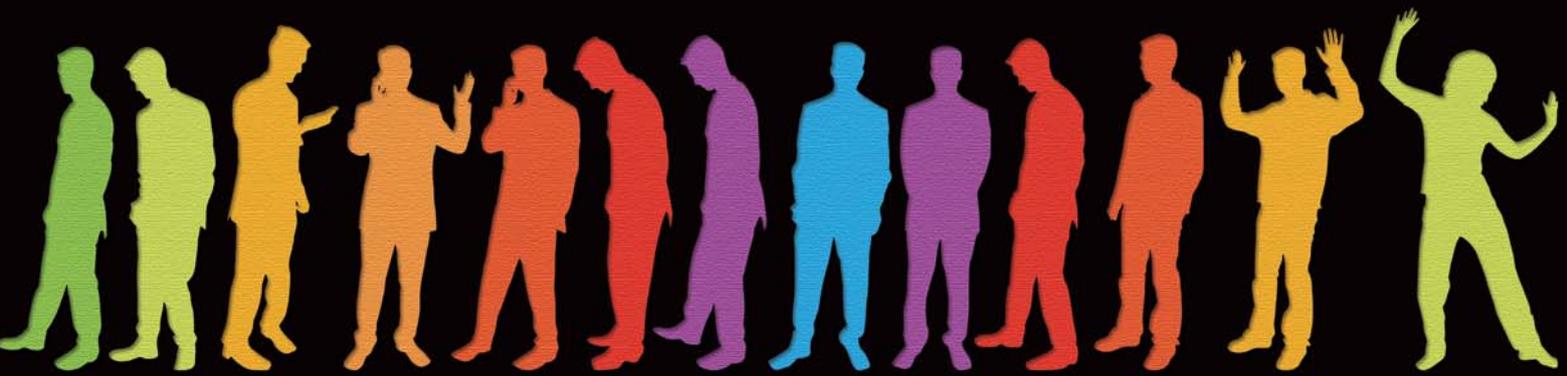


Second Opinions



2011

Summary Report of the
NSUE Survey of Members on Vision for Change

Have your voice heard... for a change



www.nsue.ie

Foreword

It is my great pleasure to introduce “*Second Opinions 2011*”, our third annual summary report of our survey of members.

Our remit dictates that we have an input not only into the planning and delivery of services, but also that we have a role in ‘evaluating and monitoring’ services, including ‘models of best practice’ and also ‘to develop and implement best practice guidelines’ (Vision for Change, Chapter 3).

Through our questionnaire, our members have had the direct opportunity of monitoring and evaluating their own local service and have also provided us with valuable information on the progress, and particularly on the principles of Vision for Change.

Our work is guided by the values of support and partnership working. With that in mind, last year, for the first time, we decided to give awards to three mental health services in different categories identified by our survey as examples of good practice, in the opinion of those who used them. The awards were presented in Dublin Castle by the Minister, Mr John Moloney T.D., and were received with great enthusiasm by the recipients who felt it was an acknowledgement of their commitment to the provision of quality mental health services and provided them with much needed encouragement for the future in this difficult economic climate.

Despite the recession NSUE, is moving forward with its remit and for 2012 will be prioritising the establishment of consumer panels which will be the mechanism by which service users and family members will have a direct input into the development and management of their own local services. It is no coincidence that award winners all come from services with a high level of service user involvement.

I would like to sincerely thank St Patrick’s Hospital, who have been unequivocal in their support of NSUE, together with HSE South, for their sponsorship of this project and for whom we will be able to give feedback on their individual services. I would also like to acknowledge all of those who filled out our questionnaires as well as all our staff, executive members and volunteers who distributed them.

Thanks are also due to Stephen Shannon for his earlier input to the questionnaire design, to Darach Murphy for his work on the qualitative analysis section of this report, to Elizabeth Donovan for her invaluable experience and help with data entry, and to Dr. Ciaran Crummey, who was responsible for the quantitative analysis and for the layout of this report. Most especially, thanks are due to John Redican, our Chief Executive Officer, for his overall direction, guidance, and editorial input.



Jennifer Kelly

Chairman

National Service Users Executive

Second Opinions

Report

Summary Report of the NSUE
Survey of Members 2011 on the Vision for Change

2011

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Introduction

This is the third successive year that the National Service Users Executive (NSUE) has carried out a national client satisfaction survey. This report has been presented in a way that we hope is easily understood by our members. That is its primary objective. The use of jargon, and complicated terminology has been avoided to the greatest possible extent.

The most important difference between the questionnaires used this year, compared to the two previous years, is that a new section was introduced to find out, or ascertain, the HSE services used by respondents within the previous twelve months. Also, a new question was used to find out the extent to which those who responded were involved in the preparation of care plans.

Based on the survey questionnaire used in 2010, a modified one was drawn up in early 2011. This was tested and further modified, and then used (appendix 1). People were invited to complete a questionnaire either from an NSUE representative who they met, or by receiving a copy that was posted to every NSUE member in the country with a stamp addressed envelope. All of the questionnaires that we received up to the end of the year were grouped together and analysed.

All surveys, including this one, have design flaws. Our main goal was to obtain as good a picture as possible about the views of our members, and what their main concerns were. We believe that we have achieved that goal. We will continue to modify and develop the survey questionnaire each year as these concerns change.

We are very grateful to everyone who participated in this survey. Your opinions are vitally important to us. They will be used to influence service improvements.

We would also like to assure those of you who completed questionnaires that your identity will not be revealed to anyone. This information is kept confidential. Many of those who filled in questionnaires were happy with the service they have received. Some were not. We would like to particularly encourage service users who are unhappy to participate in this survey in future because other surveys have shown that unhappy customers are less likely to do so.

We have also used the information we received to select three awards; the *“Best Overall Service”* award, the *“Most Effective Supports”* award, and the *“Most Improved Culture of Care”* award. This is a way for our members to highlight their overall satisfaction with services.

This report is divided into two sections; the first section deals with the quantitative findings, and the second with

the qualitative findings. Quantitative, or numerical, analyses are blunt instruments. Passionately expressed emotions are obscured in this realm because it is concerned only with numbers obtained from boxes ticked. Fortunately, qualitative analysis addresses this shortcoming. It looks at comments and analyses these for meaning. The former is all about numbers and sample sizes, whereas the latter is about substance, depth and deeper levels of meaning. Combining the two approaches is rarely easy, however.

On first reading the results of the two separate analyses in this report confirms this to be the case. The themes that emerge from the numerical analysis are pre-ordained by the way the tick boxes are arranged on the questionnaire. The comments provided respondents with an opportunity to raise anything they wanted to, including issues that the tick boxes had failed to cover. Through the written responses recorded in the various comments some important new themes were introduced, and depth and substance was added to some of the issues raised in the numerical analysis. The challenge is to combine these two sets of results in such a way that, as we move forward, we get the best of both worlds, and use this to maximum effect in order to achieve the changes in service provision that you, our members, have indicated to us are needed.

