with significant others was felt to be rather disappointing as the role of family and friends can play a significant part in the recovery journey.

Q18b

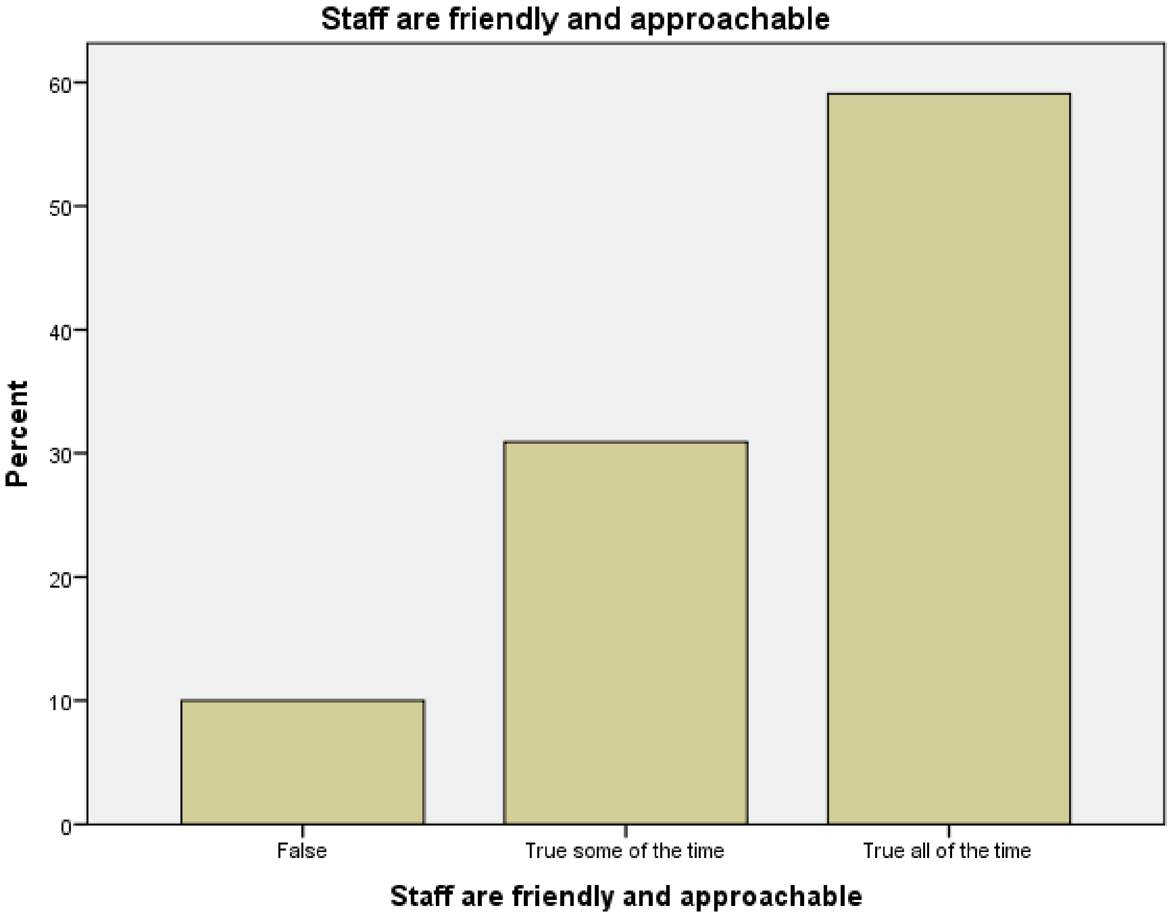


		Frequency	Valid Percent
Valid	False	19	17.4
	True some of the time	45	41.3
	True all of the time	45	41.3
	Total	109	100.0
Missing	System	2	
Total		111	

83% of participants (n = 90) suggested that staff were available either some or all of the time compared with 79% (n= 136) in 2009. This combination of answers seems to contradict the qualitative responses elicited through question number 21 in which a considerable proportion of participants suggested that increased staffing numbers would increase availability.

It is acknowledged that recent reorganisation of skill mix within Leicestershire Partnership Trust have improved the protected time offered to patients.

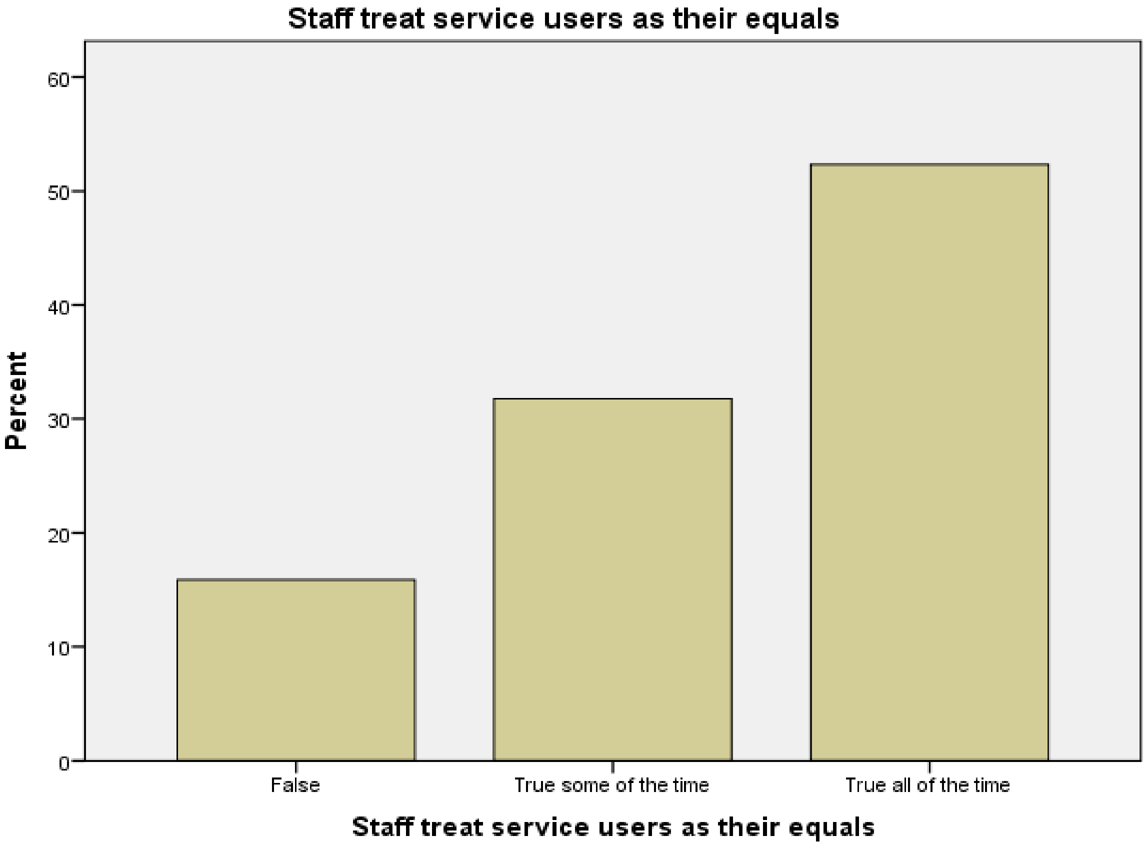
Q18c



		Frequency	Valid Percent
Valid	False	11	10.0
	True some of the time	34	30.9
	True all of the time	65	59.1
	Total	110	100.0
Missing	System	1	
Total		111	

Participants perceptions of the approachability and friendliness of the staff being true all or some of the time 90% (n = 99) compared with 97% of participants (N=162) in the 2009 study.
SUCRAN feel this is an excellent result for providers of Mental Health Services.

Q18d

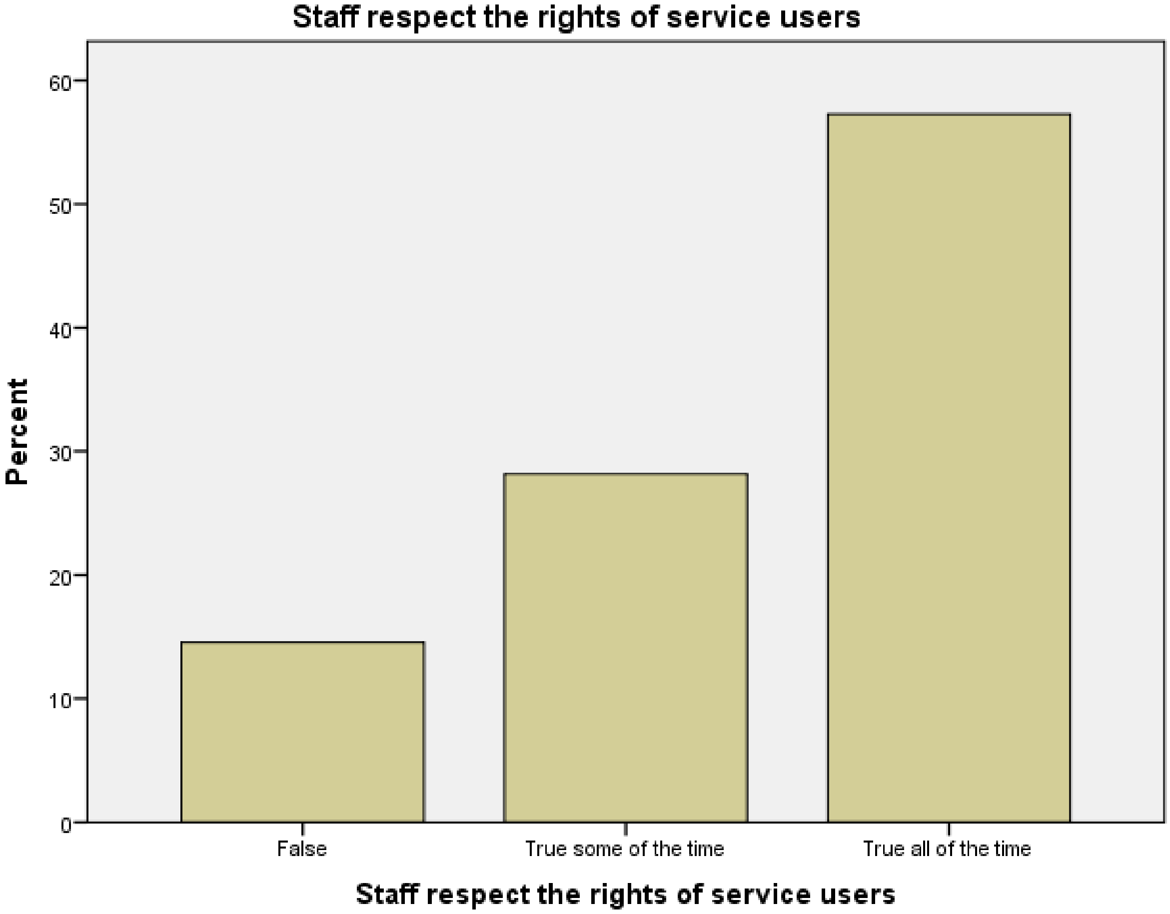


		Frequency	Valid Percent
Valid	False	17	15.9
	True some of the time	34	31.8
	True all of the time	56	52.3
	Total	107	100.0
Missing	System	4	
Total		111	

A small improvement was noted between the 2009 study and this one in that 84% of participants (n = 90) felt that staff treat service users as their equals in comparison to 77% of participants (n = 127) in 2009. 16% (n = 17) felt they did not. Again the SUCRAN 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.

The objective to Challenge “us and them” attitudes both within mental health services and in the wider society was set out in the Mental Health Charter (2008) the audit of which (SUCRAN 2011) suggested that the phenomena of being stereotyped or labelled is a real issue for people with mental health problems, suffering discrimination and prejudice reduces life opportunities in wider society, and reported that “us and them” attitudes did not feature in any of the reported answers or comment, however the 16% response in this study questions outcomes of the Charter Audit..

Q18e

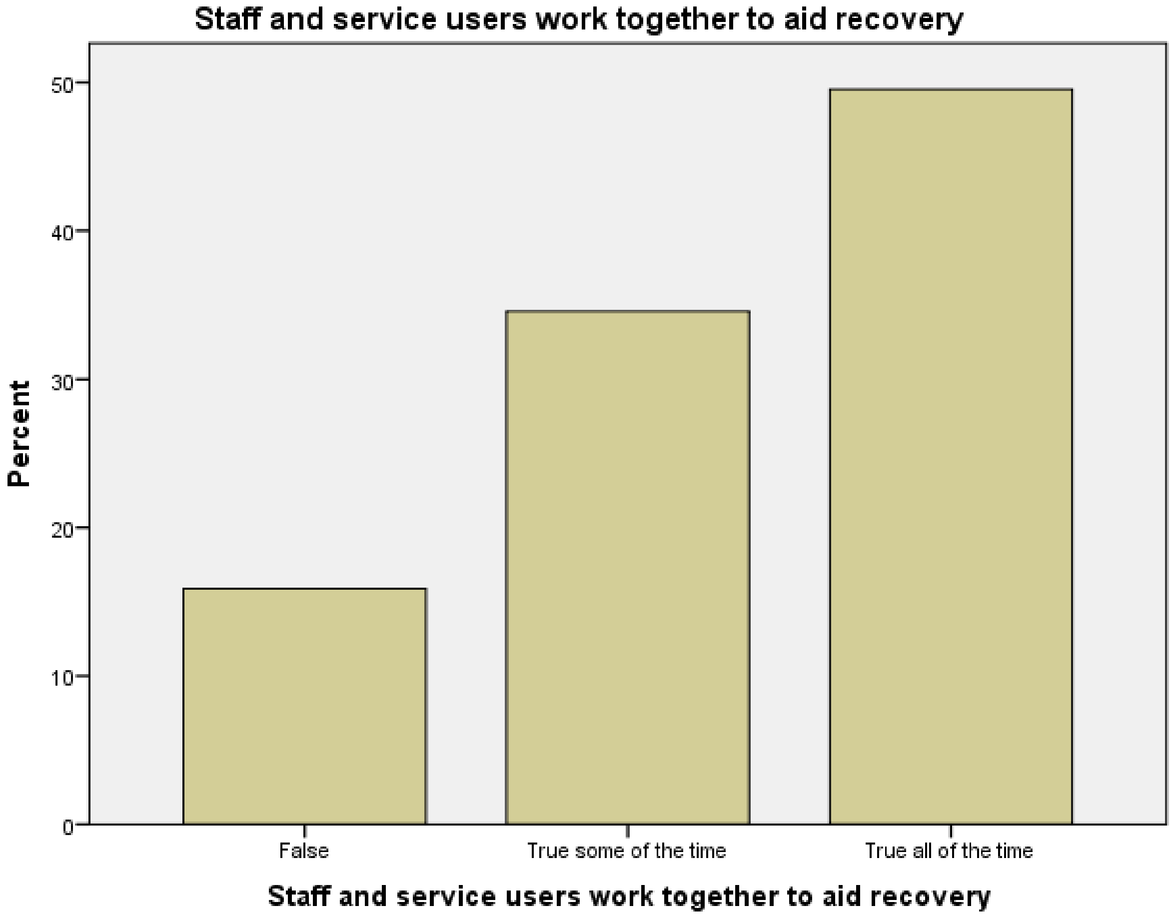


		Frequency	Valid Percent
Valid	False	16	14.5
	True some of the time	31	28.2
	True all of the time	63	57.3
	Total	110	100.0
Missing	System	1	
Total		111	

Respecting service user rights is a cornerstone of good practice and a key objective of the Mental Health Charter. With this in mind, it is rather disappointing to note that only 57% of participants (n = 63) felt that this was true all of the time. This is however an improvement on the 2009 study in which only 48% (n = 78) of participants felt this was true all of the time.

Feeling one's rights are respected, is a critical element of self efficacy and empowerment and this should be an unswerving constant in the interactions and communication with people who use services and their carers.

