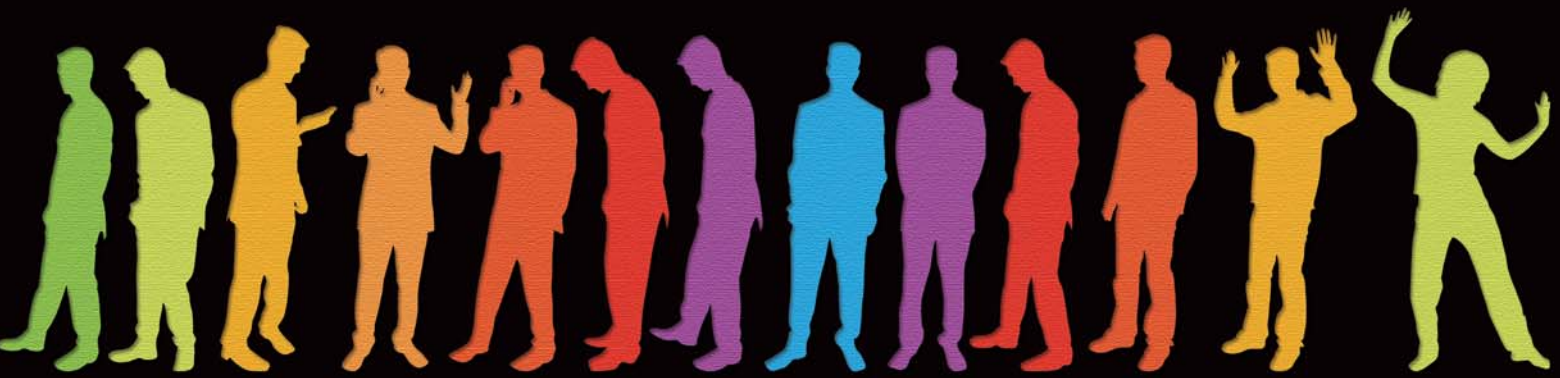


Second Opinions



2010

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”, our second 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 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 progress, particularly on the principles of Vision for Change. The survey questions included those deliberately designed to concentrate on cultural change, which in this economic climate, is cost neutral, but which is intrinsic to the provision of quality mental health services.

From the outset we have always believed that the way forward is in encouragement, not criticism, which we feel is a more positive agenda. Our survey has made it possible to identify services as examples of good practice, in the opinion of those who use them, and has been the basis for the selection of the recipients of our first NSUE awards.

The results also give us valuable feedback on the views of our members and their priorities for change.

We are now also pleased to announce that we have completed our election process with 3 service users and 1 family member elected to the executive from each of the 4 HSE areas. We move into 2011 with a clear, democratic mandate to represent the views of service users and their families/friends. Despite the current economic state of the country, we believe that we can still make a real difference to the lives of people who struggle with mental ill health and those who support them by bringing a more creative and inclusive approach to the way mental health services are delivered.

Finally I would like to sincerely thank all of those who filled out our questionnaires, all those who distributed them, and, most especially, John Redican, our National Executive Officer, who was largely responsible for designing the questionnaire, collating the information and writing and presenting this report.



Jennifer Kelly

Chairman

National Service Users Executive

The Second

Second Opinions

Report

Summary Report of the NSUE
Survey of Members 2010 on the Vision for Change

2010

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Background

'A Vision for Change' recommends that:

'A National Service User Executive should be established to inform the National Mental Health Service Directorate and the Mental Health Commission on the issues relating to user involvement and participation in planning, delivering, evaluating and monitoring services including models of best practice; and to develop and implement best practice guidelines between the user and provider interface including capacity development issues'.

Mission Statement

The Mission of NSUE is to protect, promote and represent the interests of all service users and their families while ensuring that every individual can feel confident that their own views, wishes and needs will be heard and will help shape service delivery and the strategic direction of mental health services over the coming years.