Perhaps the most positive findings in this report emerged from the qualitative analysis. It found that respondents were clear and consistent in identifying deficits in service provision; that they offered solutions which were also clear and consistent, and that, in the main, they offered a coherent rationale as to how the solutions they proposed would address deficits, and benefit their recovery.

The main points to emerge from all of this information are presented in this report.

Summary of the Quantitative findings

Surprisingly, three quarters of our respondents reported that they were happy with the services provided to them last year. This was also an increase on the previous year, 2010. This finding is surprising in the present economic climate, where resources are being reduced. We think that the most likely explanation for it is that our respondents also noticed substantial improvements in staff attitudes.

Improving attitudes is not a resource issue, and it seems to be having a greater positive impact than the negative ones being imposed for economic reasons. This is very encouraging.

Collectively, the most important issues for recovery were to be treated with dignity and respect, to be listened to, to be asked what they want, and to less stigma and discrimination. These too are all about changing attitudes.

Although better than the previous year, over a third of respondents last year felt that they did not have enough information about medication. This figure should be reduced. Recovery was important for 80% of participants. Only about half felt that the supports they had received had helped them to deal more effectively with their problems.

Although the overall results are encouraging, widespread variations between services were observed for quality of service, happiness levels, supports received, and attitudes. Some services did badly, and others did very well.

Summary of the Qualitative findings

Adding comments adds depth and substance to how questions are answered. They are very important. In this analysis themes were identified in relation to the research question;

"How can service supports be improved based on service user feedback?"

Within our sample of comments three groups were identified; those with very negative views, those in the middle, and those with very positive views. The middle group was by far the biggest.

Their constructive criticism included disappointment with the high turnover rates of their doctors, consultation times being too short and infrequent, poor communication between professionals, lack of involvement in care planning, improvements in the physical environment, better food, not having enough money, and having better educational skills. Many complained that communications with their doctors was very one way; that they were not being listened to. Many believed that they were not included properly in their care and treatment plans. Many also complained about the lack of treatment options. A lot reported that some of the information they received was difficult to access. In some cases literacy was a problem. A substantial number felt that they were provided with either no, or only partial, information on their medication. All of these issues should be addressed in the context of improving overall quality of service ratings.

Those with very positive views commended services for enhancing and saving lives, exclaiming that everything was always done in the service users best interests, and openly acknowledged the immense value of the help they had received from doctors and nurses. Those with very negative views said that service users had died through not being listened to, and that staff attitudes had gotten worse, pointing out that this possibility was not included in the survey questionnaire.

The reader is encouraged to read all of the comments in this section and to consider the points that resonate most strongly with their own experiences.

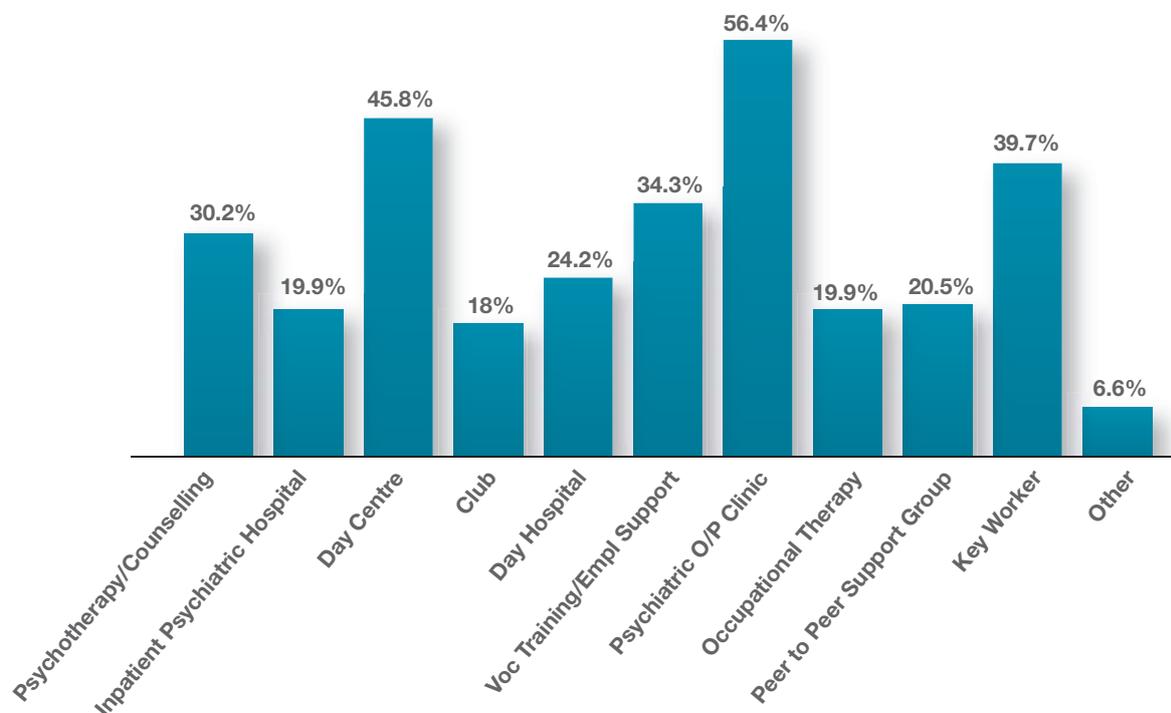
Section 1 - Quantitative Findings

We received a total of 1549 questionnaires from all over the country (excluding Northern Ireland), and from this a valid sample for quantitative (the boxes ticked) analyses of 1519 was obtained. This figure excluded a total of 30 (1.9% of the total) questionnaires that were returned that had either been incompletely filled in, or had been completed on the wrong questionnaire.

HSE services used

These are shown in figure 1.

Figure 1: HSE services used in the previous 12 months.



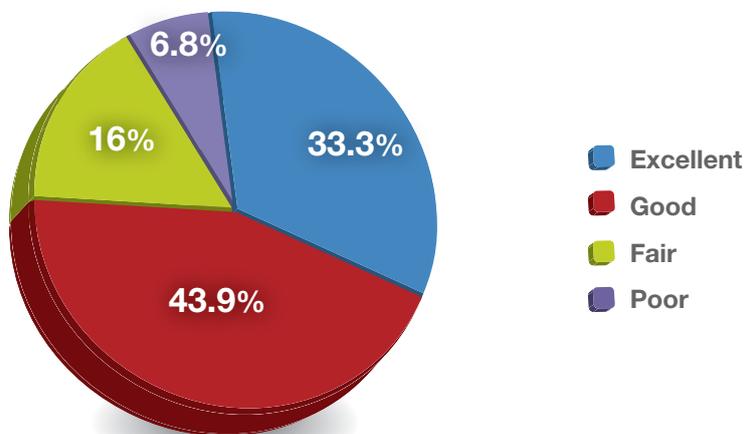
Nearly a third of respondents (30.2%) had used psychotherapy or counselling in the previous 12 months. Just under a fifth (19.9%) had been in a psychiatric hospital. A high percentage (63.8%) had availed of either day centres or clubs, and roughly a quarter (24.2%) had availed of day hospitals. Over a third (34.3%) were involved in vocational training or employment support.