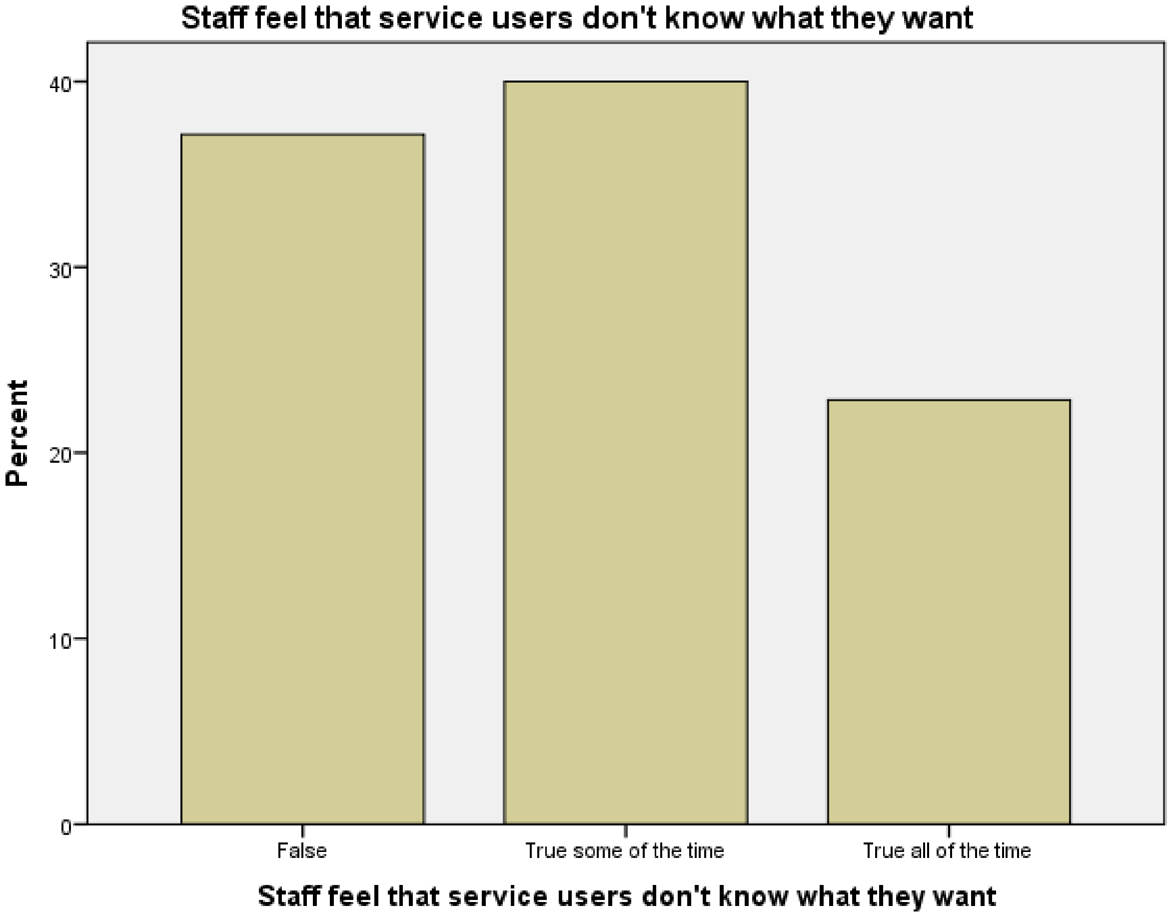
Q18f



		Frequency	Valid Percent
Valid	False	17	15.9
	True some of the time	37	34.6
	True all of the time	53	49.5
	Total	107	100.0
Missing	System	4	
Total		111	

SUCRAN believe that working together is a critical element of the recovery process and 84% of participants (n = 90) suggested this was true some or all of the time. These figures are broadly similar to the 2009 study where 89% of participants agreed. This result represents a high degree of collaboration
and this is an excellent result for providers of Mental Health Services.

Q18g



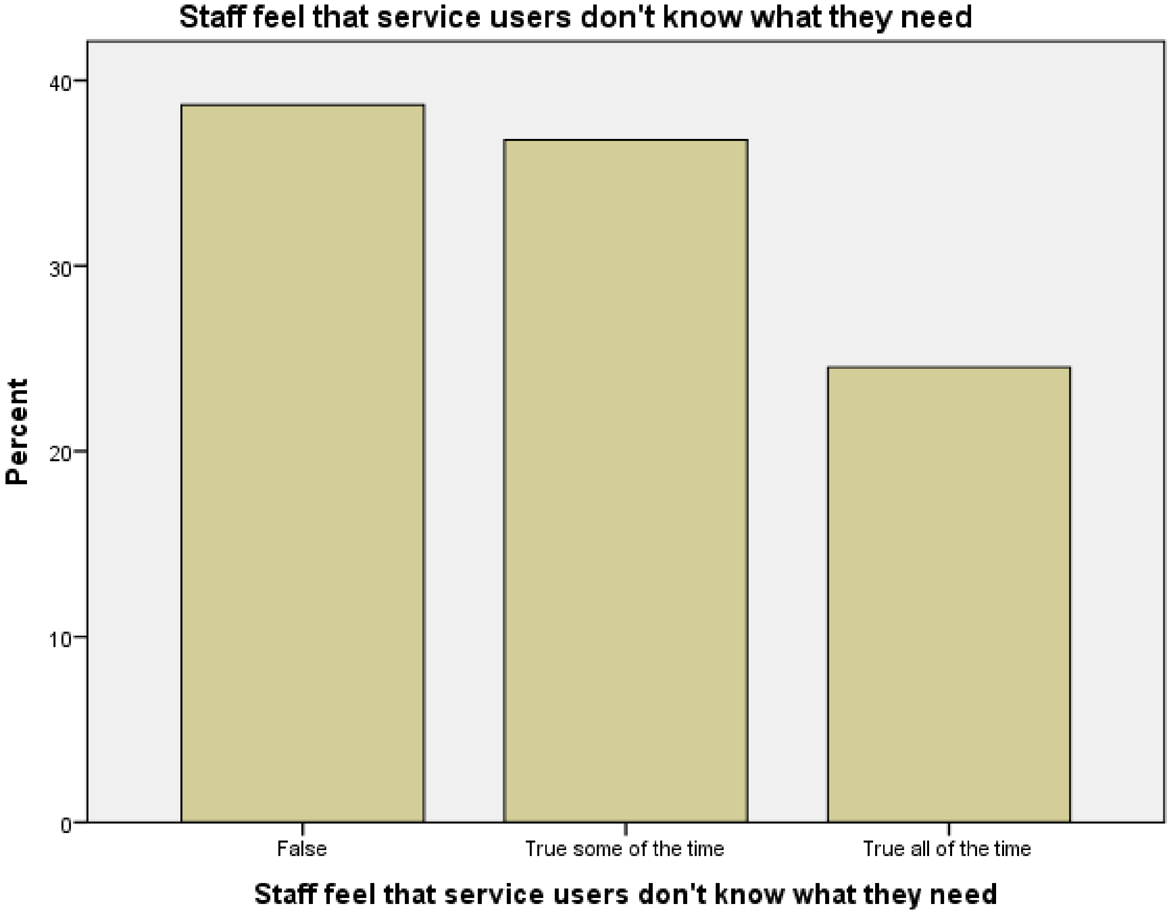
		Frequency	Valid Percent
Valid	False	39	37.1
	True some of the time	42	40.0
	True all of the time	24	22.9
	Total	105	100.0
Missing	System	6	
Total		111	

It is the perception of 63% (n = 66) of participants (74% (N=111)in 2009 study) that staff feel service users don’t know what they want, and this is disappointing in the light of answers for question 17 f where there is a high degree of collaboration. SUCRAN 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.

To understand that each person has a unique culture, life experiences and values is a target of the Mental Health Charter (2008), and SUCRAN recognise that the demands placed upon service providers to deliver bespoke services that are tailored to the needs of that individual is challenged by an increasing emphasis on pathways of care. These bundle similar symptoms, diagnoses and presentations together to inform the actions, behaviour and treatment options that are available to mental health providers. And whilst every individual is unique, the analysis team recognise that services must be provided within the available resources.

Mental Health Charter Audit (2011) revealed that 85% (n = 104) of participants felt they were treated as a whole person and given all the necessary information to make decisions, which was endorsed by 73% (n = 90) who felt they were able to use life skills, capitalise on them and develop new personal challenges. In addition, staff were felt to be interested in the participants culture. This fact however must be placed in the context of the majority of participants being of a white ethic origin and an assumption that the majority of staff delivering care were also white.

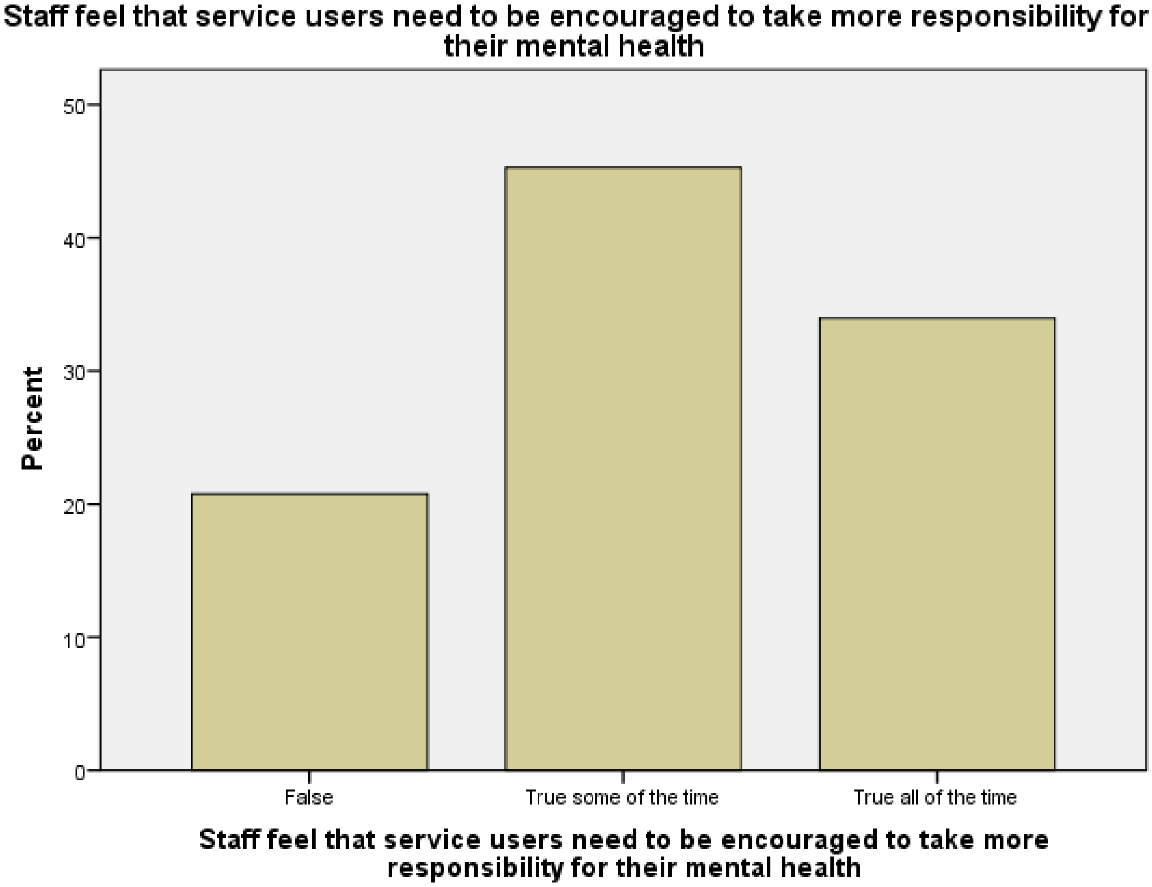
Q18h



		Frequency	Valid Percent
Valid	False	41	38.7
	True some of the time	39	36.8
	True all of the time	26	24.5
	Total	106	100.0
Missing	System	5	
Total		111	

Another disappointing outcome which suggests that 61% (n = 65) of participants were unsure that staff have the confidence in them to know what they need. These responses however are more positive than the 2009 study in which 78% of participants (N=124) expressed the opinion that staff feel service users don’t know what they need, and again surprising in the light of answers for question 17 f where there is a high degree of collaboration.

Q18i



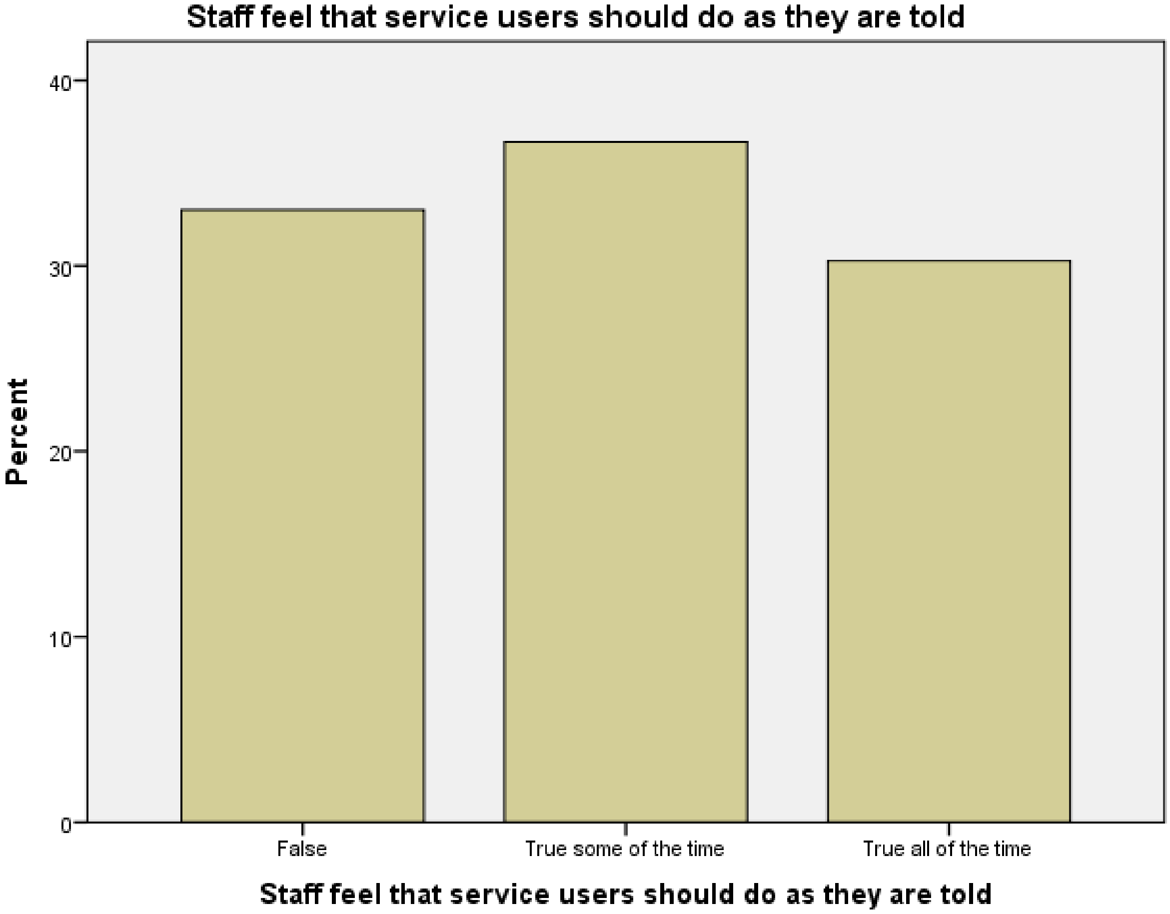
		Frequency	Valid Percent
Valid	False	22	20.8
	True some of the time	48	45.3
	True all of the time	36	34.0
	Total	106	100.0
Missing	System	5	
Total		111	

The perception of participants that staff feel they do not take sufficient responsibility for their own mental health is an interesting one, which assumes someone else is taking that responsibility. This was true for 34% (n = 36) all of the time and for 45% (n = 48) some of the time. (38% (n = 65) and 43% (n = 74) respectively in the 2009 study).

Whilst ownership of one's own mental health is a key part of the recovery process but ownership is supported by information, knowledge and understanding which participants have been deprived of (See Questions 6,7 and 8 for example).

SUCRAN suggest that service providers need to respond to this result by providing better information, actively improving service user knowledge about their condition and the availability of support mechanisms to enable informed choices. Improvements in these areas will enable greater self advocacy, improved self efficacy and an increased likely-hood of self responsibility.