The fundamental underlying principle is that service users and their families are central to mental health service provision. All agencies and organisations that provide mental health services should therefore work in partnership with service users and their family members/friends. It is essential for all stakeholders to acknowledge the value of the service user perspective. Service users have a unique insight and expertise to contribute to the development of quality mental health services and of systems and strategies which promote positive mental well-being. This comes from their familiarity with psychological/ emotional distress, their understanding of the principles underpinning recovery and their knowledge and experience as recipients of services.

The Process

The National Service Users Executive has been established since 2008 and now has high levels of engagement and participation with the HSE and the Mental Health Commission. What had been lacking we felt, was our ability to evaluate and monitor services and to discover and encourage models of best practice in line with both our mandate and our mission statement. We therefore decided that the simplest way of achieving some momentum in these areas would be to ask our members to participate in a short survey, in order to ascertain their views on the services that they were using and to establish a baseline for future review and appraisal.

We chose questions that we felt were appropriate both in regard to the progress of Vision for Change and also essential to establish a recovery ethos in service delivery. We also asked people to nominate the factors which they felt helped with their own recovery journey.

Regional and local meetings were held in order to inform people of the survey and in addition, the survey document (Appendix 1) was posted to each individual member with a pre-paid business reply envelope.

The response was, once again, hugely encouraging. People welcomed being given the opportunity to comment. We received 1054 completed surveys, a 97% increase on the inaugural survey of 2009. The completed returns contained both quantitative and qualitative data. It should be remembered that this was never intended as a piece of deep-seated research, but a very simple instrument for feedback from service users, their families and friends. The depth and richness of the information we received, however, will enable us to pinpoint areas where best practice is developing and through a programme of continual engagement, identify the critical factors and actions that will make these skills and practices transferable.

Results and Comparisons

The results capture the genuine subjective experiences of respondents. As with all such surveys, there was a fairly wide variation in responses across the country. The overall national results are encouraging, but even more heartening are the results from some local service areas, where satisfaction levels with the services are extremely high. Thanks to the increased response to our annual survey, we are pleased to announce that we will be holding an awards ceremony based the 2010 survey. The categories in which awards will be given are as follows:

Best community mental health team

Best day centre/day hospital

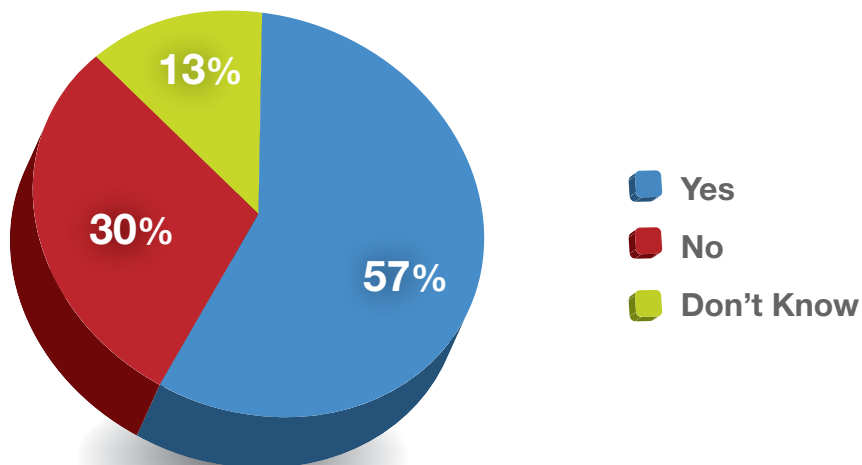
Most improved service

Comparative National Responses 2009/2010

Our 2009 survey showed that 52% of respondents were happy overall with the services provided. Figure 1 below shows the 2010 response.