Not surprisingly, many of the respondents (56.4%) had attended psychiatric outpatient clinics, and roughly a fifth (19.9% & 20.5% respectively) had availed of occupational therapy and peer to peer supports. Just under two fifths (39.7%) had used key workers. The “other” services used category included GP’s, community nurses, home help, depot clinics, support hostels, SHINE & GROW. The respondents used an average of 3.15 services in the previous 12 months.

It is encouraging to see that 30% of respondents availed of talking therapies, and 20.5% used peer to peer supports. The key worker concept appears to be relatively well developed; 39.7% of respondent’s availed of them.

Quality of Service

Figure 2: How would you rate the quality of service you have received overall?



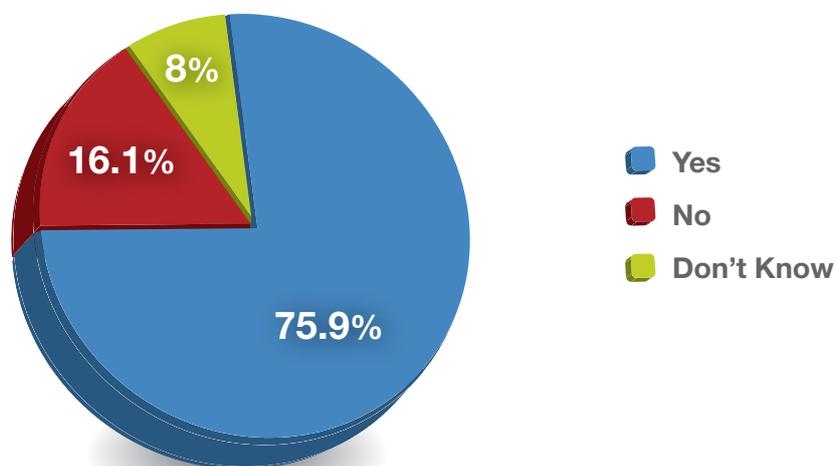
As indicated in Figure 2, just over a third of respondents (33.3%) reported that they felt that the quality of the service they had received was excellent. Just over two fifths (43.9%) reported that they thought it was good. Two thirds of service users rated service quality as less than excellent, so ways of improving this need to be explored.

The results shown are the overall national results. There were widespread variations in quality of service ratings between services, ranging from very low to very high.

Levels of Happiness with the Service Provided

These results are shown in Fig 3.

Figure 3: Are you happy overall with the services provided to you?



In terms of overall happiness with services (Fig 3) the picture seems to be broadly similar to that of quality of service; 75.9% were happy overall. This result can be compared with the 2009 and 2010 second opinions reports. In 2009 52% were happy (based on a sample size, n, of 536), and in 2010 the corresponding figure was 57% (n=1054). Overall happiness levels with services have increased markedly this year, based on this data.

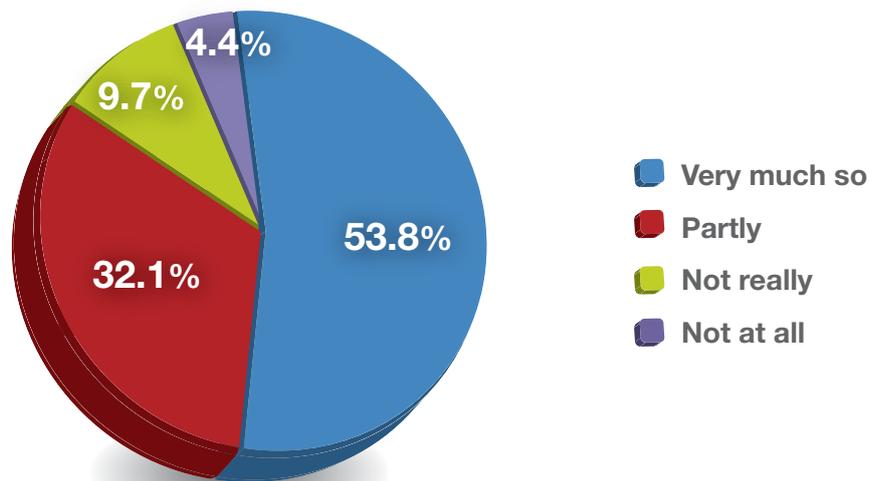
It is however noteworthy that there were also widespread variations between services in “yes” happiness ratings, ranging from very low to very high.

However, the overall picture that emerges is surprisingly positive. Overall levels of happiness with services increased substantially last year, compared to one before, and this trend has been upwards for the past three years. That this has occurred despite the present economic climate suggests that the changes that have taken place that have produced this positive feedback are not resource dependant (a question of money). Attitudes do not cost money, but they can make a big difference.

Supports received

These results are shown in Fig 4.

Figure 4: Have the supports you received helped you to deal more effectively with your problems?



In response to being asked if the supports you received had helped you to deal more effectively with your problems (Fig 4), just over half (53.8%) responded positively with “very much so”. A further 32.1% responded with “partly” and a total of 14.1% responded with “not really” and “not at all”. When compared with the above more favourable responses for quality of service and happiness with services provided, this finding suggests that improvements in satisfaction levels with supports could be achieved. Just under half (46.2%) felt that the supports they had received had either only partly, not really or not at all helped them. Ways of finding the right support for each individual need to be improved.

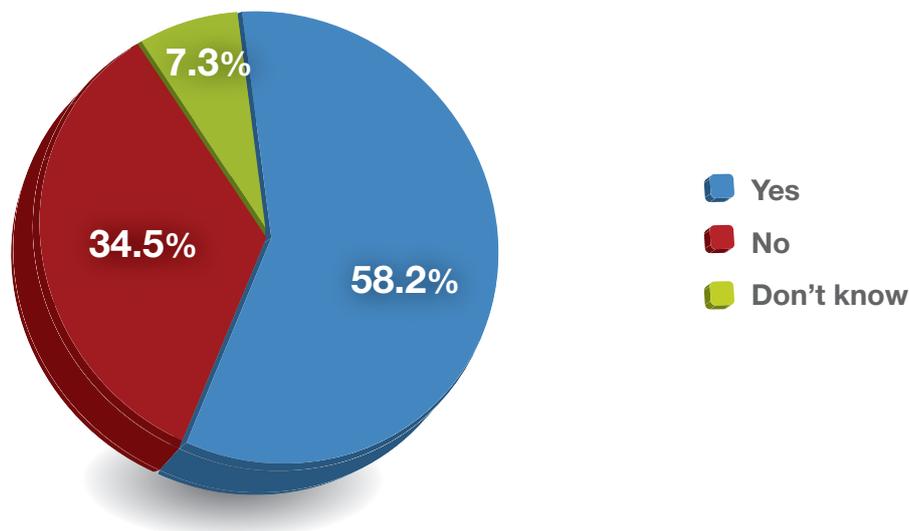
There was considerable variation in support satisfaction ratings between services, from very low to very high.