Q18j

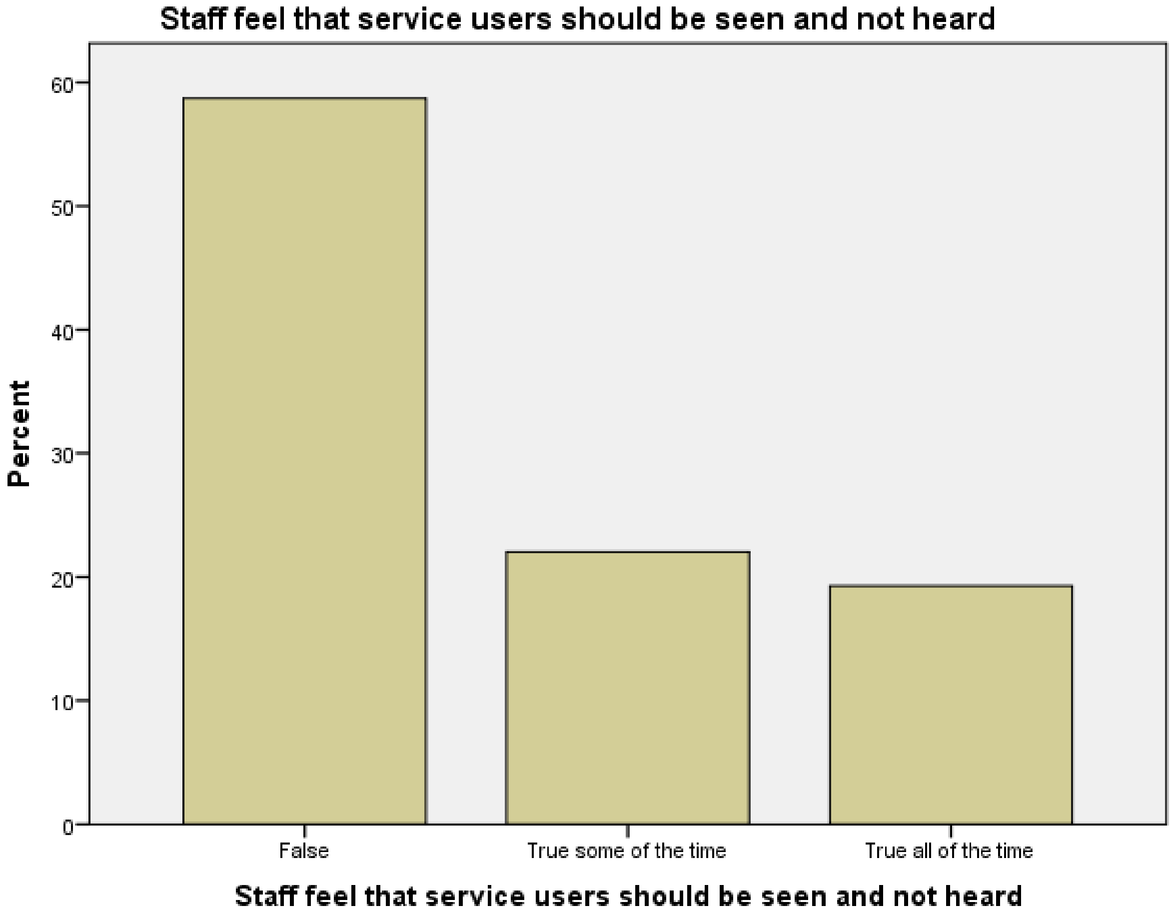


		Frequency	Valid Percent
Valid	False	36	33.0
	True some of the time	40	36.7
	True all of the time	33	30.3
	Total	109	100.0
Missing	System	2	
Total		111	

This question explores the participant's perception of the power difference between themselves, and the staff who care for them. "Doing as you are told" implies a level of paternalism within the relationship and disempowerment as a response to this. The outcomes of this question suggest that this is true for 67% of participants (n = 73). This compares to a true response rate of 74% of participants (n = 128) in the 2009 study.

SUCRAN 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; however this perception does nothing to enhance therapeutic relationships or promote independent thinking. Clinical regimes that rely on compliance rather than concordance are out of date and counter therapeutic.

Q18k



		Frequency	Valid Percent
Valid	False	64	58.7
	True some of the time	24	22.0
	True all of the time	21	19.3
	Total	109	100.0
Missing	System	2	
Total		111	

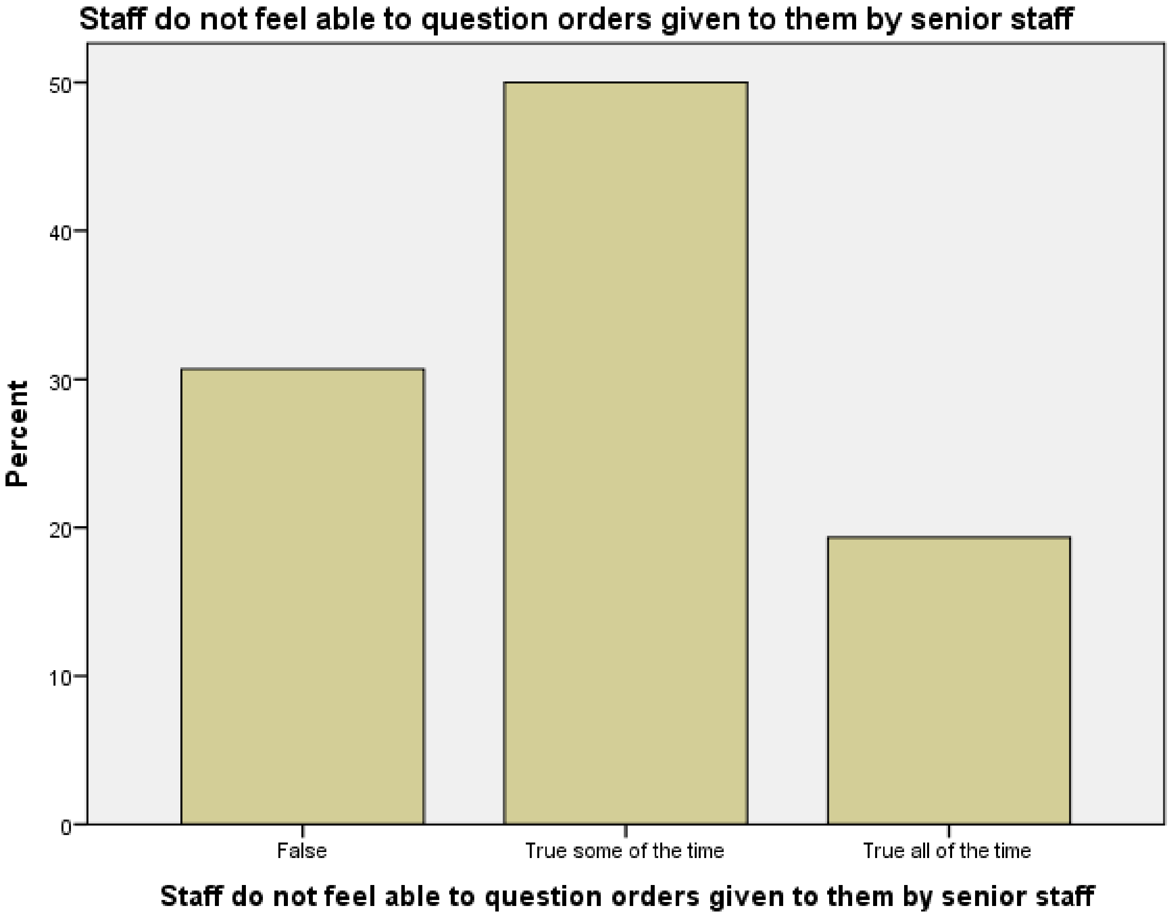
The perception of 41% of participants (n = 45) is that staff feel service users should be seen and not heard some or all of the time.

This endorses the outcomes of question 18j and is not dissimilar in proportion to the answers for the same question in the 2009 study in which 53.7% of participants (N=87) expressed the same opinion.

A system which engenders these perceptions is not a therapeutic one and SUCRAN believe that the milieu of any clinical environment should not only be encouraging of the service user voice, but provide a platform for it to be heard.

There was strong evidence within the Mental health Charter Audit (SUCRAN 2011) to show that for some service users, staff were listening to them and took action, however a significant proportion (approximately 19% n = 23) were less satisfied with changes made based upon what they had said. The positive response may be related to the service user's ability to articulate these requests and the language skills associated with ethnic origins may have contributed to this.

Q18l



		Frequency	Valid Percent
Valid	False	27	30.7
	True some of the time	44	50.0
	True all of the time	17	19.3
	Total	88	100.0
Missing	System	23	
Total		111	

69% of participants (n = 61) expressed the opinion that staff do not feel able to question orders given to them by senior staff in comparison to 77.6% (N=104) in 2009), and SUCRAN feels that there may be an empathetic alliance between junior staff and patients in that they are equally disempowered, and unable to challenge the instructions from senior staff. Service providers should enable increased opportunities for users to explore “orders” or decisions within ward fora and community meetings, encouraging the role of advocates to represent service user views.

Q18m

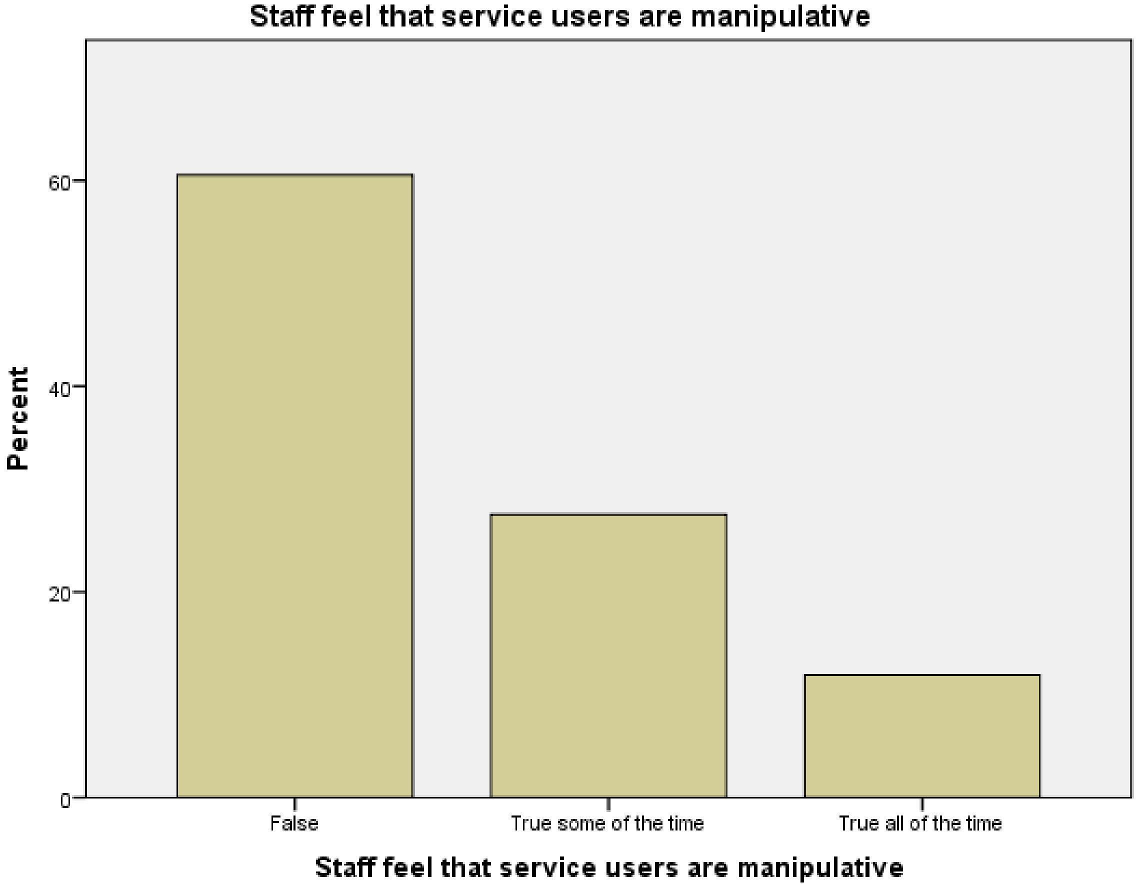
		Frequency	Valid Percent
Valid	False	52	48.1
	True some of the time	24	22.2
	True all of the time	32	29.6
	Total	108	100.0
Missing	System	3	
Total		111	

Feeling as if one is treated as a label is disempowering and depersonalises the individual. Being defined by one's diagnosis, either attributed by professionals, or the often stigmatised and insulting labels ascribed by the public, is a recognised difficulty encountered by people with mental health problems. A single encounter with services, or on-going interventions, do not elevate mental health services into the most important aspect of a person's ability to function, or their life as a whole.

Treating the label places the development of a therapeutic alliance in jeopardy, and undermines the potential of developing social capital within the service user. It is with this in mind that SUCRAN express a deep concern that for 52% of participants (n = 56) felt this is true some or all of the time. These outcomes are slightly better than the 2009 study which identified 64.4% of participants (N=103) who expressed the same opinion. The anticipate improvements cited in the 2009 study have been marginal.

The positive responses (False, 48% n = 52), identified that care providers have recognised the person behind the diagnosis and perhaps the complex nature of what is needed to maintain good mental health as a person, allowing people to recognise themselves as autonomous individuals with skills, abilities and the capacity to shape their own lives beyond the limitations of a diagnosis.

Q18n

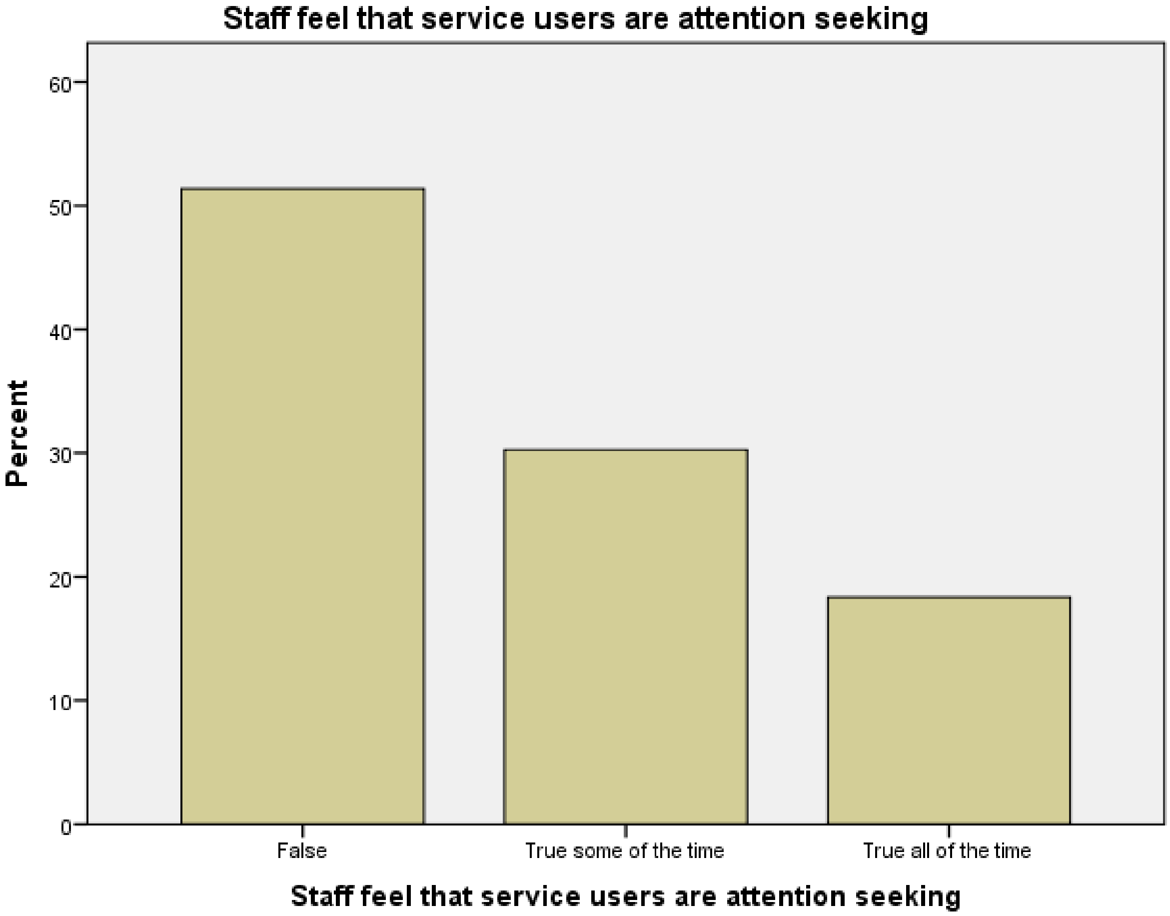


		Frequency	Valid Percent
Valid	False	66	60.6
	True some of the time	30	27.5
	True all of the time	13	11.9
	Total	109	100.0
Missing	System	2	
Total		111	

SUCRAN feel that most people attempt to influence a positive outcome for themselves, and these results do not necessarily reflect a negative position, however, feeling that the staff who are caring for you consider you to be manipulative, places service users in a very defensive position. One where justification of thinking, feeling and behaviour may consume emotional energy that would be better used to assist recovery. If in fact staff do see service users as manipulative, this will stereotype interventions and typecast that person.

40% (n = 43) expressed the opinion that staff feel service users are manipulative. This outcome is better than the 2009 study where 64.4% of participants (N=103) perceived this situation.