Figure 1 - Responses to the question:

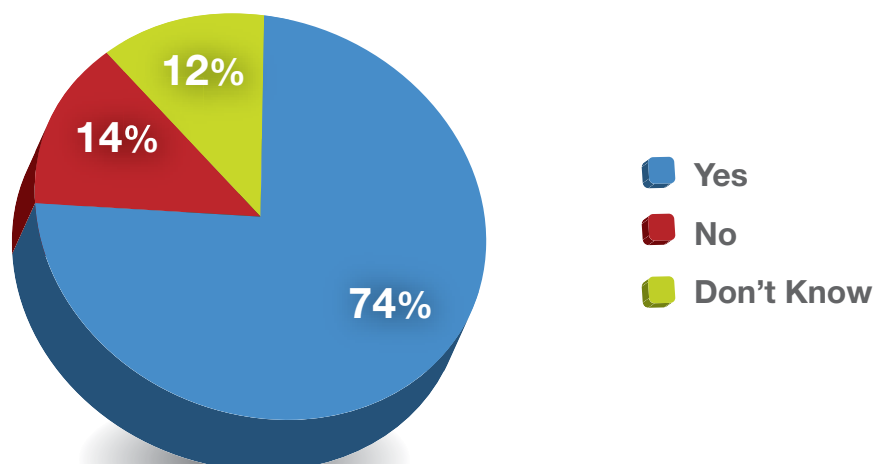
Are you happy overall with the services provided?



In the context of the current economic situation, and the reduced staffing levels resulting from the recruitment moratorium, a 5% rise in satisfaction with services nationally is a remarkable result. Even more remarkable, perhaps, were the responses to the question - "Are you hopeful that improvements in your local service will happen?", which in 2009 elicited an extremely positive response, with 72% of those surveyed feeling that improvements would occur, showed another upbeat movement as demonstrated in figure 2 below.

Figure 2 - Responses to the question:

Are you hopeful that improvements in your local service will happen?



Whilst a 2% rise in confidence may not seem too significant, this is an increase on an already high value, and together with figure 1, not only demonstrates the value of this repeat survey, but, as many individual respondents noted, is a tribute to the commitment and dedication of all the staff working in both the statutory and voluntary mental health sector today. The steadfastness of those using the services also emerged:

"I'm getting great supports from living in the Simon community and a good psychiatric team".

"In the day hospital, the service is good. The nurses are lovely and the yoga teacher is excellent. The staff are overworked, the team is excellent".

"Doctors and nurses are doing their best with poor facilities".

"Yes, I have faith in this, you have to look forward".

An awareness of the future challenge also came out -

"With the recession, health services will be greatly curtailed. I would wish to see NSUE put a lot more pressure on government to deliver".

"I am hopeful that the services will improve, but I feel that a lot of these improvements will come through service users finally using their voices".

A 6% increase also occurred in the responses of those who affirmed that they felt treated with dignity and respect at all times. This is a very welcome step forward in what is a basic right for all citizens in all walks of life.