Anecdotally we have heard that some of the problems that our members experience are outside of the range of clinician expertise. We would like to see how satisfaction ratings with supports can be improved, and this was the main goal of the qualitative analysis presented in the second part of this report. All of the comments were considered in relation to the research question *“How can service supports be improved, based on service user feedback?”*

Information on medication

Last year's 2nd Opinions report drew attention to the relatively high numbers (46%) who felt that they did not have enough information about medication. The results for 2011 are shown in Fig 5.

Figure 5: Do you feel you have enough information on medication?



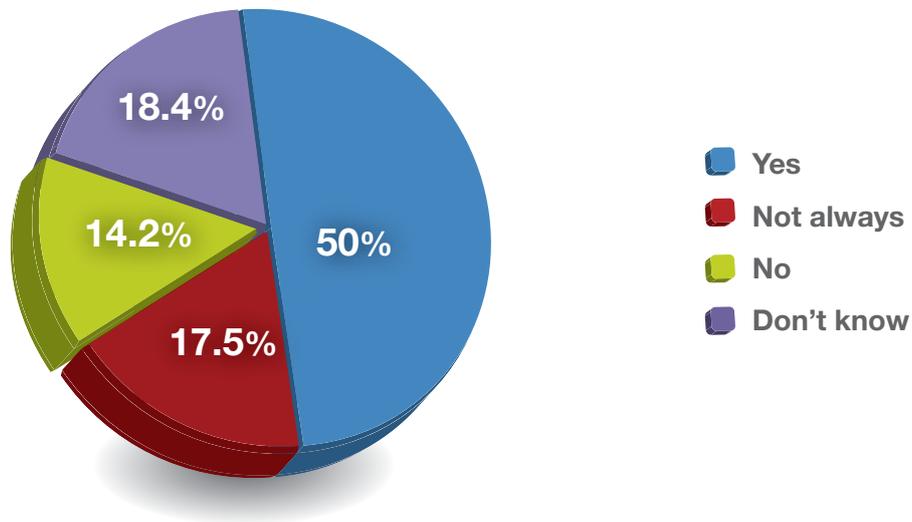
As shown in Fig 5, nearly 60% (58.2%) felt that they had enough information on medication. This however left a substantial proportion (41.8%) who either did not know, or definitely felt that they did not have enough information. The same question was asked in the 2010 second opinions report (n=1054). Then, 47% felt that they had enough information on medication. Therefore, there was a substantial increase in 2011 with those who were satisfied with the information they had. However, a considerable number of respondents (34.5%) felt that they did not have enough information on medication. Although this number has decreased since last year, it is still a worryingly high figure.

From the comments about sources of information about medication, the most important source was psychiatric staff (37.2%), followed by leaflets (27.1%), GPs (15.7%), the Internet (11%), Pharmacist (7.2%), and others (1.7%).

Involvement in the preparation of care plans

Government policy in mental health is laid down in a report called Vision for Change. According to this policy care plans should reflect your particular needs, goals and potential and should address community factors that may impede or support your recovery. Your needs should be discussed with you in order to make a detailed, or comprehensive, care plan. Care plans should be written in language that you understand before it is agreed with anyone else. This point is very important. If you don't understand it, then it is pointless. Care plans should include a time frame, your goals and aims, and how and what you need to achieve these. They should also include ways of measuring and assessing what happens to you in the future that can be compared with what you would like to plan for now. The results for this part of the survey are shown in figure 6.

Figure 6: I have been directly involved in the preparation of my care plan.



Only 50% reported that they had been directly involved in the preparation of their care plans (Fig 6). A total of 32.6% were either never involved in its preparation, or did not know what they were. A further 17.5% reported that they were not always involved in the preparation of their care plans. This indicates that some care plans are being prepared by clinicians without proper service user input. 32.6% were either not involved in preparing their care plans, or did not know what a care plan was. These figures indicate that care planning is slow in evolving into a system that supports the individuals unique needs, goals, and recovery journey.

Opinions about the importance of recovery to care and treatment plans.

“Recovery involves restoring hope. Acceptance of what has happened can be too terrifying in the absence of hope.” (Russinova, 1999).

According to O’Doherty and Doherty (2010), the core category of recovery for those who had experienced mental health problems for two years or more was ‘reconnecting with life’. It had three subcategories; reconnecting with self; reconnecting self with others, and reconnecting self and others with time.

Traditionally, care providers focused on deficits caused by mental health difficulties. Recovery oriented care identifies and builds upon each of our assets, strengths, and areas of health and competence. This is a radically new way of thinking. Within a recovery based system we are no longer viewed simply as “cases”, and clinicians are no longer viewed as “managers”.

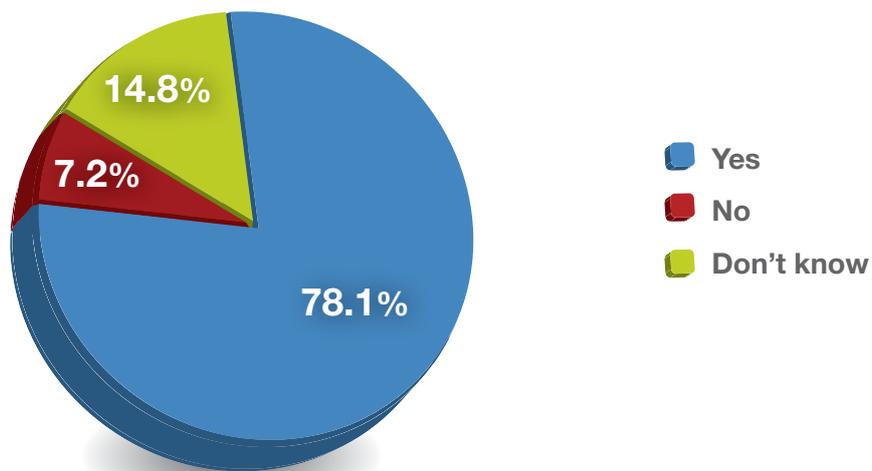
Mental illness is not something we need to do away with in order to have a life. Rather, for most of us, it is something we need to learn to live with as we go about having, and enjoying, our lives. More than anything else, recovery is about putting us in the driving seat of our own treatment, and replacing fear, which was endemic, with hope, which has often been in short supply. Our members views about the importance of recovery are summarised in Fig 7.

References used in this section;

Kartalova-O'Doherty, Y., and Tedstone Doherty, D., (2010). *Reconnecting with life: personal experiences of recovering from mental health problems in Ireland*. HRB Research Series 8. Dublin: Health Research Board.

Russinova, Z., 1999. *Providers hope-inspiring confidence as a factor optimizing psychiatric rehabilitation outcomes*. Journal of Rehabilitation. 16:50-57

Figure 7: I feel that recovery is central to my care and treatment plans.



A high proportion (78.1%) reported that recovery was central to their care and treatment plans (Fig 7). However, nearly 15% (14.8%) reported that they did not know if this was the case or not, and 7.2% felt that recovery was not central to their care and treatment plans.

Recovery has to be pursued: it does not simply occur in response to medication or other treatments. We are individually responsible for pursuing our own recovery. It is something that we do for ourselves. Professionals can only support us on this journey.