Q18o

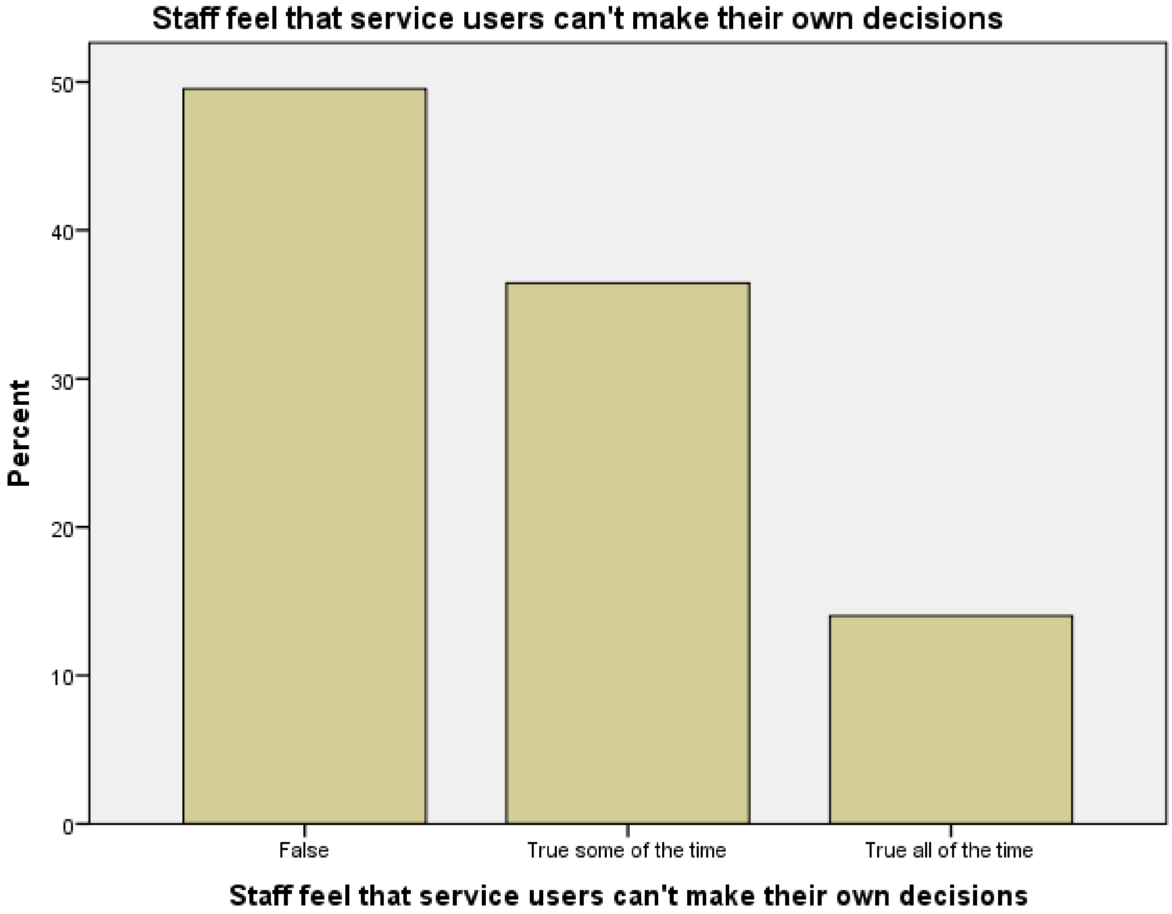


		Frequency	Valid Percent
Valid	False	56	51.4
	True some of the time	33	30.3
	True all of the time	20	18.3
	Total	109	100.0
Missing	System	2	
Total		111	

49% (n = 53) expressed the opinion that staff feel service users are attention seeking some or all of the time, compared to 71% of participants (n = 114) in the 2009 study.

SUCRAN believe that seeking attention is a natural phenomenon particularly when a person is feeling vulnerable or lonely. This outcome, whether real or perceived, reflects the interactions between service users and care staff giving us an insight into the legacy of that interaction for service users. If legitimate requests for professional attention are branded as attention seeking behaviours by staff, service users are less likely to seek that support in future, which may have a negative impact upon the quality of care.

Q18p



		Frequency	Valid Percent
Valid	False	53	49.5
	True some of the time	39	36.4
	True all of the time	15	14.0
	Total	107	100.0
Missing	System	4	
Total		111	

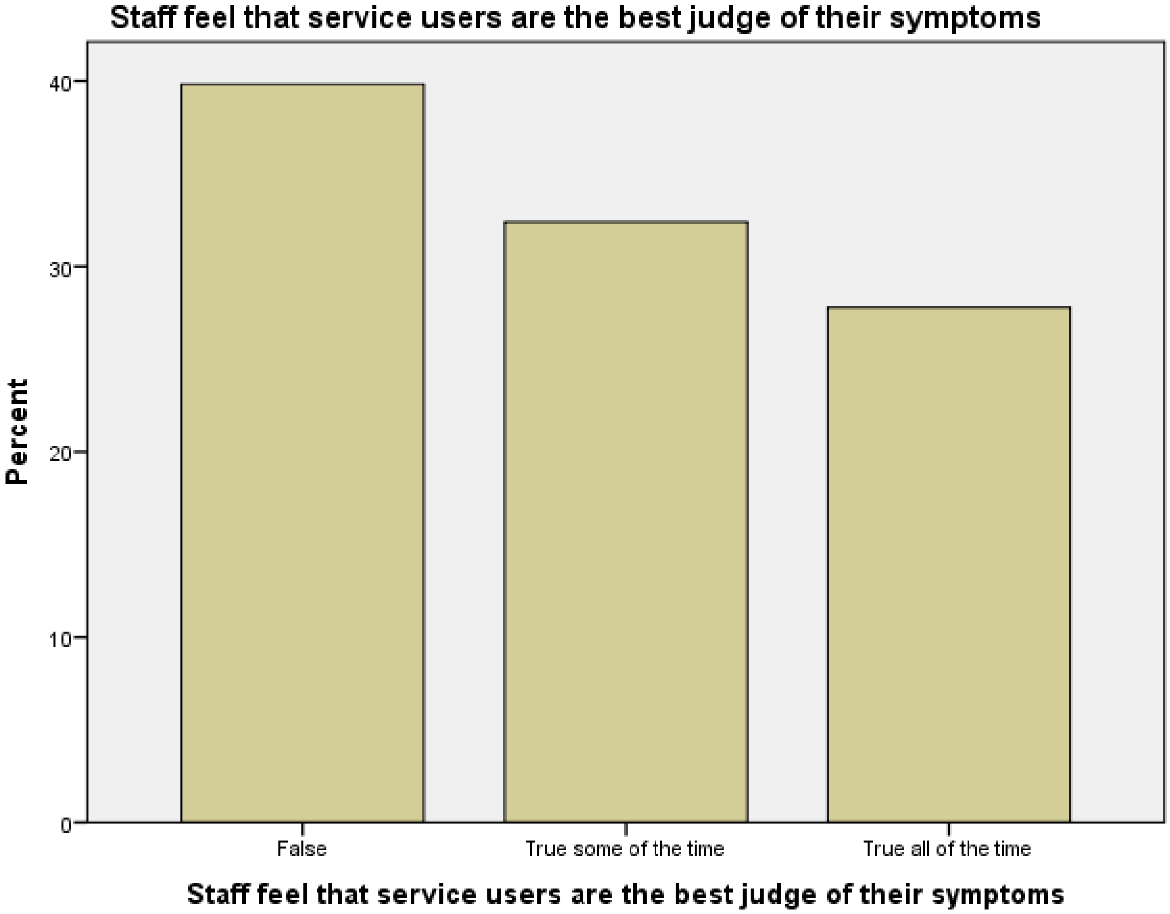
The perception that staff feel service users can’t make their own decisions some or all of the time’ was expressed by just over 50% or participants (n = 54) demonstrating a reduction of 20% from the 2009 study (70.1% of participants (N=113)). Informed decision making will be improved with better information, knowledge and the opportunity to discuss things like medication.

The ability to recognise and respect the contribution that people make to their own care and wellbeing is an important element of the partnership between professional care giver and the recipient of that care This is underscored by the need to recognise, respect and support the role of carers, family and friends.

Treating everyone as a capable citizen who can make choices and take control of their own life was a key element of the Mental Health Charter (2008) and it is interesting to note that the SUCRAN audit of this charter identified the importance of a partnership between the health professional and the service user stating that “the recognition of a person’s skills, and establishing the goals that the service user wants to achieve is a very important part of services promoting self efficacy. Without this the partnership between provider and recipient of services will not achieve his or her full potential. 81% of participants felt that staff treated them as a responsible partner to some extent which is a positive outcome, and there is strong evidence that this statement is true. Over 75% of participants replied “yes definitely” although the 25% who were less positive may indicate a shortfall in the recognition of service users having the capacity to take, or retake control of their own lives. This may relate to risk taking on the part of staff who are reluctant to work outside of what they consider their scope of practice, job role or perceived sphere of competence. This said, care giving staff may not be best placed to facilitate choice although signposting to someone who is, may enhance choice, capability and control”

Whilst making one’s own decisions is an important part of recovery, it is recognised that complete independence may lead to isolation so with this in mind the analysis team support the interdependent relationship a person may have with their care provider.

Q18q

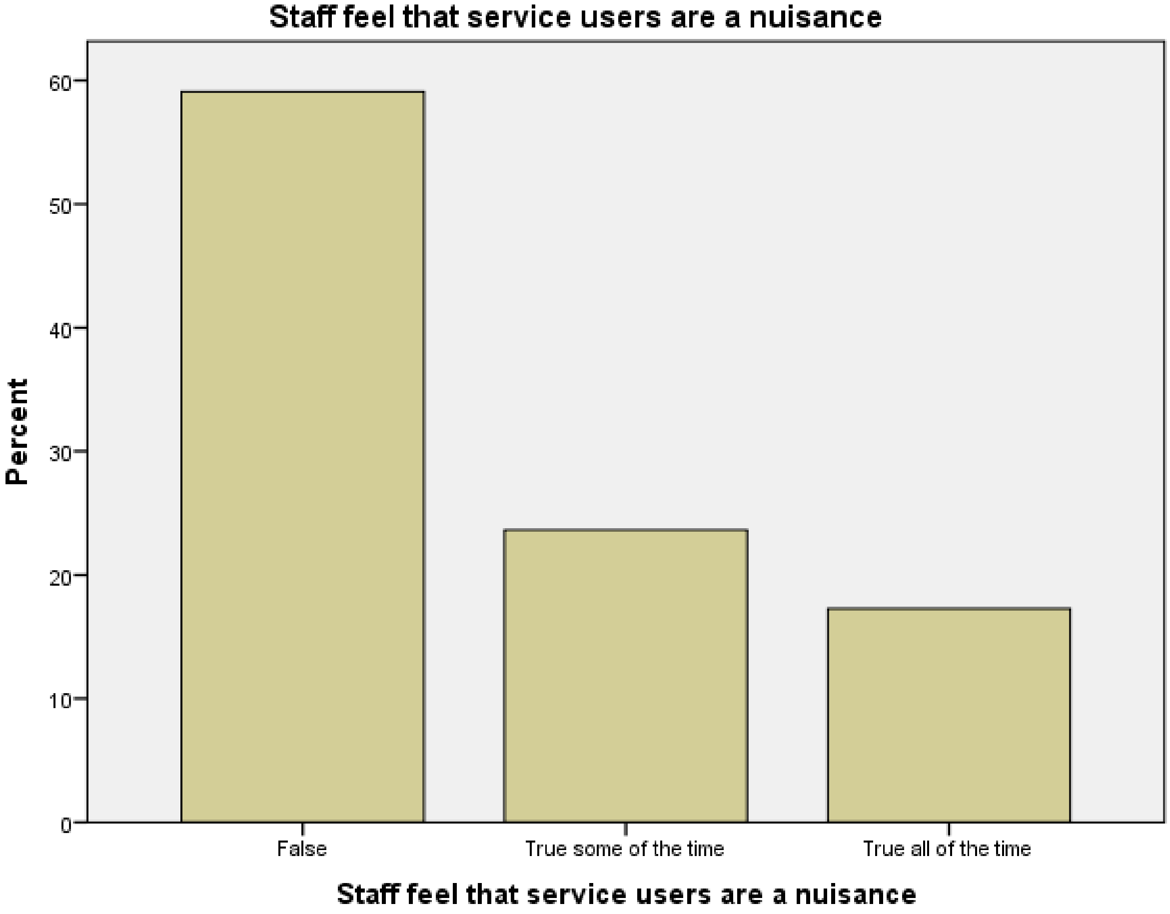


		Frequency	Valid Percent
Valid	False	43	39.8
	True some of the time	35	32.4
	True all of the time	30	27.8
	Total	108	100.0
Missing	System	3	
Total		111	

An improvement of just under 10% has been noted comparing the 2009 study to this one in that, 72% of participants (n = 65) expressed the opinion that staff feel service users are the best judge of their symptoms in this study, rather than 63% of participants (N=100) in 2009.

SUCRAN assume that the notion of the “expert patient” and the importance of the lived experience has begun to influence the credibility of staff perceptions of the service user viewpoint.

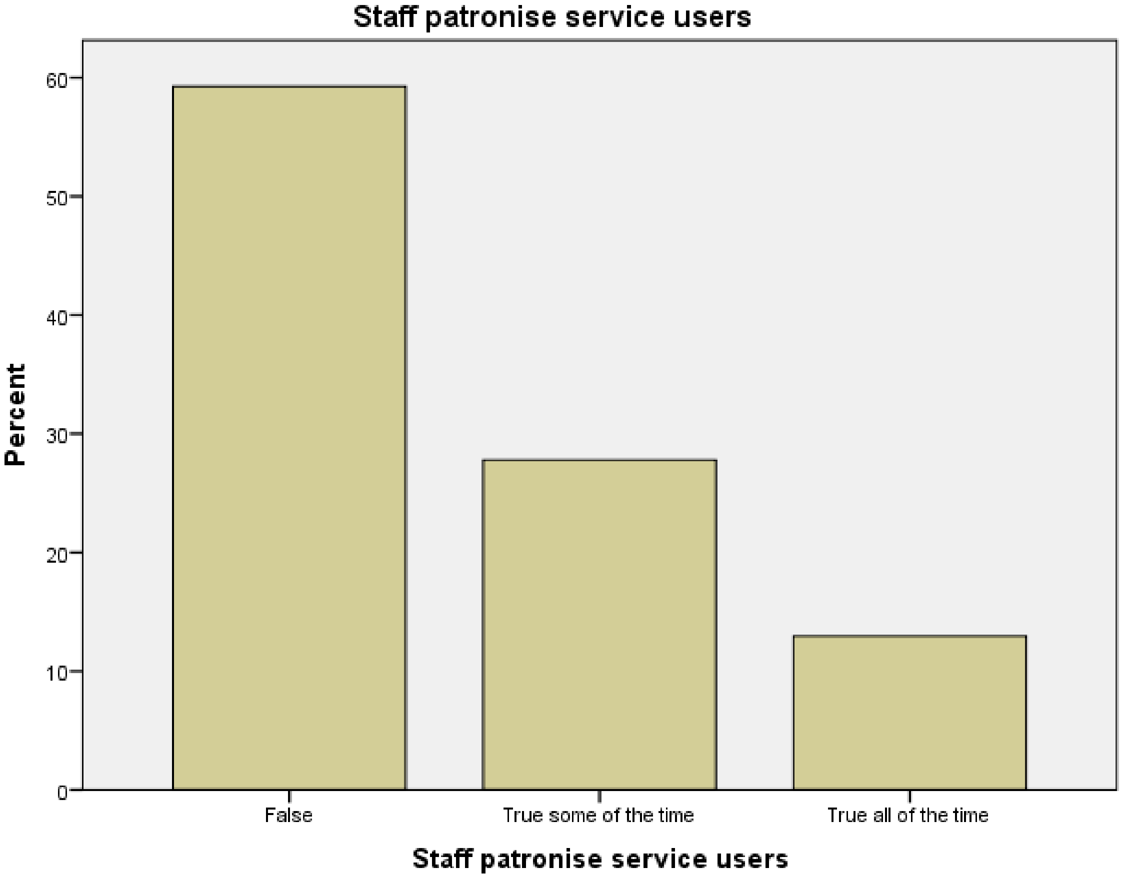
Q18r



		Frequency	Valid Percent
Valid	False	65	59.1
	True some of the time	26	23.6
	True all of the time	19	17.3
	Total	110	100.0
Missing	System	1	
Total		111	

41% of participants (n = 45) expressed the opinion that staff feel service users are a nuisance compared to 57% (n = 92) in 2009. This 16 % reduction is a welcome decrease and seems to follow the trend of perceptions of attention seeking for example (Question 18o reduced by 22%). However, the outcome of 41% remains unacceptably high.

Q18s



		Frequency	Valid Percent
Valid	False	64	59.3
	True some of the time	30	27.8
	True all of the time	14	13.0
	Total	108	100.0
Missing	System	3	
Total		111	

41% of participants (n = 44), expressed the opinion that staff patronise service users some or all of the time compared with 59% (n = 94) in 2009. This perception relates to the way service users' feel following interactions with staff, and without doubt influences satisfaction levels of a mental health care experience. SUCRAN feel the vulnerability of being an in- patient for example may lead to some misinterpretation of legitimate communication being perceived as patrony.