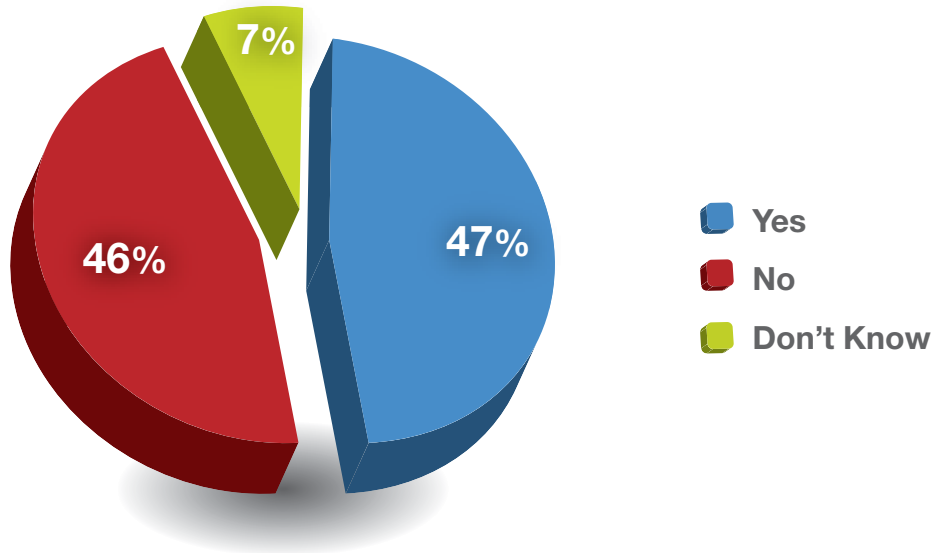
Information Deficits

High numbers of individuals who did not know about either the National Policy, A Vision for Change (43%) nor about the role and function of the Mental Health Commission (55%) gave rise to some concerns. As a large portion of our members do not have regular access to broadband or other internet services, the current move towards providing information mainly on the websites of various bodies (including ourselves), needs to be rethought. We plan to develop some information leaflets in partnership with other stakeholders which can then be delivered through the mail, or via leaflet displays in health services or available for distribution at symposiums and conferences.

The lack of information in one particular area caused more severe concerns, illustrated by figure 3 below:

Figure 3 - Responses to the question:

Do you feel that you have enough information on medication?



With less than half of all respondents feeling confident that they had sufficient information on the medication that had been prescribed for them, there is a clear risk factor here that needs to be addressed. Some respondents who had sufficient information commented on where they sourced this, for example:

"I get my information mostly from the internet", "I look it up myself", "I tend to look meds information up online as doctors don't always have the time".

"Yes, the chemists I go to are very helpful", "Thanks to my pharmacy" and "I read up on my meds at the local library".

"The main source of information for me on medication is the leaflet enclosed with tablets", "Only what gets prescribed and the leaflet that comes with it", "Yes, people can read the leaflets provided by the drug companies".

Others felt that there was a need for change in some practices:

"I believe more attention must be exercised on informing patients", "There should be a good discussion between doctor and patient before medication is prescribed", "As someone who takes medication I feel that I am the one who has to find the info".

While others were clearly all at sea:

"I don't know what my medication is even for and I would like to know, but in ordinary everyday language I understand", "Find it hard to understand what one of my medications actually does", "I know little about it", "Just given a tablet and told it will make you better".

Our own view is that information on medication should be given at source of prescription and in clear terms, using the simplest possible language. The leaflets provided by pharmaceutical companies can be problematic in terms of the language used and the size of the lettering, which can sometimes be difficult to read without magnification. We believe that this would mitigate any risks, improve the patient experience, foster more equal relationships and cost nothing in financial outlay.

As figure 5 demonstrates later, more information on what is available is seen by many as especially important to their recovery, so that any information deficits that can be identified either locally or nationally, should be immediately addressed.

Priorities - Recovery and the recovery agenda

The recovery paradigm

People often struggle to understand exactly what is meant by recovery. It is a highly individualised concept i.e. the definition depends largely upon the individual's own perceptions and ideas. Recovery is a person-centred approach which builds upon an individual's sense of control and responsibility in the process of getting well.

It requires that the services provide care and treatment that are specific to each individual, instead of attempting to fit an individual into pre-existing services. It requires that information and choice are freely available to each person using the mental health services, and thus "represents a movement away from pathology, illness and systems to health, strengths and wellness" (*Making recovery a reality: Sainsbury centre for mental health 2008*).

The recovery ethos also changes the relationship between the doctor and patient, "*Clinicians on tap, not on top*" (*Perkins 2006*).

Recovery is unique to each individual, who, in a real sense, decides upon and maps out their own recovery journey and the route that they wish to take.