Changes in staff attitudes

Respondents views about changes for the better in staff attitudes are shown in Fig 8.

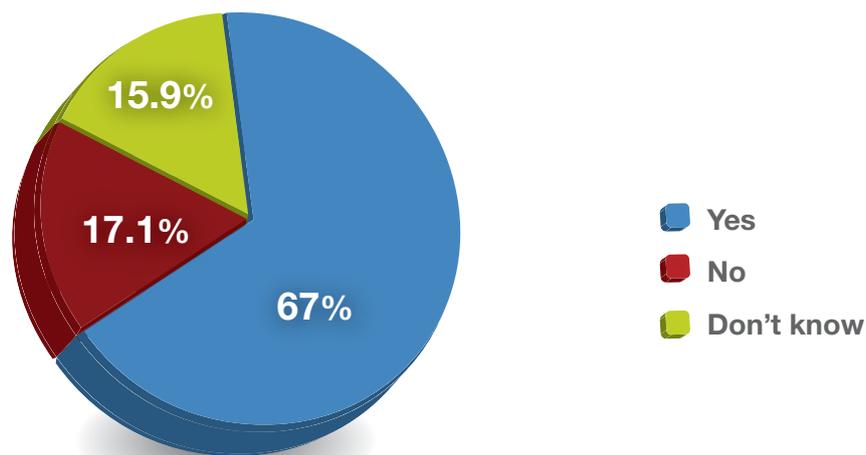
67% reported that they had noticed changes for the better in staff attitudes (Fig 8). A total of 33% either had not noticed changes for the better, or did not know. It is worth mentioning that not noticing changes for the better is somewhat ambivalent if staff attitudes have always been excellent.

There was widespread variation between services in the happiness ratings.

Overall happiness with services levels have progressively increased over the past three years, from 52% in 2009, to 57% in 2010, to 67% last year. This is a remarkable finding in light of the present climate of financial cutbacks and reducing resources.

Judging from the results for local services, we believe that staff attitudes improve with levels of service user participation. The services with the biggest positive changes in staff attitudes also had the highest levels of service user involvement.

Figure 8: I have noticed a change for the better in local staff attitudes.



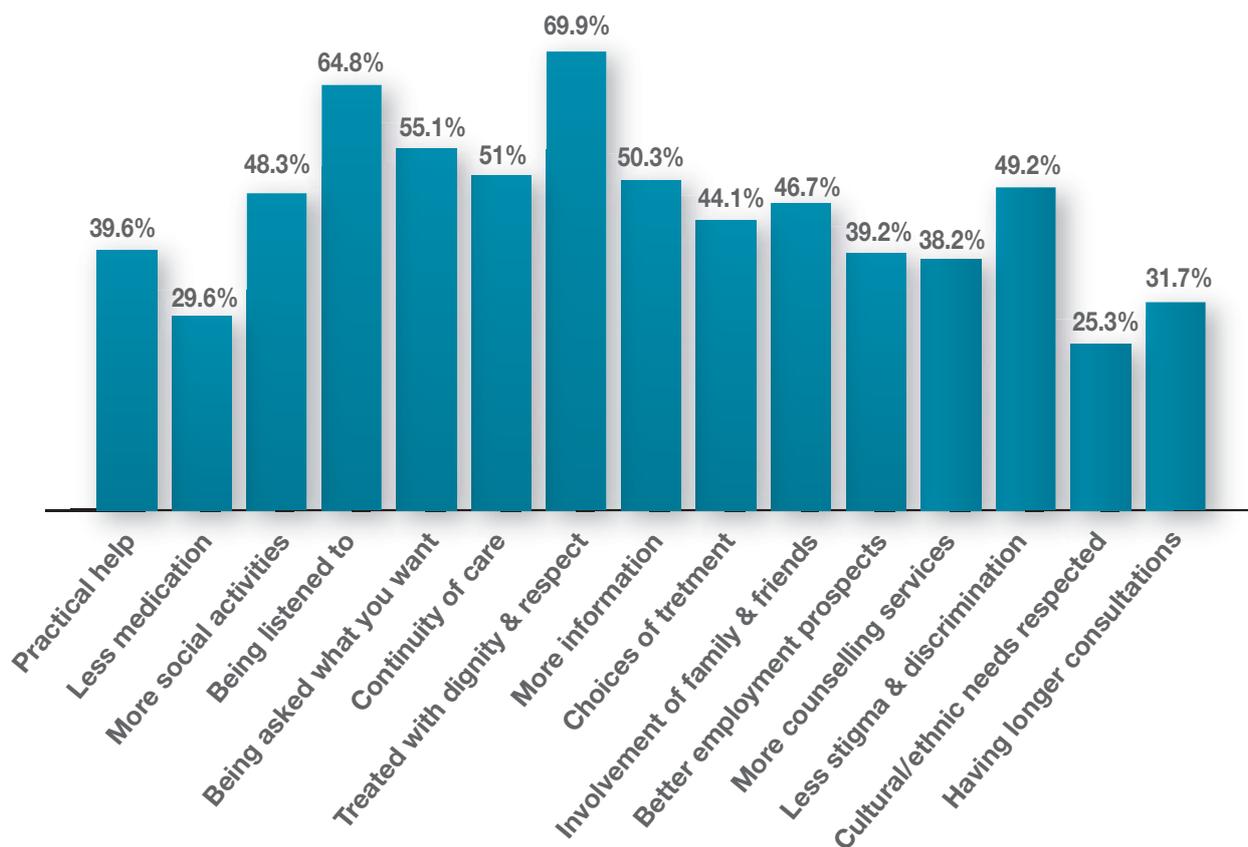
No answers

In general we noticed that the non-completion of answers increased progressively through the questionnaire. This suggested that respondents became less attentive as they went through it.

What is important for your own recovery?

These results are shown in Figure 9.

Figure 9: What would you say is important for your own recovery? (n=1519)



Respondents were given a list of 15 headings and asked to indicate which of these were important for their recovery. The five most frequently listed items were; being treated with dignity and respect (69.9%), being listened to (64.8%), being asked what you wanted (55.1%), continuity of care (51%) and having more information on what is available (50.3%). Respondents selected, on average, 6.8 of the 15 headings.

The five least frequently listed items were; having better employment prospects (39.2%), having more counselling services (38.2%), having longer consultations (31.5%), having less medication (29.6%) and having your cultural/ethnic needs respected (25.3%)

Of the 15 recovery items that were included in the 2011 questionnaire, 14 of these were also included in the 2010 questionnaire, and the top five were printed in the 2010 report. Table 1 shows how the 2010 top five compare with those for 2011.

Table 1: Comparison between 2010 top five & 2011 ranked equivalent items of importance for recovery.

Table 1: Comparison between 2010 top five & 2011 ranked equivalent items of importance for recovery.

Recovery items	2010	2011
Being listened to	1	2
More Information	2	5
Less stigma & discrimination	3	6
Being asked what you want	4	3
Involvement of family and friends	5	8

Note to table 1: Being treated with dignity and respect, ranked 1st in 2011, was not included in the 2010 questionnaire.