Respect, dignity and compassion were a feature of the 2011 SUCRAN Audit of the Mental Health Charter (SUCRAN 2011) where there was “strong evidence” to show evidence across all services, but the negative responses should prompt a reminder that registered nurses who must abide by the NMC (2008) Code of practice which states: “make the care of people your first concern, treating them as individuals respecting their dignity and treat people as individuals not discriminate in any way, treat people kindly and considerately and act as an advocate for those in your care, helping them to access relevant health and social care, information and support”.

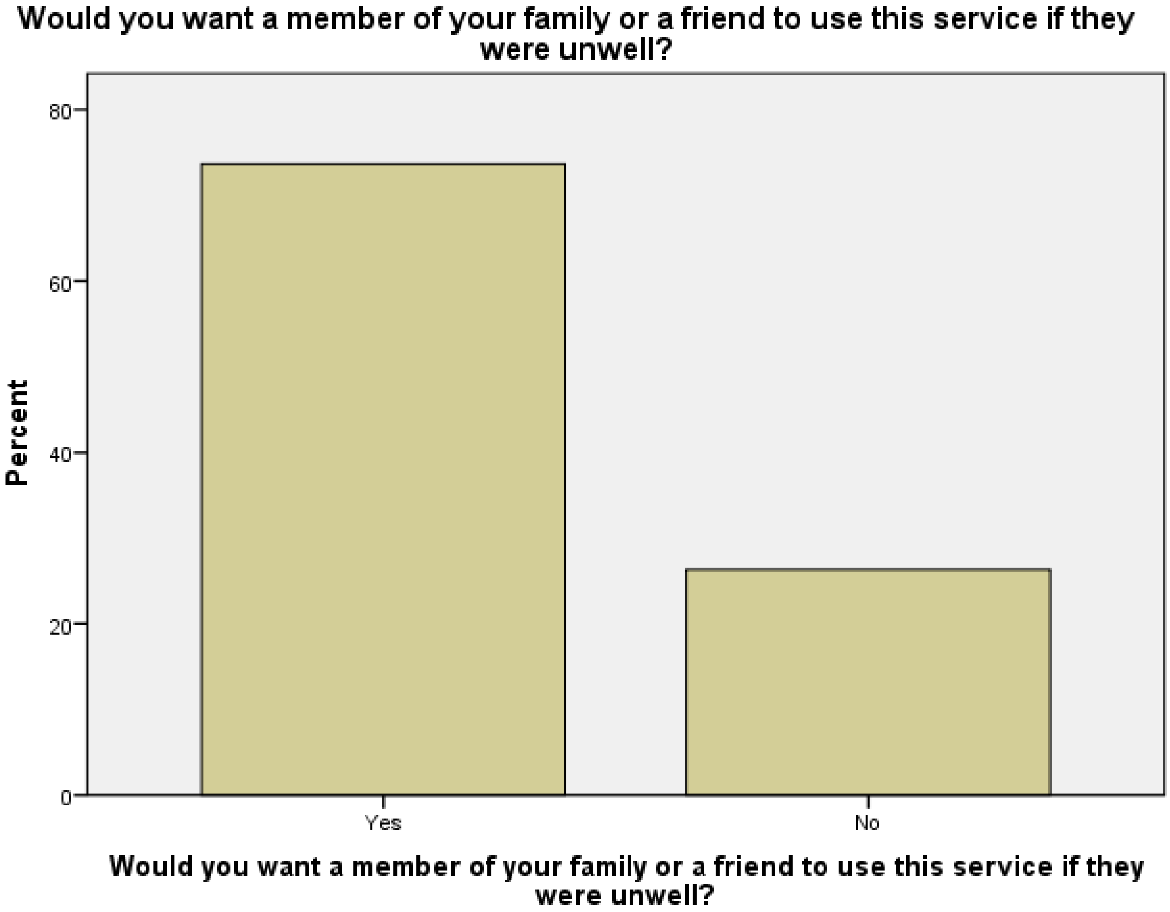
Furthermore, the government’s strategy DH (2010) to improve the quality of fundamental aspects of nursing care cites communication as one of its 10 key benchmark areas and to communicate with each person in the way that is right for them was a key target of the Mental Health Charter (2008). The SUCRAN audit of the Charter suggested that 80% of participants were encouraged to express feelings, and that for 82%, staff ensured that information was understood. These were reassuring results and may again reflect registered nurses adherence to the code of practice NMC (2008p6), that instructs nurses to:

“Collaborate and listen to the people in your care and respond to their concerns and preferences. Support people in caring for themselves to improve and maintain their health and make arrangements to meet people's language and communication needs”. Similarly registered nurses are must share with people, in a way they can understand, the information they want or need to know about their health.

The National Patient Safety Agency (2010) support this with their suggestion that openness in communication has benefits for healthcare professionals too, as it can help to reduce stress through the use of a formalised, honest, communication method; alleviate the fear of ‘being found out’; and improve job satisfaction.

These factors demonstrate the importance of ensuring that service users do not feel patronised and underscore the disappointment of responses to this question.

Q19



		Frequency	Valid Percent
Valid	Yes	81	73.6
	No	29	26.4
	Total	110	100.0
Missing	System	1	
Total		111	

The outcomes for this and the 2009 study are almost identical 74% (n = 81) and 70% (n =116) respectively, however just over one quater, 26% (n = 29), stated that they would not recommend the service, which is a significant proportion.

Q20

		Frequency	Valid Percent
Valid	Yes	69	62.7
	No	41	37.3
	Total	110	100.0
Missing	System	1	
Total		111	

63% (n = 69) of participants suggested that staff did spend enough time with them compared to 66% (n = 109) of participants in 2009. However, participants 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”.

Q21
Are there any other issues around staff attitudes and communication that you want to tell us about?

A review of the qualitative evidence raises a number of significant factors which go some way to explaining the quantitative results contained within this report.

A selection of comments raised during interviews within question 21 are divided into staff, resources together with organisation and management for ease of reference. A simple content analysis was performed to group comments into the themes and cite the most powerful and relevant observations.

The analysis team noted that "when we looked at all the tick boxes earlier, the feedback seemed overall positive, but looking at the qualitative feedback it seems when patients actually thought about their own experiences in detail there were a lot more negative responses than positive – especially to staffing levels and staff attitudes".

Staff

The overall impression given by the qualitative feedback on staff attitudes and behaviour is mixed, with some service users clearly experiencing greater levels of satisfaction than others. Comments suggested that staff seem to be overworked and have little time to spend with the people who use their service. This results very often in negative reactions to patients' needs such as being ignored, not being treated equally and not being treated with respect. The comments below illustrate this very well.

> "All the problems I have faced related to the inpatient wards, e.g. staff attitudes, but I am happy with the community Mental Health Team".
>
> "They bully you, ignore you and sometimes they are cruel"
>
> "Staff are irresponsible, and incompetent, unprofessional and inept" (no main service cited)

> "I had a member of staff behaving inappropriately towards me but it was dealt with by senior staff and I was happy with the outcome".

> "Staff feel unable to question the decisions of managers which could be explained by the lack of training or knowledge of particular areas".

> "Staff suffer from "Career Compliance Disorder". Staff are afraid to disagree with Ward and Hospital Managers".

> "I had a problem in the past getting staff to accept that I was reacting badly to treatments".

> "Staff should recognise symptoms and try to help and not wait for someone to ask for help as this is often hard to do".

> "A service user fainted and was on floor … staff offered a pillow and told her to crawl to bed when she could. The service user discharged self because she didn't feel respected … resulting in an emergency re-admission"

> " Staff at the drop in centre have nothing to do with the service users. Service users are supposed to be able to approach them. At times staff do not introduce themselves at the drop in. Service users are not aware of who they are".

> "Staff should take more interest in patients and ask how are you doing".

> "My male CPN treats me not as a person".

Resources

Feedback regarding staffing levels points to a lack of sufficient staff for service users' needs. This results in staff being too busy to give patients the support they need and also patients not being allocated key workers or CPN's. Also, because of lack of resources, wards are of mixed sex.

> “I had problems getting a CPN because of short staffing”
>
> “Not enough staff”.
>
> “Staff always busy”.
>
> “Takes ages to get things done”.
>
> “Short staffed wards are too mixed, i.e. men and women, detox programmes, etc”.
>
> “Wash bowl not big enough. In toilet areas no mirrors ….difficult to shave. Soap dispenser in the way. No hooks on the wall”.

Organisation/Management

The communication systems operating between staff in a department and between different departments is not operating effectively or efficiently. It is not clear if this is due to lack of overall staffing and resources or ineffective management.

> “Someone forgot to check their diary and forgot that I needed an injection. Next day due to go on holiday for 2 weeks … added panic for the holidays”.
>
> “Physical conditions are not looked after as well as mental health issues”.
>
> “Discharge communication – missed 1 appointment due to father being in hospital.Next contact was a letter telling me I was discharged. No checking and a point where I needed most support”.
>
> “Communication system is poor. Telephone ring-back system not effective. Support worker didn’t attend meeting”.
>
> “No continuity of care” Could improve”.

A consistent theme of concern is captured in the comment “Financial cutbacks are threatening and scary”. This for many seems to be raising their anxiety about the future of services, and where they may get help in the future.

> “Would like drop in centre to continue next year”
>
> “Service is brilliant (Network). Concern is the outcome of the cuts in future”.
>
> “Want to continue with activities but cutbacks may affect this”.

The variable care received by patients may be caused by the lack of training and by the over reliance on the use of Bank Staff.

> “Over-use of Bank Staff. I think they work just for the money”.
>
> “More training on mental health for all staff”.
>
> “Admitted for 1 week before seeing an Registered Doctor. Sick for 4 days and they didn’t do anything”.

The overall positive responses came from organisations in the wider community and not from in - patient hospital feedback. Smaller organisations in the community from the voluntary and independent sector seemed to be identified for most praise, and were considered to be more proactive instead of reactive which may account for them presenting a more organised and caring approach.

> “I think the drop in centre in Loughborough is brilliant. This is the only thing that got me out of my house”.
>
> “Melton Group and the drop in centre at Loughborough Welcome House and Cricket Ground are fantastic”.
>
> “Service is brilliant (Network for Change). Concern is the outcome of the cuts in future”.
>
> “Staff attitudes extremely positive and helpful. There is sometimes a lack of staff and staff are not available”.

> “I am very happy with the way I am treated at the centre”.

Working with respect, dignity and compassion is a key aspiration of the Mental Health Charter (2008) and the SUCRAN audit (SUCRAN 2011)suggested a more positive outcome than some of the qualitative comments suggest within this study confirming that respect, dignity and compassion were a feature of most participants contact with services, and 91% of participants suggested this was their experience. Of those, 76% were very positive, and stated “yes definitely”.

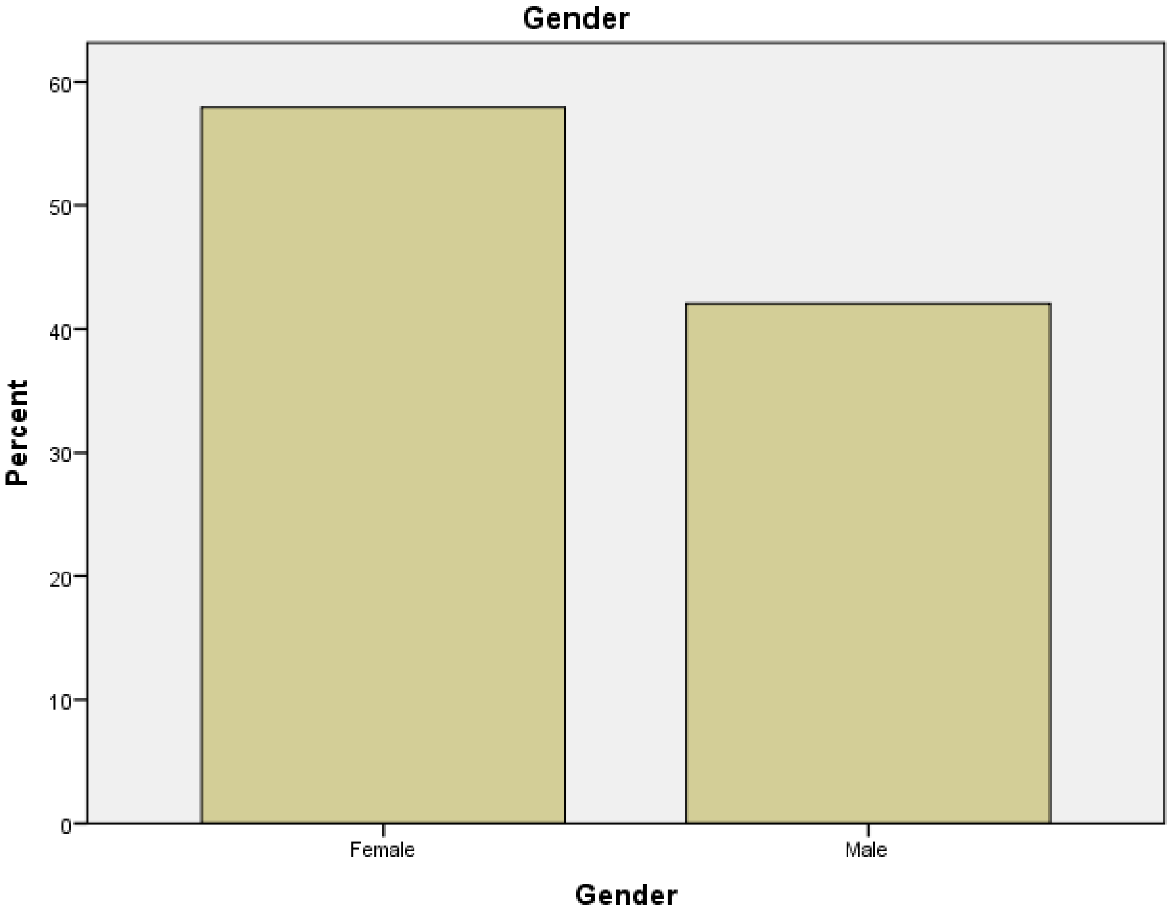
“This is strong evidence that shows respect, dignity and compassion are evident across all services, and service providers should be congratulated on the significant positive response. However these results emanate from an 83% cohort of participants who described themselves as white British. Evidence would suggest (Cortis 1998, SCMH 2002), that issues such as respect, dignity, compassion and communication failures are factors which feature strongly in complaints from people from alternative ethnic backgrounds”. (p67)

It was suggested that the positive results may reflect the care that is provided by registered nurses who must abide by the NMC (2008) Code of practice which directs nurses to

> “make the care of people your first concern, treating them as individuals respecting their dignity and treat people as individuals not discriminate in any way, treat people kindly and considerately and act as an advocate for those in your care, helping them to access relevant health and social care, information and support”.

However it appears that it is the voluntary/ independent sector that is not necessarily bound by this code who have received the majority of praise in this study.

Q22



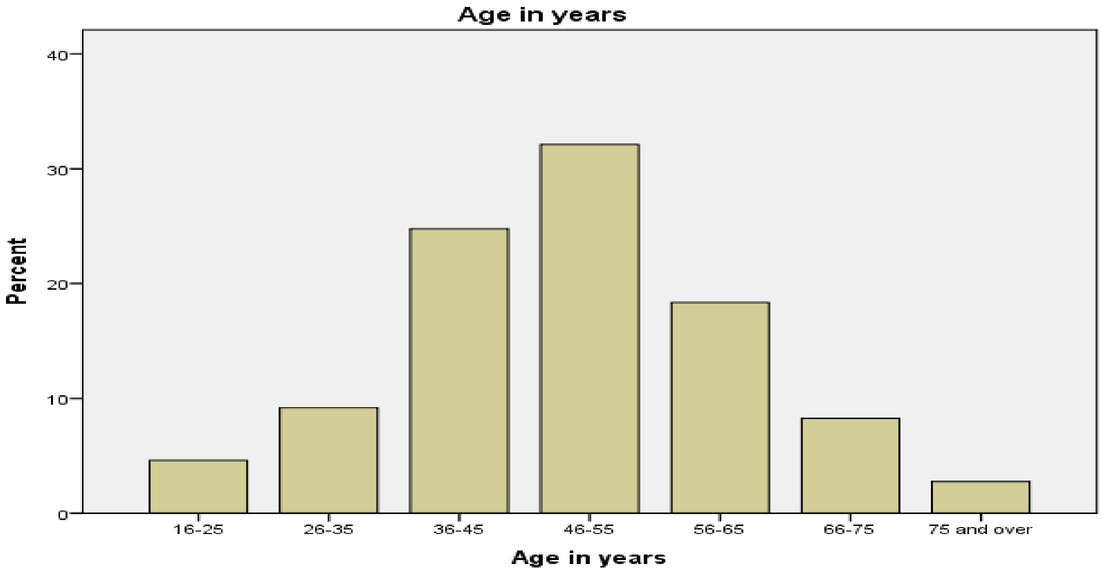
		Frequency	Valid Percent
Valid	Female	62	57.9
	Male	45	42.1
	Total	107	100.0
Missing	System	4	
Total		111	

58% of those who responded to this question identified themselves as female (n = 62) whilst 42% (n = 45) were male.