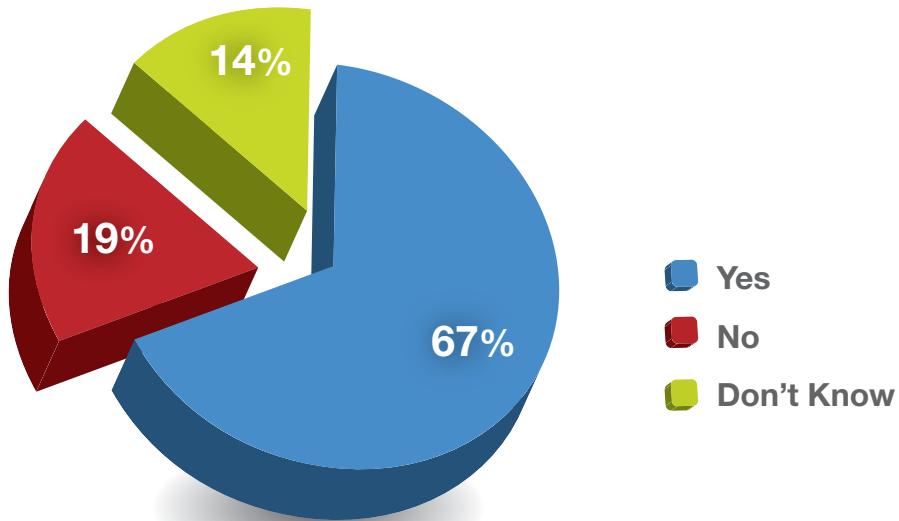
Greater social inclusion is a key feature of recovery and the inclusion of family and friends is important both in its own right and as a step towards greater integration within the community, with a resultant impact on stigma.

RECOVERY

We received a hugely encouraging response to the question, “Do you feel that recovery is promoted by your service?” as can be seen in figure 4 below.

Figure 4 - Responses to the question:

Do you feel that recovery is promoted by your service?



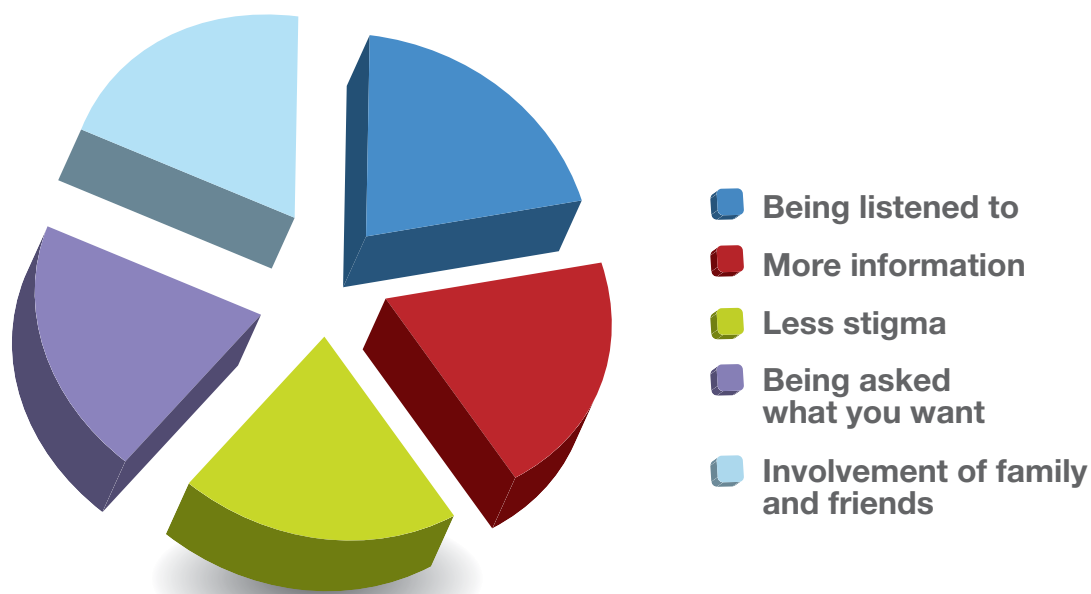
An impressive 67% of respondents affirmed their services commitment to the recovery ethos, securely underpinning the workings of a modern mental health system. Priorities for each individual may differ, but there were common themes as can be seen in the next graphic display.