From Table 1 it can be seen that being listened to has consistently been in the top two rankings over these two years. Being asked what you want was 4th in 2010 and 3rd in 2011. Less stigma and discrimination was 3rd in 2010 and 6th the following year, in 2011.

Based on these results, our members particularly want to be treated with dignity and respect. Next, they want to be listened to, and then they want to be asked about what they want. Less stigma and discrimination is also a big issue for them. All of these themes have one thing in common; they are primarily about attitudes. They are not about resources, or money. Improving attitudes in these areas must continue to be given priority.

Section 2 - Qualitative Findings

All of the comments from the first 84% (1272) of the returned questionnaires were considered in this qualitative thematic analysis. It was restricted to surface content, rather than trying to find hidden content. Themes were identified in relation to the research question;

"How can service supports be improved based on service user feedback?"

A considerable number of service users held either extreme positive or extreme negative opinions of their services. However the majority fell between these two extremes offering what could be termed constructive criticism combined with an acknowledgement of what was working well. In order to provide a thematic analysis covering all of the comments, 3 groups, of service users were identified representing distinct stances towards services. Since we are concerned with how service supports can be improved based on service user feedback, attention was focused on an analysis of the middle group, the 'constructive criticism' group. For each comment, the questionnaire number to which it pertains is shown.

Group 1 - Service Users offering constructive criticism

These respondents represented the majority of service users and they seemed to adopt a positive and constructive approach when commenting on their services. Their comments, both critical and complimentary, seemed to be motivated by a desire to see an improvement in the quality of services which would contribute to greater recovery for themselves and their fellow service users.

The overarching themes elicited from the views expressed by this cohort of participants were:

- ***Service users were clear and consistent in identifying deficits.***
- ***Service users offered solutions which were also clear and consistent***
- ***In the main, service users gave a coherent rationale as to how the solutions they proposed would address deficits and thus be of benefit to their own recovery, and beyond.***

For clarity and coherence the focus of participants comments were separated into structure, process and information. Sub-themes are bullet pointed below.

Structure

DOCTOR CONTINUITY:

Problem: a large number of participants expressed disappointment at the frequent turnover of their treating doctors, e.g., *Frequent changes of doctor in the public system makes it difficult and causes problems of continuity (49);*

Proposed Solution: People were clear that they wanted the same doctor to treat them over as long a period as possible, e.g., *I would like to see the same psychiatric doctor instead of someone different every time I attend (618); [I would] Like to see same doctor each time (53); I would like to see the same doctor each time I have an outpatient appointment (86).*

Rationale: People believed that good familiarity between the doctor and his patient would allow a more trusting and knowledgeable relationship to develop. One potential spin-off envisaged to an improved relationship would be that better medical judgements would be made e.g. *I would like to have the same psychiatrist doctor seeing me as then they would be able to gauge my health in regression (1070);*

TIME ALLOTTED FOR CONSULTATIONS:

Problem: a number of participants complained that their consultations with their doctors were too infrequent and too short, e.g., *any time I visited the clinic I was never allowed to see the consultant (31); [I want] to be able to see the doctor more often and a better 24 hour service (35); I don't get much time with the psychiatrist on appointments (88).*

Proposed Solution: Longer and more frequent visits: e.g., *When seeing the psychiatrists would rather he or she would have more time to talk to you (687)*

Rationale: Service users realised that time with professionals should be linked with need, e.g., *[There should be] more time for people that need it (87).*

COMMUNICATION BETWEEN PROFESSIONALS:

Problem: Some participants expressed the opinion that there was sometimes poor communication between different professionals, especially professionals from connected, though separate services, e.g., *I attend [centre name], [another centre] and my GP. Seems no communication between them all. E.g. GP does not know what hospitals prescribe for me (1081); Only for my pharmacist doing research for me, my health would be very bad; I feel my team is the GP, the counsellor, but they are not a team (714).*

Proposed Solution: People wanted better communication between those treating them, e.g., *[I would like] communication better between GP and different hospital specialists which one attends (1181).*

Rationale: People believed that poor communication between professionals could have a negative impact on their treatment and recovery, e.g. *being prescribed one drug by one hospital that can't be taken with another (1081).*

CARE PLAN:

Problem: some participants expressed the view that they did not have a care plan, e.g., *Until this moment, I did not know such a thing as a care plan existed (632); But I don't have plan after being in service for last 12 years approx (1284).*

Proposed Solution: A very large majority of participants expressed an interest in having a personalised care plan, e.g., *A care plan is set out as a guide. Yes its' a good idea, but I feel a care plan is central to recovery not the other way around (132).*

Rationale: A coherent care plan seemed to add a degree of confidence and empowerment to service users sense of recovery, e.g., *My recovery is my responsibility (206); Every person is unique and has different needs..... (54); help is essential (13).*

ENVIRONMENT:

A number of participants expressed a desire for the physical surroundings of their services to be improved as they felt it would help the general atmosphere and perhaps aid recovery, e.g., *hospitals and other institutions make them more contemporary (14).*

FOOD:

Many participants complained about the food available at their service (For some service users this was their only complaint!) e.g. *Food was very poor (358); Food! The food in [centre name] was beyond belief, and occasionally inedible. More creativity in kitchen, please (82)*

MONEY:

Many participants expressed the view that their disability allowance did not allow them to partake in services and activities which they may otherwise have done, e.g. private counselling, college, better food.

EMPLOYMENT, TRAINING, AND EDUCATION:

Problem: Many participants expressed a wish to receive educational and training skills which would aid them to achieve paid employment and ensure their recovery was sustainable, e.g., *left out of hospital [name]. No one to see on the outside. At home on my own day after. Very down. Low (28).*

Proposed Solution: Services users desired more opportunities for educational and training activities leading to employment.

Rationale: Many participants expressed a wish to 'move through' services and saw recovery or healing as being inextricably linked and bound up with *paid* employment, educational achievements etc., e.g. *Linking recovery to life, work, education, listening and being heard and respond to current needs as they arise (269); More integration into employment as I feel this is very important for overall health after complete therapy (133); no work , no activities no lift in mood; to develop independence through the services (44).*

Process

COMMUNICATION STYLE:

Problem: Many patients complained that their communications with their doctors, and sometimes nurses, were unidirectional, in that mostly the professional spoke and the service user listened, e.g., *I was not allowed to discuss alcohol problems. Instead I found myself answering yes/no to questions (205); [I would like it if]G.P not fobbing off patient (365); They do nothing except ask the same questions (87).*

Proposed Solution: Patients expressed a preference for 2 way communication, so that professionals would sometimes take the listening role and allow them to express their opinions and experiences, e.g., *I would like if this consultant would listen to me and let me have my say (951); e.g. I would like to have a more practical conversation with my psychiatrist perhaps talk about my grandchildren and husband & family and my interests (367).*