This compares to 48% (n = 80) female and 52% (n = 86) male in 2009.

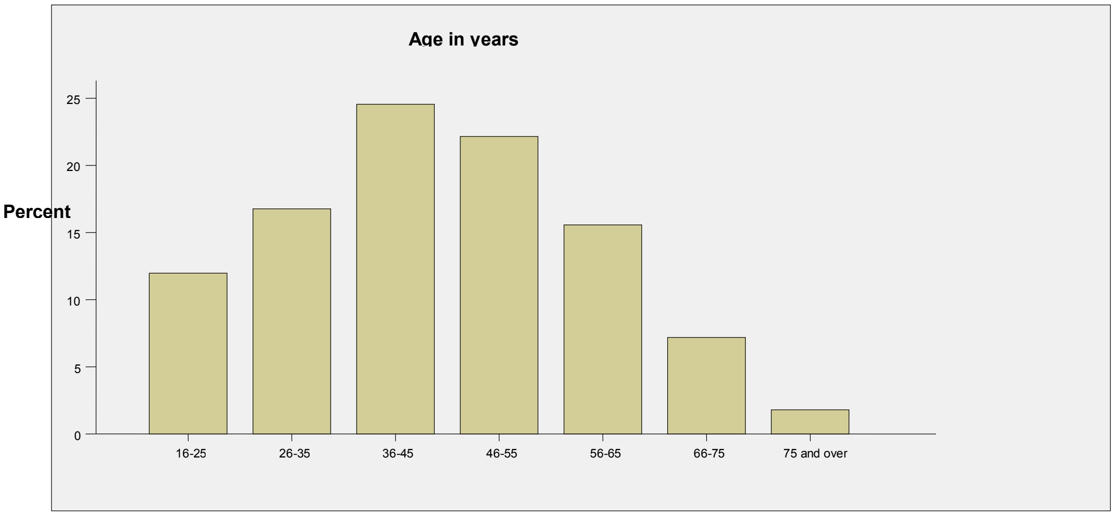
Q23

2011 Study

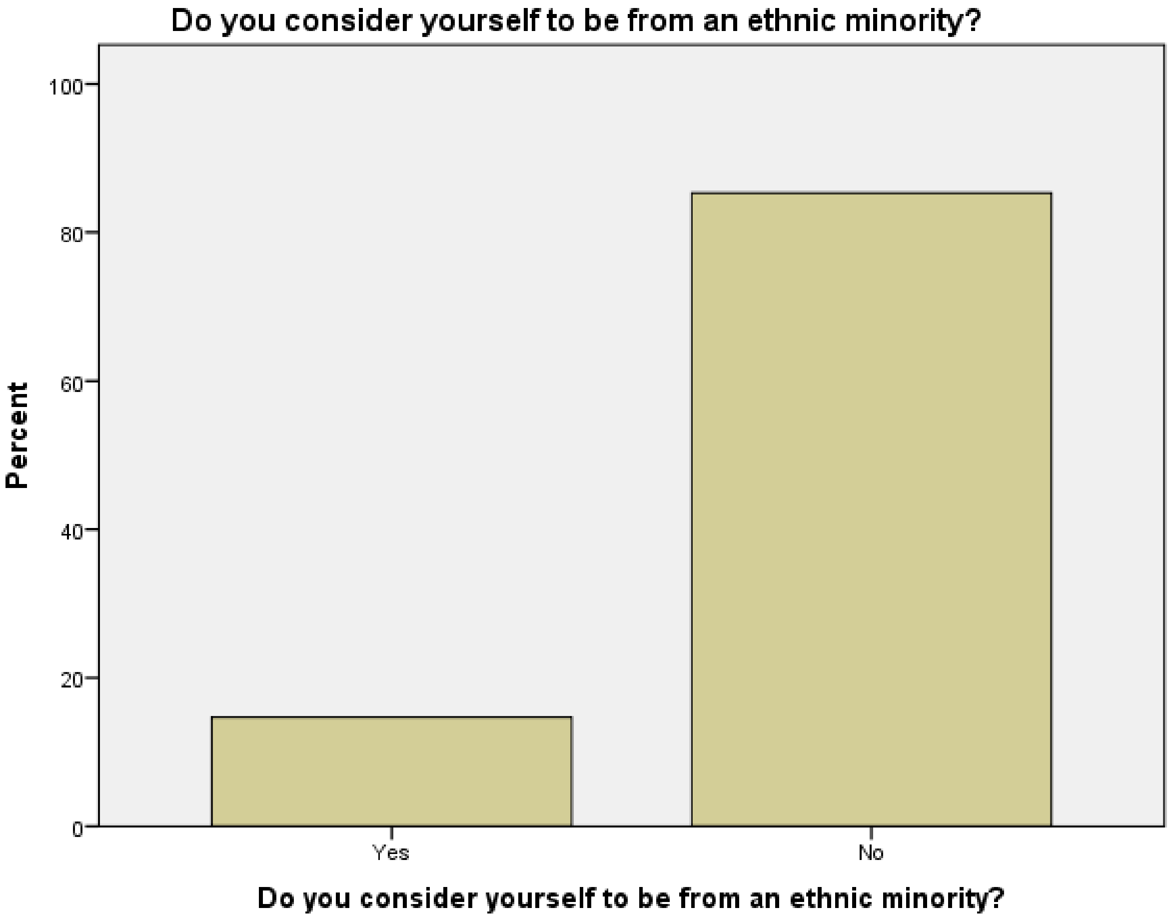


		Frequency 2011	**Valid Percent 2011**	Frequency 2009	Valid Percent 2009
Valid	16-25	**5**	**4.6**	20	12
	26-35	**10**	**9.2**	28	16.8
	36-45	**27**	**24.8**	41	24.6
	46-55	**35**	**32.1**	37	22.2
	56-65	**20**	**18.3**	26	15.6
	66-75	**9**	**8.3**	12	7.2
	75 and over	**3**	**2.8**	3	1.8
	Total	**109**	**100.0**	167	
Missing	System	**2**		6	
Total		**111**		173	

2009 Study



Q24

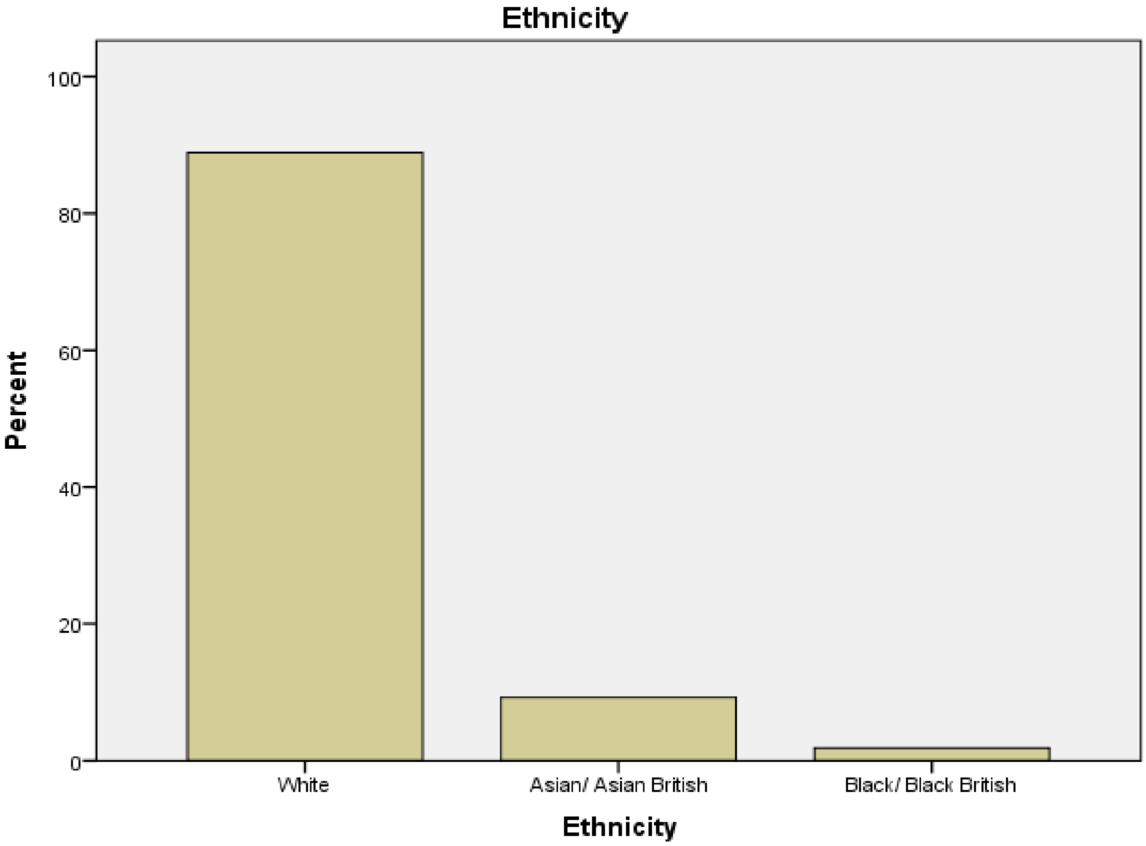


		Frequency	Valid Percent
Valid	Yes	16	14.7
	No	93	85.3

	Total	109	100.0
Missing	System	2	
Total		111	

Of those participants who answered this question only 15% (n = 16) considered themselves to be from an ethnic minority compared to 24% (n = 39) in the 2009 study. However, reported evidence from research interviewers suggests that considering oneself from an ethnic minority has no relationship necessarily to culture or colour. Considering the ethnic breakdown of Leicester, Leicestershire and Rutland combined SUCRAN would have hoped to capture a more representative sample of the population and incorporate the views of the BME communities living in these areas. Possible explanations for this absence of representation may include the lack of uptake of mental health services , which correlates with previous research, or a lack of willingness to express views and to be interviewed. The ethnic mix of interviewers is sufficiently robust to obviate any influence in terms of not wanting to engage with a person from an alternative background.

Q25



		Frequency	Valid Percent
Valid	White	96	88.9
	Asian/ Asian British	10	9.3
	Black/ Black British	2	1.9
	Total	108	100.0
Missing	System	3	

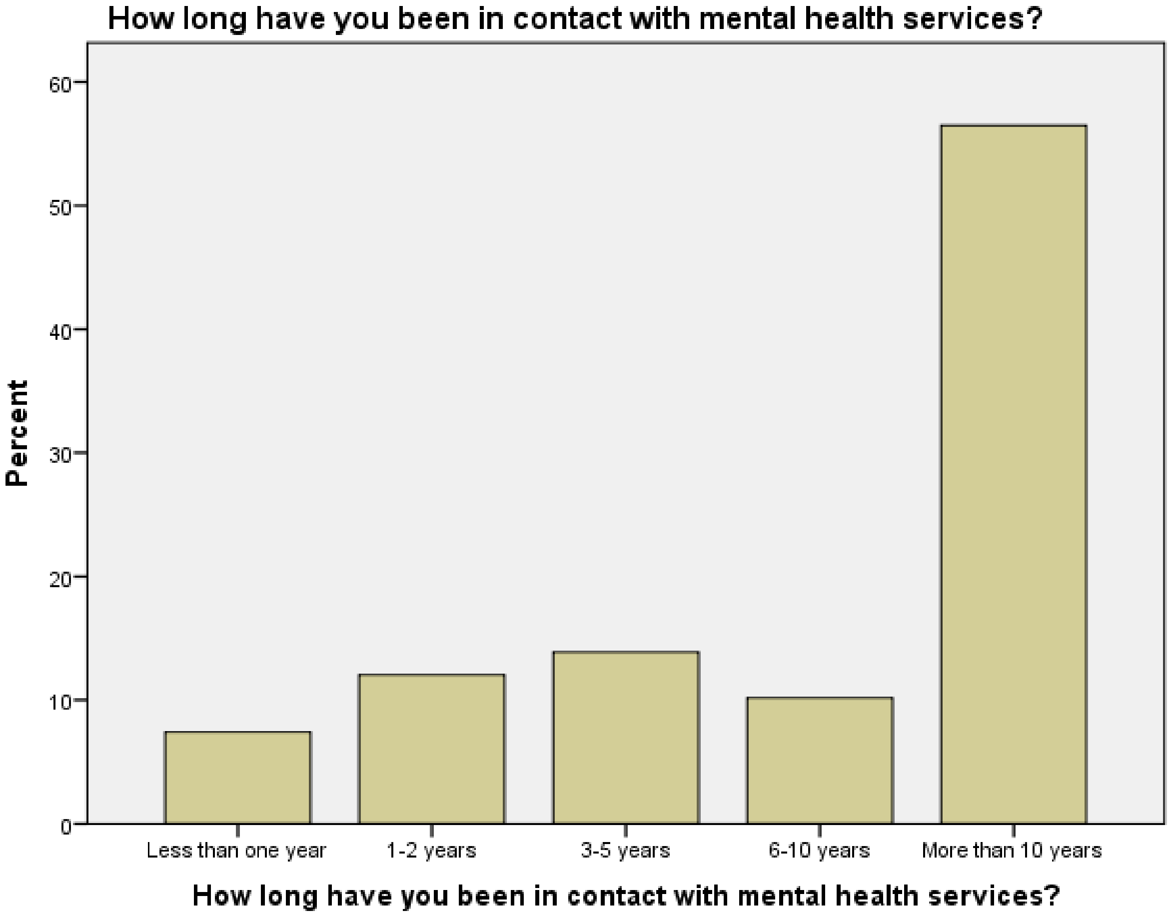
Total	111	

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.

These results are similar in nature to the outcomes of 2009 in which 88% (n = 151) described themselves as White, 9% (n = 15) as Asian/Asian British and 3% (n = 5) as Black / Black British.

Q26

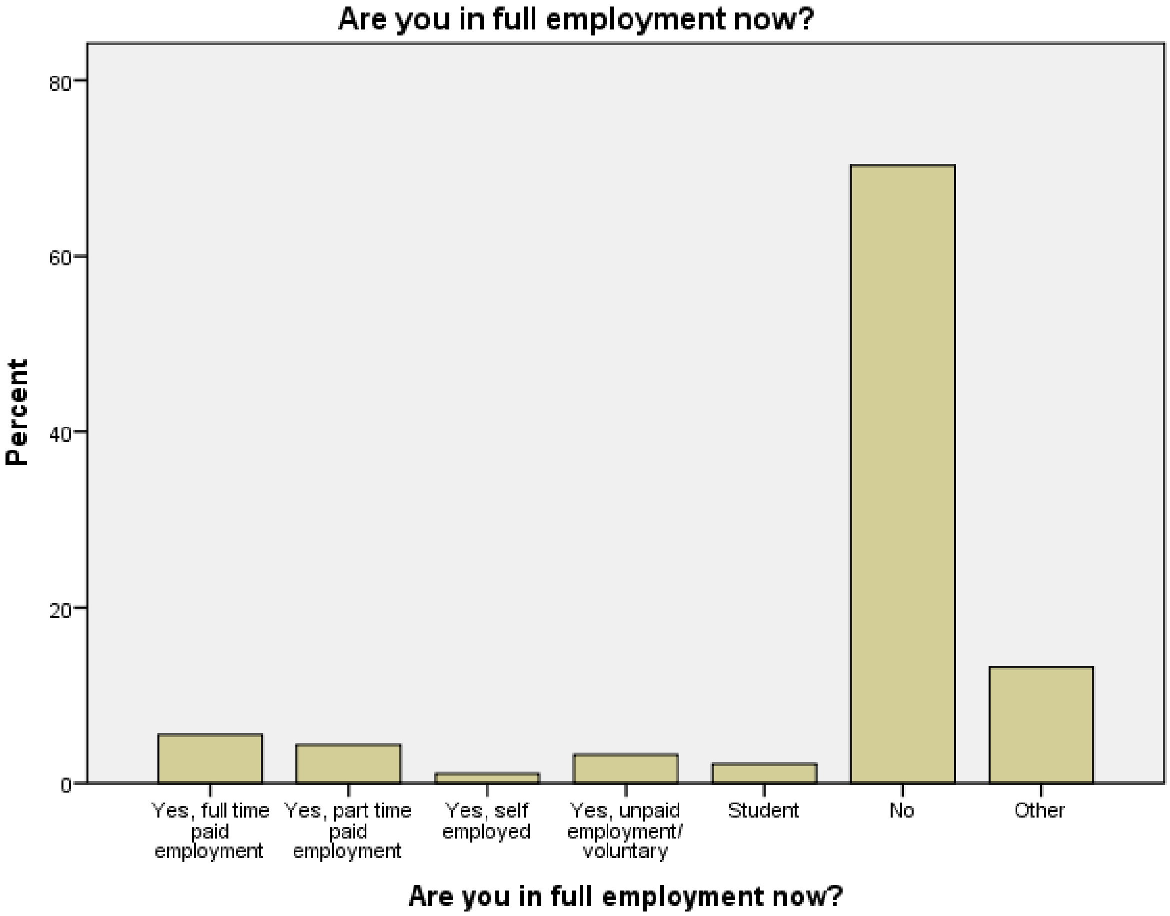


		Frequency	Valid Percent
Valid	Less than one year	8	7.4

	1-2 years	13	12.0
	3-5 years	15	13.9
	6-10 years	11	10.2
	More than 10 years	61	56.5
	Total	108	100.0
Missing	System	3	
Total		111	

The majority of participants 57% (n = had been in contact with mental Health Services for more than 10 years in comparison for the majority within the 2009 study of 44.6 % (n = 74). This fact may have influenced answers to questions about who helped the individual in the early stages of their illness and within the last year.