The Recovery Agenda

All individuals were asked, “ What would you say is important for your own recovery?”
The top five answers are represented in order of priority in Figure 5 below:

Figure 5 - Responses to the question:

What is important to your own recovery?



Amongst the narrative which some people chose to explain their response, were the following: *“A more holistic approach to wellbeing”, “Focus on healing”* and *“More promotion of support groups by the professionals in HSE”*. Some respondents named the voluntary organisations which they felt had been useful in this regard e.g. *“My involvement with the Shine resource centre is a great help to my recovery”* and *“I have found Grow very helpful”*.

The number one priority, *“being listened to”* was both expanded upon and also incorporated some of the other priorities: *“Family and friends to understand and not underestimate my awareness. To be truthful in their dealings with me and to talk things out”, “I would like people to listen when you are talking to them and understand what you are going through at difficult times”, “More explaining/education to spouse and family of medication, how it works, risks and time to help diagnosis and what the patient needs to do for himself, along with support of family friends and health personnel”*.

Future Action

Year on year we intend to use the results of our annual survey to set an agenda for positive change in the coming months, as we see this as an opportunity to progress those parts of Vision for Change that are most important to our membership and which can be achieved despite the current economic situation. The recovery agenda should be always to the fore, and it is important to remember that the changes required in order to produce an underlying recovery ethos are largely cost-neutral. Clear commitment and dedication to the task ahead will be needed by all involved. The explanations and anecdotes that many individuals attached to the survey document allows us to identify specific locations, policies and personnel where best practice exists as well as those to whom it needs to be transmitted.

We are hopeful that the good practices unearthed by our survey will lead to their adoption elsewhere, and will engage with those who have the necessary influence to ensure that this occurs.

It is probable that the continuance of the moratorium on recruitment will continue to hinder progress, although improvements have been shown to occur despite this negative influence. It may also hold future benefits, as newly qualified staff who relocate to other jurisdictions may in time return, bringing with them fresh ideas and initiatives.

We have already engaged with the assistant national care group manager for mental health and have been assured the support of his office as we work together to use these results to promote a National agenda for positive change.

This survey will be repeated next year, and annually in upcoming years. The awards are an important tool for recognition of the undoubted hard work and positive commitment of high-performing services. They will be decided by the best judges of all, those who are engaging with these services in their everyday existence. We can find no international evidence of any similar initiatives in mental health, and therefore find the prospect exciting.

I would like to take this opportunity to thank all of those members of NSUE who responded to this survey. Without your tremendous input, none of this would have been possible. The enthusiasm was palpable and the levels of erudition mean that the survey exceeded its objectives.



John Redican

National Executive Officer

The Awards

As mentioned earlier in this document, thanks to the heartening results from many local services, we are pleased to announce that we will be holding an awards ceremony based on the 2010 survey. The award categories and award winning services for 2010 are as follows:

Best Community Mental Health Team:

Loughrea/Athenry Community Mental Health Service

Best Day Hospital/Day Centre:

Tara Suite Mental Health Day Centre, Dunshaughlin

Most Improved Service:

West Cork Mental Health Services

The awards will be presented at the official launch of this document on 24th January 2011 in Dublin Castle. The profiles of the award winning services can be seen in figures 6, 7 & 8 below. The first two categories were decided by the responses to question 10 - "Are you happy overall with the services provided?" where local services were identified, and the third category based on the responses to question 3 - "Do you think your local services have improved in the last three years?"

Figure 6 - Responses to the question:

Are you happy overall with the services provided?