Rationale: Service users believed that for the purpose of more effective treatment it was important that clinicians listened and paid attention to their views. They also believed they had a right to be heard, e.g. *I would like to be listened to more as I know how I feel (601); I would like if this consultant would listen to me and let me have my say with regard to medication and other issues we all have rights (951); It would be nice to be told why my medication is being changed (924)*

INCLUSION:

Problem: Some participants believed that they were not included in aspects of their own recovery such as their care plan and their treatment, e.g., *The supports I have received have not helped me, other people think so but I feel my feelings are being discounted (1076); Care plans are done in favour of the primary care team and not [the] patient (463);... people feel that a care plan may exist that they do not know about;.. but I do feel that one is not sufficiently involved in ones own progress (621); I would like to see clients have more say in mental health matters. Of course clients must obey their doctors treatments and keep appointments, but should be able to complain if medication is not working satisfactorily (629).*

Proposed Solution & Rationale: *[if we are included, services are] empowering suitable service users, like me, along with the local team to work together.. for the betterment of all (879); I find I understand myself more than the doctors (1222); unless you have it you have no idea what its like(1012); Trust in what the patient says (898); I'm not always asked my opinion on the care plan prepared for me and I don't always feel I'll benefit from what is planned (104).*

CHOICE:

Problem: Many service users complained about a lack of treatment options, e.g., *Every person is unique and has different needs, listen to you (54); I did not get support as I dealt with developmental issues and relationship issues. The assumption was that if I complied with directions on medications that all other issues in life would resolve themselves (114); The only thing I was ever offered was medication. My husband (RIP) specifically asked to be referred to a psychotherapist. He was told that there was no one better able to help him than 'a qualified psychiatrist' (89).*

Proposed Solution: Service users expressed a desire for treatment options beyond medication: e.g., *[I would like] to see the psychiatric opinion as an equal option among many choices of treatment (632).*

Rationale: Many service users believed that greater choice in treatment options provided the flexibility required to deal with sometimes complex problems, e.g., *Drugs don't solve the root of the problem (96); I would like to believe that the psychiatric approach is valid in the sense of being potentially successful, otherwise I would like access to alternative treatments (632); Depression is an emotional response to life trauma. People will come out of it naturally in a soft warm environment without medication. These drugs upset the natural rhythm of response suppressing emotions and set up a roller coaster of medication for life (458);It is about getting a balance in everything(1).*

Information

INFORMATION STYLE:

Problem: Many service users expressed a belief that some information provided was difficult to access because language was complex and esoteric, written information was too small in size or, in a small number of cases literacy was a problem, e.g. [Doctors] *need to provide information appropriate to the patient's level of education (48).*

Proposed Solution: [I would like] *more community based information (90).*

Rationale: Those service users who desired an improvement in information believed that such an improvement would give them more understanding and confidence in their treatment, e.g. *I find it difficult to understand why I have to take so many tablets (405)*

CARE PLAN:

Problem: Many participants complained of a lack of or insufficient information on their care plans, e.g., *Didn't know they existed, this is the first I heard of them. I can [t] imagine what they are, sound like a good idea (524);*

Solution: Service users wanted at the very least, information on care plans, e.g., *That the doctor explained in simple terms (1164);*

Rationale: Service users believed that their recovery was enhanced by knowledge and participation in treatment plans, e.g., *If I am to recover fully I need to be explained what my plans are (858)*

MEDICATION:

Problem: A substantial number of service users felt that they were provided with either none or partial information on the medication they were prescribed, e.g., *My medication is supplied in plastic bags with no information (430). G.P rarely explains effects and side effects to medication, you feel you're in the dark, and confused when you start having different feelings as a result of new medication (365); In all my 45 years as a psychiatric patient I have never heard my psychiatrist talk about side effects of tablets before (367).*

Solution: People wanted readily available, full and accessible information at the point of prescription, e.g., *I would like to know more about side effects as I am not sure of the actual results.*

Rationale: People believed that full information gave them more control and confidence in their treatment, e.g. *I think the more aware [you are] of your treatment the easier it will be to get well (804); [it would make all the] difference to me to know my medication, side effect on my other medication and how to deal with it in a sensible way*

FAMILY AND FRIENDS:

Problem: A number of service users expressed regret that their family and friends lacked information on their diagnosis and treatment (Comments referred mostly to medical information).

Proposed Solution: Information to be made available to their family and friends, e.g., *Education to other people to what having mental health difficulties means (explained) (112).*

Rationale: Participants believed that if loved ones were more aware of their condition and treatment they would be in a better position to understand and support their recovery, e.g. *.Other people need to know your illness is real; [I would like] more family or close friends understanding of person's psychiatric illness.*

Group 2 - Service Users offering high praise, gratitude and appreciation of services

Note (a): *An in-depth analysis of this group was outside the remit specified by the research question. Thus quotes providing only a 'sense' of this group are provided.*

1002: *Everything is always done with my best interests at heart*

1031: *from my experience in [name of centre] I could not ask for better understanding*

344: *The fact that the [?] there for me when I am unwell means that a more serious situation can be nipped in the bud.*

382: *My psychiatrist since 2000 has been wonderful and the care I have received from my GP has kept me out of hospital since then*

643: *[Names of two voluntary organisations] are partly funded by HSE, I believe they really help, you are not alone.*

736: *This centre has helped me a lot - you are not criticised here if you make a mistake. They see the person as a whole.*

782: *I am learning to live with my illness and lead a productive and happy life.*

827: *The last 2 consultants I've seen have been wonderful. Also the [name of HSE centre] team can't do enough to help you get back on your feet*

841: *I would not be as mentally well today were it not for the nurses & doctors at [name of day hospital].*

774: *[Names of three voluntary organisations] are invaluable at different stages of recovery*

1121: *[Name of voluntary service] has been the primary reason for my recovery in the last 12 months. It is an excellent programme and more of them are needed*

Group 3: Service Users expressing deep unhappiness with services

Note (b): An in-depth analysis of this group was outside the remit specified by the research question. Thus quotes providing only a 'sense' of this cohort are provided.

394: *My daughter's young life has been destroyed by an appalling service she has received [? ?] the damage to our family.*

1076: *I would like to be treated like a human being....*

47: *No service They created more unnecessary anxiety to the point I completely shut down - psychosis as described by private Dr. Couldn't sleep for months chronic pain increased no help at all. Left in hysterical state allowed to drive home on Friday afternoon with no service available (not even G.P.) over the weekend.*

443: *The so called "supports" you speak of have caused 95% of all the problem's in my life, have in fact destroyed my life, caused me endless misery and driven me to the brink many times.*

520: *[I am] treated like a number*

1089: *... by being with the mental Health make[s] me so much worse through time.*

625: *"Care" is not something I associate with my HSE experience.*

47: *I believe I could have recovered 10 years ago if assessment and access to entitled services were offered*

443: *Abysmal, criminal, systematically destructive of human potential.*

108: *people have died through not being listened to*

Further possible themes

Note (c): This took the form of an analysis of the surface content of the data. However some data (examples below) pointed to the possibility that an analysis of hidden content may have yielded other themes which might have contributed to a fuller representation of participant responses.