Q27



		Frequency	Valid Percent
Valid	Yes, full time paid employment	5	5.5

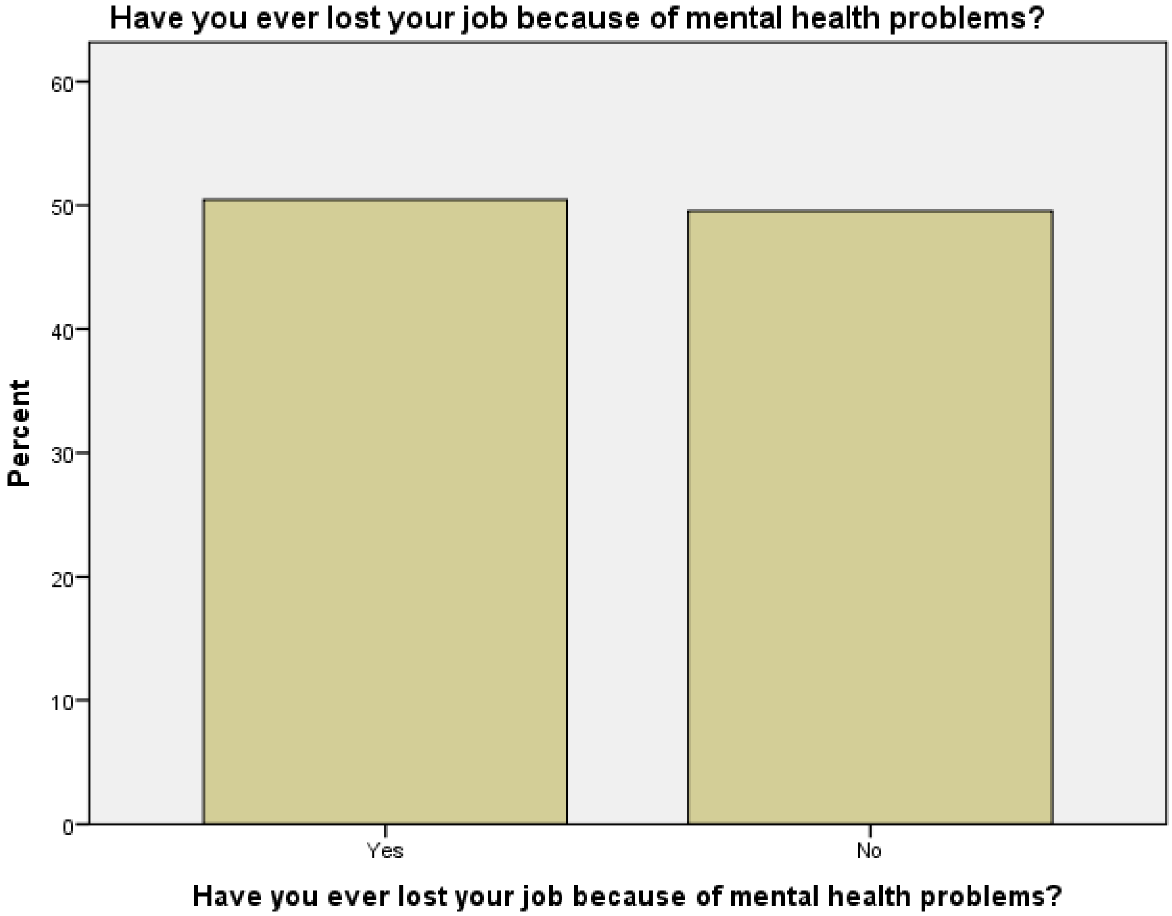
	Yes, part time paid employment	4	4.4
	Yes, self employed	1	1.1
	Yes, unpaid employment/ voluntary	3	3.3
	Student	2	2.2
	No	64	70.3
	Other	12	13.2
	Total	91	100.0
Missing	System	20	
Total		111	

Those participants who benefit from paid employment either full or part time amount to only 10% (n = 9), one of which was self employed, in comparison to the 2009 study in which this outcome was 12% (n = 20) at the time of the interview. SUCRAN 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.

Work has a central role in most people's lives, Shepperd (1989) offering rewards beyond that of income. Employment provides not only a monetary recompense but also ‘latent’ benefits — non-financial gains to the worker which include social capital, identity and status, contacts and support beyond the care offered from professionals. Employment is a way to structure and meaningfully occupying time. The very basic notion of activity, participation and involvement brings about a sense of personal achievement self efficacy and stature. These outcomes echo the SUCRAN 2011 Audit of the Mental Health Charter and considering the importance of work as a key preventer of social exclusion, Bond (2008), Burns (2009) Schneider (2009) this is a very disappointing set of circumstances for most service users.

When we compare the outcomes to the general population claiming job seekers allowance in Leicester City, Leicestershire County and Rutland we see that just over 10% of the total population (LCC 2012) are seeking work which is almost a mirror image of the situation mental health service users find themselves in.

Q28



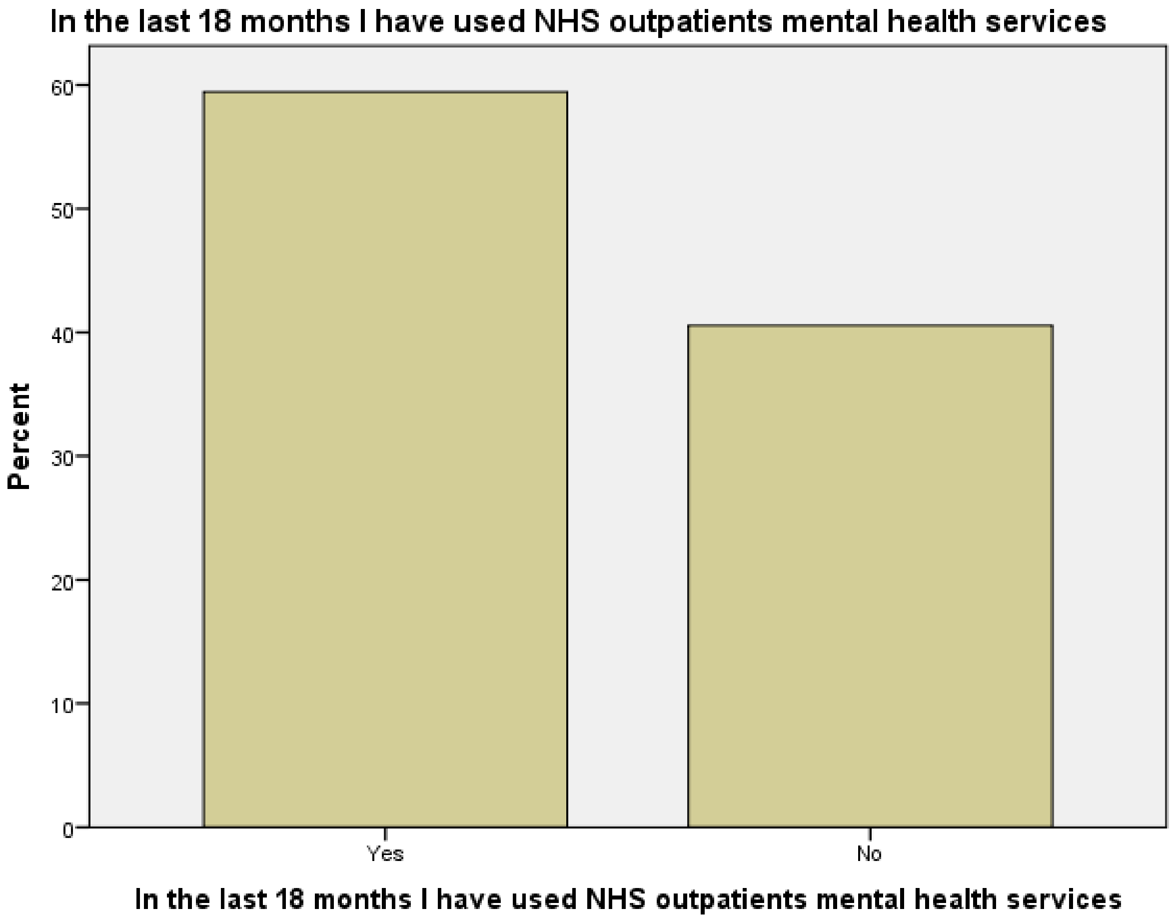
	Frequency	Valid Percent

Valid	Yes	55	50.5
	No	54	49.5
	Total	109	100.0
Missing	System	2	
Total		111	

The perception that the individual had lost a job because of their mental health problems was reflected in 51% of answers to this question (n = 55 compared to 43% (n = 71) within the 2009 study.

Service providers should be alerted that mental health issues seem to impact on a person’s ability to sustain employment and perhaps use connections with employers to raise awareness, address the stigma and to become more empathetic.

Q29a

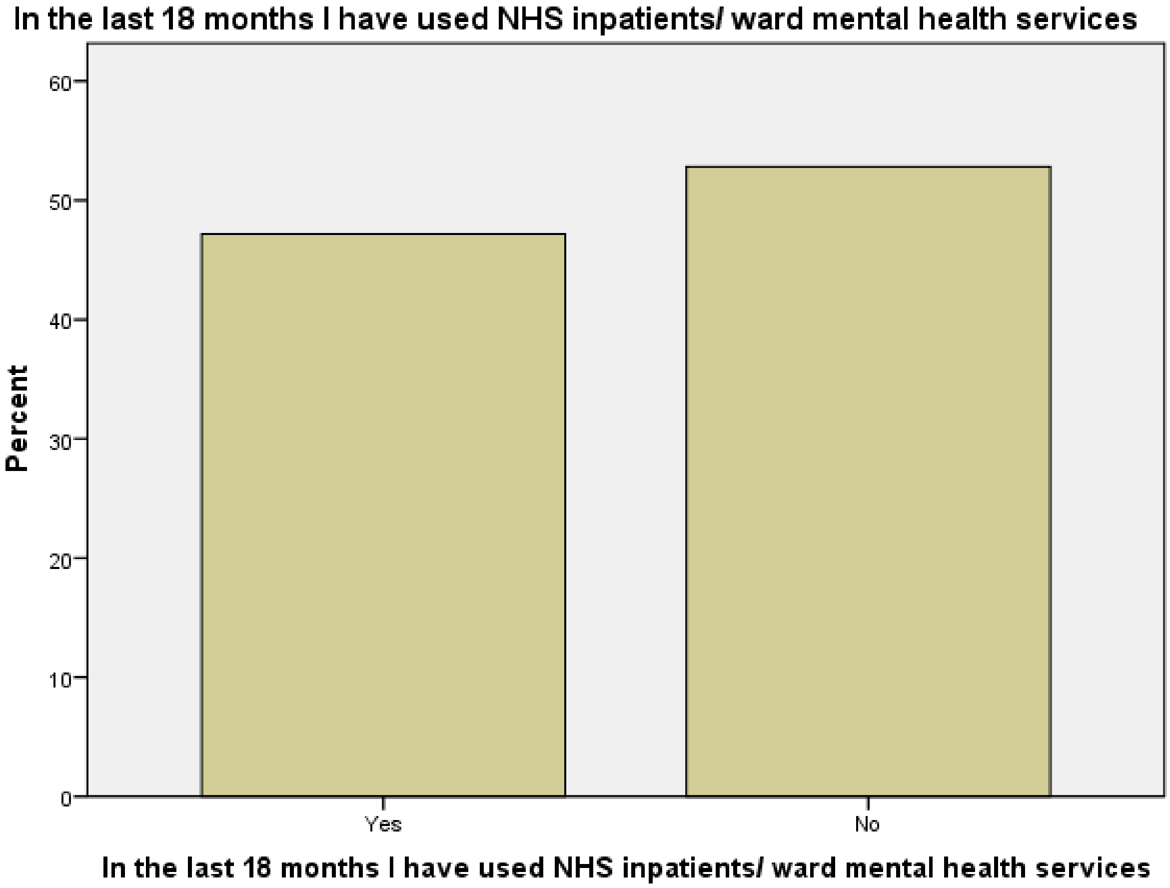


		Frequency	Valid Percent
Valid	Yes	63	59.4

	No	43	40.6
	Total	106	100.0
Missing	System	5	
Total		111	

In the preceding 18 months NHS outpatients was used by 60% of participants (n = 63) in comparison to 77 % (N=127) in the 2009 study, representing a 17% reduction in demand.

Q29b



In the preceding 18 months NHS inpatient services were used by

% of participants (n =) in comparison with 60.6 % (n = 100) in the 2009 study.

Q29c

		Frequency	Valid Percent
Valid	Yes	73	69.5
	No	32	30.5

	Total	105	100.0
Missing	System	6	
Total		111	

In the preceding 18 months NHS outpatients was used by 70% of participants (n = 73) in comparison to 62% (n = 102) in the 2009 study.

Q29d

		Frequency	Valid Percent
Valid	Yes	27	25.7
	No	78	74.3

	Total	105	100.0
Missing	System	6	
Total		111	

In the preceding 18 months mental health social service providers were by 26% of participants (n = 27) in comparison to 42% (n = 69) in the 2009 study.

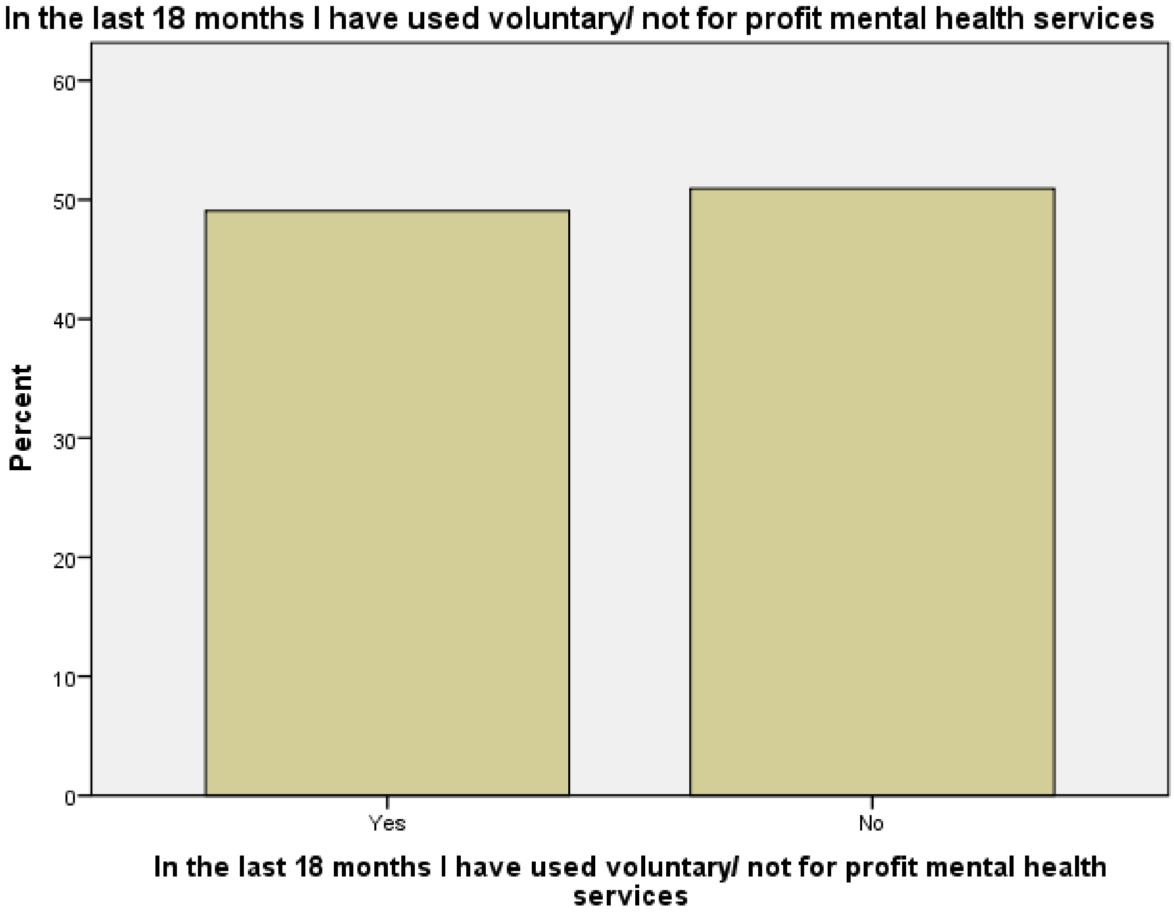
Q29e

		Frequency	Valid Percent
Valid	Yes	18	17.0

	No	88	83.0
	Total	106	100.0
Missing	System	5	
Total		111	

In the preceding 18 months independent sector mental health services were used by 17% of participants (n = 18) in comparison to 18% (n = 31) in the 2009 study.