1328: The care plan was sorted by my doctor so I just done as asked

567: The nurses and [name of voluntary organisation] have prepared a care plan for me and if I do what I am told I can only get well.

918: When you suffer from a mental illness you can feel inferior and therefore not inclined to assert yourself.

579: Recovery is a lifestyle choice not part of medication or treatment courses.

554: Injection every 2 weeks (entire response to whole questionnaire of one participant)

397 & 43: Everything's fine (entire response to whole questionnaire of one participant)

51: Listen (entire response to whole questionnaire of one participant)

62: Tis a lot better now (entire response to whole questionnaire of one participant)

344: I believe not in recovery per se but in being better or worse. I am succeeding the better I am and am receeding when I stay worse.

124: Perhaps enough for my current needs as side effects on product leaflets and internet searches have proven to act as a disincentive to taking what I need to take

858: If I am to recover fully I need to be explained what my plans are, however, I understand that this is not always beneficial to me, saying that if the GP's are to be involved that they should be educated in that respect.

443: Staff attitudes have actually got worse. I note you haven't included this possibility.

941: Staff attitudes improve as one improves or that is how they maybe proceed. Complying with treatment keeps staff happy.

949: Most of multi-disciplinary team members are themselves institutionalised and have very set ideas and ways of treatment.

28: Please help me [name and address supplied]

96: Do I have to shoot someone before doctor listens to me?

99: My doctor trusts me to regulate my tablets with her help

1313: I was always advised by my psychiatrist as to what was best for me rather than involved in a care plan.

AWARD WINNERS

The winning margins in all three categories were extremely small.

In the best overall service category two services tied on an extremely high score on question 3 (overall happiness with services) and so question 2 (quality of service) was used as a tie break.

The most effective supports award was judged on the responses to question 5 (effectiveness of supports received) where the margin of victory was only 1%.

The most improved culture of care award was based on question 10 (positive change in staff attitudes), and was again very tight with four services in close contention, with Carlow winning by a very short head.

Standards were high amongst all the awards contenders with 19 services jostling for position in all three awards.

Overall, rural services seemed to fare better than densely populated urban ones. We may attempt to address this next year and give an award for the best urban service.

The enormous response to this year's survey will ensure that it remains a central part of our future actions, and the qualitative views expressed will help frame our next phase of strategic planning and contribute to our ongoing philosophy of demonstrating the primacy of the service user experience through constant engagement and promotion of their views.

The “Best Overall Service” award went to

The Clifden Mental Health Service

The “Most Effective Supports” award went to

The Mallow Mental Health Service

The “Most Improved Culture of Care” award went to

The Carlow Mental Health Service

Appendix 1

NATIONAL SERVICE USERS EXECUTIVE QUESTIONNAIRE - 2011

Name (optional) _____ Service User Family Member /Friend HSE Service _____

Q. 1 Within the HSE service that you used in the last 12 months, what supports did you avail of?

Psychotherapy / counselling	Yes/No	Vocational training/ employment support	Yes/No
Inpatient psychiatric hospital	Yes/No	Psychiatric outpatient clinic	Yes/No
Day centre	Yes/No	Occupational therapy	Yes/No
Club	Yes/No	Peer to peer support group	Yes/No
Day hospital	Yes/No	Key worker	Yes/No
Other (please specify):			

Q.2 How would you rate the quality of service you have received overall? (Please tick)

Excellent Good Fair Poor

Q. 3 Are you happy overall with the services provided to you?

Yes No Don't Know

Q. 4 What would you most like to see improve?

Q. 5 Have the supports you received helped you deal more effectively with your problems?

Very much so Partly Not really Not at all

Q. 6 Do you feel you have enough information on medication?

Yes No Don't Know

Q.7 Where do you get most of your information on medication, side effects, etc.?

Q.8 I have been directly involved in the preparation of my care plan

Yes Not Always No Don't know what my care plan is

Q. 9 I feel that my recovery is central to my care and treatment plans.

Yes No Don't Know

Q.10 I have noticed a change for the better in local staff attitudes

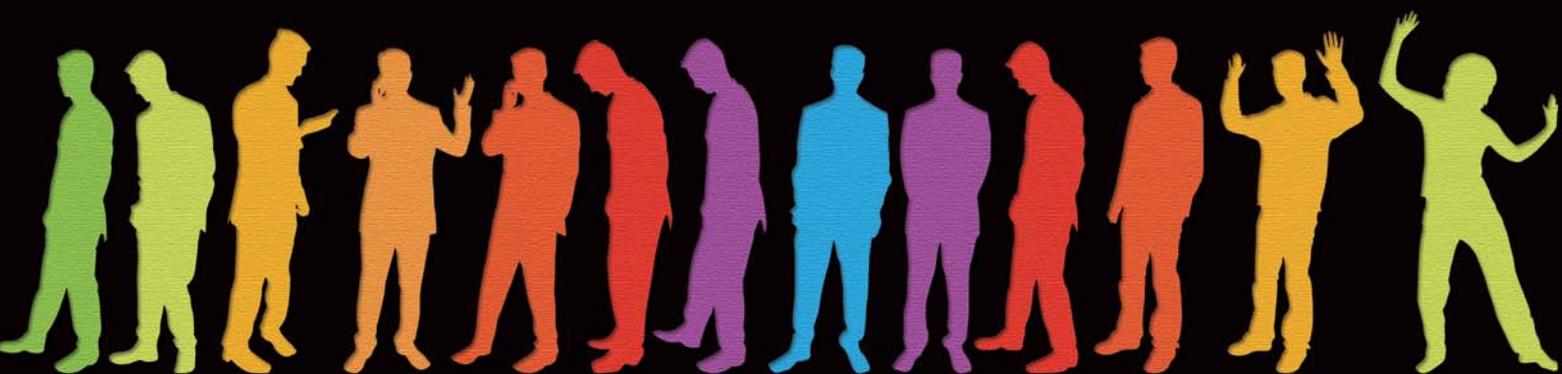
Yes No Don't Know

Q.11 What would you say is important for your own recovery? (Please tick as appropriate)

- | | |
|---|--|
| <input type="checkbox"/> Practical help with stressful home situations | <input type="checkbox"/> More information on what is available |
| <input type="checkbox"/> Less medication | <input type="checkbox"/> Choices of treatment (not just choices of medication) |
| <input type="checkbox"/> More social activities | <input type="checkbox"/> Involvement of family and friends |
| <input type="checkbox"/> Being listened to | <input type="checkbox"/> Better employment prospects |
| <input type="checkbox"/> Being asked what you want | <input type="checkbox"/> More counselling services |
| <input type="checkbox"/> Being included in decisions | <input type="checkbox"/> Less stigma and discrimination |
| <input type="checkbox"/> Continuity of care (being seen by the same person) | <input type="checkbox"/> Having your cultural/ethnic needs respected |
| <input type="checkbox"/> Being treated with dignity & respect | <input type="checkbox"/> Having longer consultations |
| | <input type="checkbox"/> Other (Please specify) |

Thanks for your time and expertise. Please return to:

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2011

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