Q29f



		Frequency	Valid Percent
Valid	Yes	52	49.1
	No	54	50.9

	Total	106	100.0
Missing	System	5	
Total		111	

In the preceding 18 months voluntary/not for profit mental health services were used by 49% of participants (n = 52) in comparison to 34% (n = 55) in the 2009 study representing an increase of 15%.

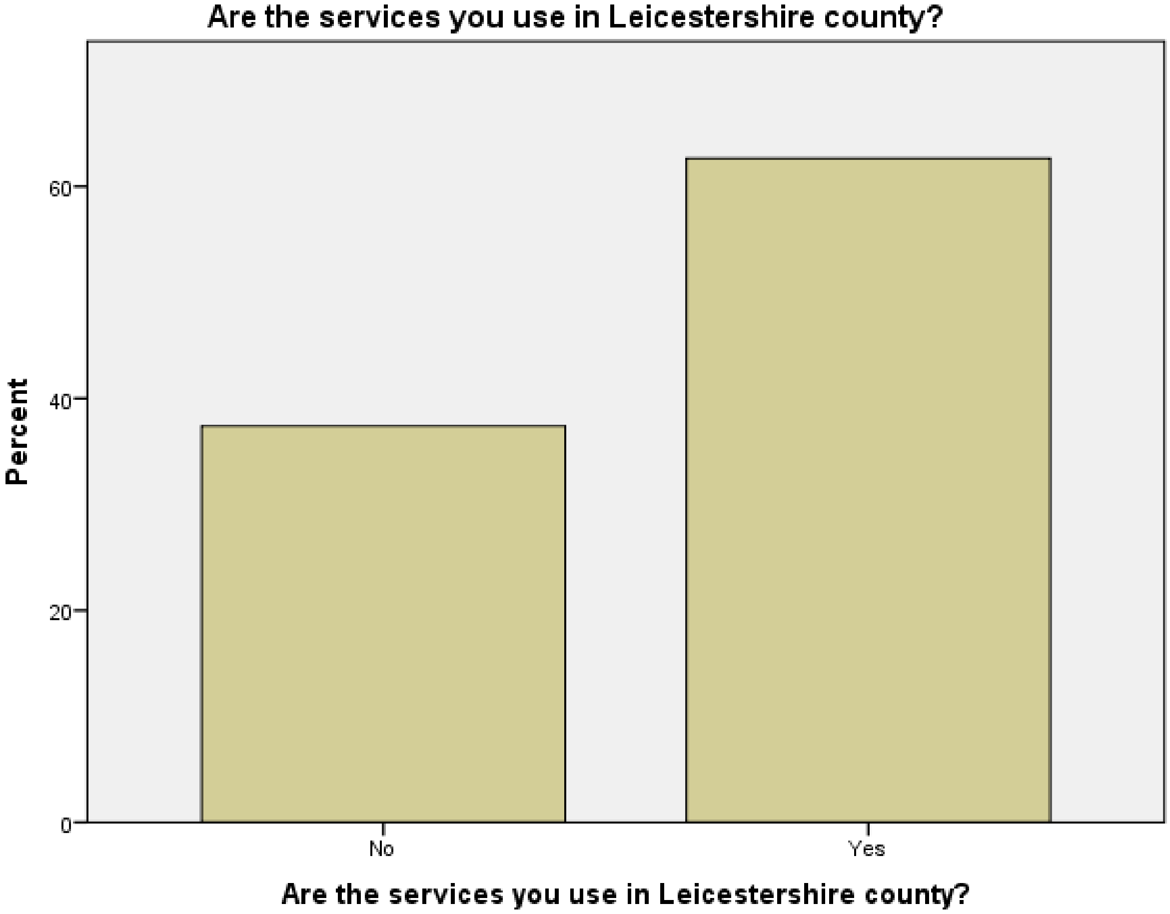
Q30a

		Frequency	Valid Percent
Valid	No	66	61.7
	Yes	41	38.3
	Total	107	100.0

Missing	System	4	
Total		111	

38% of participants (n= 41) used Leicester City based services.

Q30b

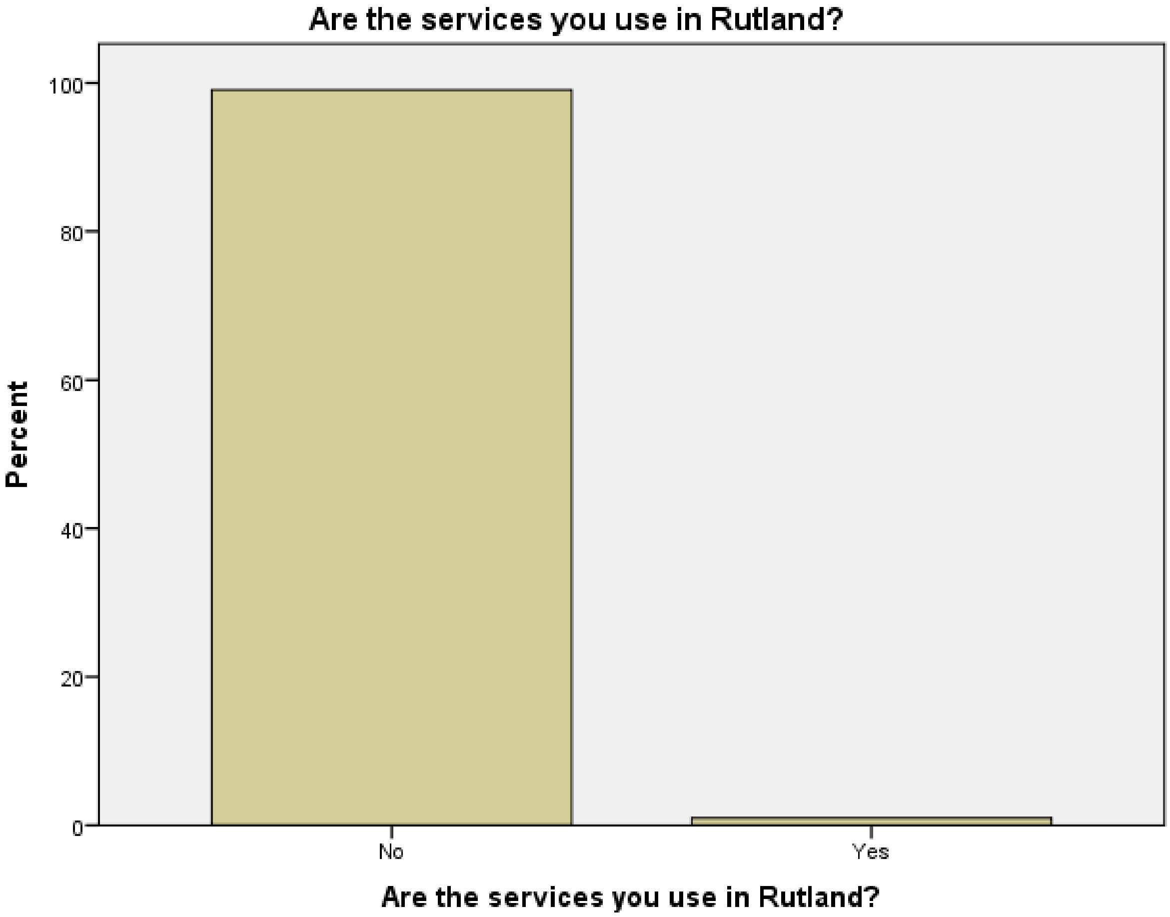


		Frequency	Valid Percent
Valid	No	40	37.4

	Yes	67	62.6
	Total	107	100.0
Missing	System	4	
Total		111	

62% of participants (n= 67) used Leicestershire County based services.

Q30c

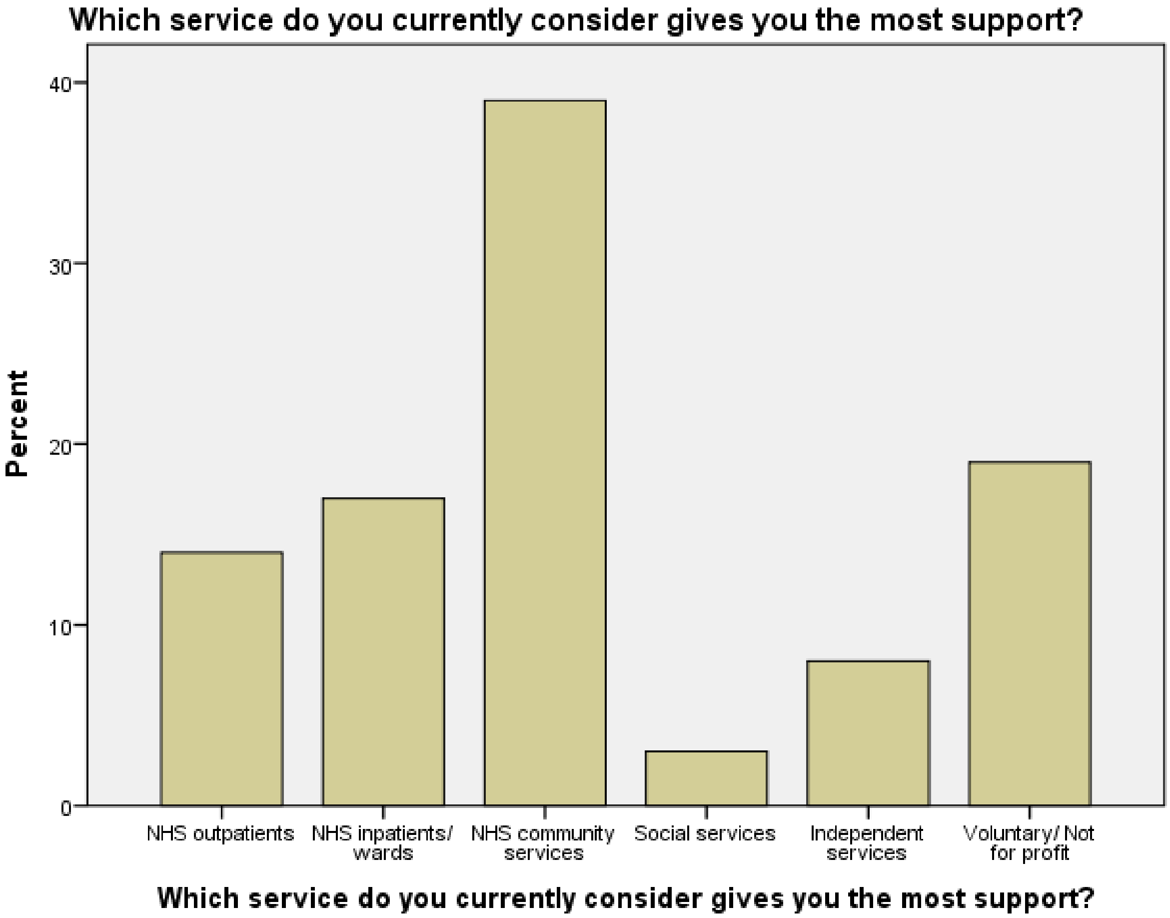


		Frequency	Valid Percent
Valid	No	105	99.1
	Yes	1	.9
	Total	106	100.0

Missing	System	5	
Total		111	

0.9% of participants (n = 1) used services based in the County of Rutland.

Q31



		Frequency	Valid Percent
Valid	NHS outpatients	14	14.0
	NHS inpatients/ wards	17	17.0

	NHS community services	39	39.0
	Social services	3	3.0
	Independent services	8	8.0
	Voluntary/ Not for profit	19	19.0
	Total	100	100.0
Missing	System	11	
Total		111	

Discussion and Conclusions

The 2009 study achieved many successful outcomes in terms of the process of design, the methods used for gathering data, and the analysis of that data.

SUCRAN were instrumental in the selection of interviewers and for steering this project towards the achievement of its aims which are tested by the revisit audit to establish the response of provider organisations to those results.

SUCRAN hoped the 2009 study would 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. To some extent this seems to have been achieved, but whilst this report contains many positive endorsements, there are areas where little progress seems to have been made. This is surprising considering the introduction of the “Charter for Mental Health” (2008) and the clear set of statements for service users, carers and provider organisations about what they can expect from local mental health services in Leicester, Leicestershire and Rutland. Furthermore, the audit of the impact of the Charter (SUCRAN 2011) alerted providers to their obligations in a range of arenas that effectively support people's recovery from mental distress some of which are explored within this report.

The two reports combined give us the views of 284 service users and coupled with the outcomes of the Mental Health Charter Audit with a further 123 participants provide a longitudinal vista of 3 years. Participants represent 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 study for example, and 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. The geographical spread of received services showed that participants from the County were in the majority

(63%) and 39% from the City and the remaining 1% receiving services from Rutland, constituting a representative sample from the 3 target areas.

When considering the representativeness of the sample for both studies, one striking point is the low involvement of the BME community. A review of the selection process reveals that a sufficient number of groups were invited to participate from African, Caribbean and South Asian origins, but this raises the point that despite advertising and the request to organisations and individuals, people from these backgrounds were unable or declined to become involved. The questionnaires were in English however translation services were offered and available for those whose first language wasn't English. One service for African Caribbean service users, actively refused access to the researchers because we could not (and did not feel it appropriate to) guarantee an interviewer from the same ethnic background as the participant. This has been the subject of much debate within the SUCRAN Steering Group, however there is strong evidence to suggest that the ethnicity of the interviewer does not adversely influence the quality of responses. (Weeks and Moore (1981), Davis (1997a), Davis, (1997b), Chevannes et al (1998a), (1998b), Dotinga et al (2005), Bhagavathula (2004), Blaydes and Gillum (2011)). This said, the Steering Group recognise that people whos ethnic background is not white British, may have not understood the advertising poster or been reluctant to participate for some other reason. This fact does however uphold the results of the 2008 study, "Mental health needs of Black and Minority Ethnic communities in Leicester, Leicestershire and Rutland" which identified that people from Asian/Asian British communities in Leicester, Leicestershire and Rutland who experience mental health problems are generally under-represented in many of the secondary mental health services, including general psychiatry outpatient episodes and inpatient admissions, crisis resolution, dynamic psychotherapy and specialist services. LPT (2008 p 9). However against the backdrop of people from minority ethnic groups being over-represented in psychiatric hospitals, (CQC 2009), with 22% of adult inpatients in England & Wales being from minority ethnic groups, under representation in this study is of concern.

We can conclude therefor that every possible effort was made to engage with the diverse populations of Leicester, Leicestershire and Rutland, but will redouble our efforts to capture these viewpoints within future studies. Despite these issues the 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 and the empowerment of people who have been involved.

The peer status of the interviewers, may have positively influenced the numbers of participants opting into the study, and consequently enhanced the richness by increasing the number and volume of answers. 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.

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, and be a change agent in areas that need it. Furthermore, this report provides some very positive perceptions that should be seen as an opportunity to congratulate staff performance in the areas which have been well evaluated.

What Has Been Learned?

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

Overall the questions were well phrased and easily understood, although we can identify that Question 9 caused some confusion and so, did not produce a conclusive outcome or results which were as reliable as they could have been.

The majority of interviews took at least 35 minutes with some needing up to one hour to complete. An interview briefing pack and preparatory training for interviewers worked well and should be considered an essential element of preparation for future studies.

The block of questions considered in question 18, 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 participants’ feelings of trust and confidence in the staff who provide care, and being listened to, and treated with respect and dignity. Service users in the main felt listened to, and these feelings reflected in their willingness to recommend the providers to friends and family. However there were some perceptions of not being equal, being patronised and seen as attention seeking for some participants.

Where providers have fallen below expectations further 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 surprising, 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 perceived level of intolerance within the workplace. This subject will be the focus of a SUCRAN study later in 2012/2013.

Overall SUCRAN believe that being treated by a mental health provider in Leicester, Leicestershire or Rutland makes a positive difference indicated within all 3 studies. Evidence suggests that participants experiences have been largely beneficial to their mental health.

Research Limitations and Shortcomings

SUCRAN 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 conclusive responses were not achieved, care has been taken to sustain objectivity within the context of question. Questions that obtained insignificant results in the 2009 study have been trimmed from the revisit.

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 SUCRAN 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 Welfare 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 of 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. 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 in the 2009 study and an attempt was made to address this in the 2012 report.

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

SUCRAN 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.

- 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.

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

- SUCRAN 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.

SUCRAN 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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