Best local response - community mental health team

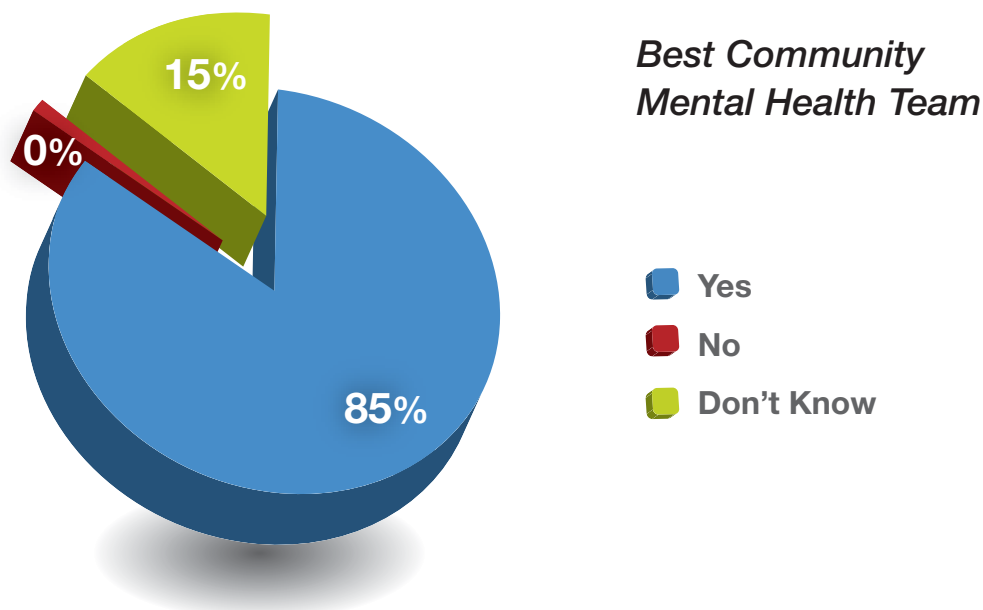
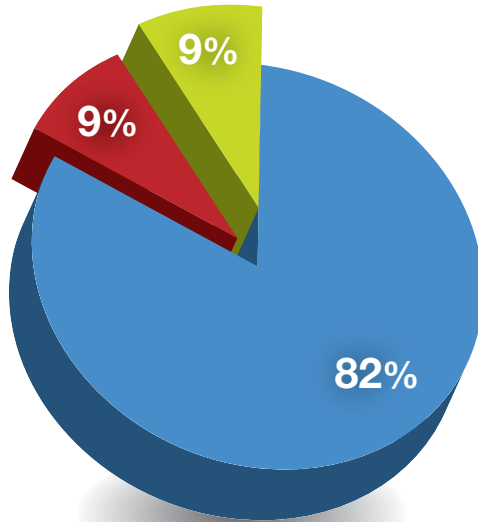


Figure 7 - Responses to the question:

Are you happy overall with the services provided?

Best local response - Day centre/day hospital



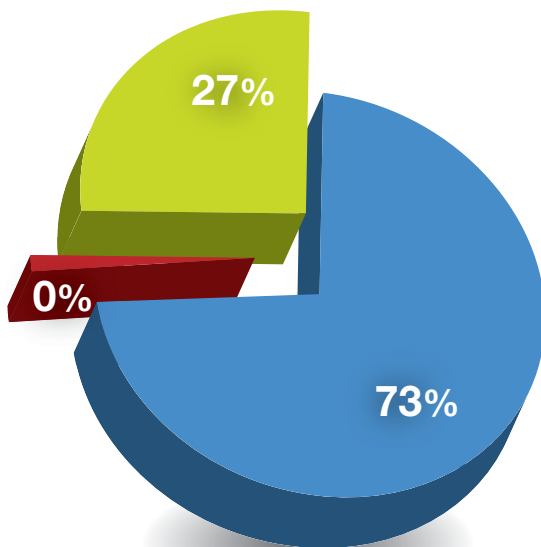
*Best Local Response
Day centre/day hospital*

- Yes
- No
- Don't Know

Figure 8 - Responses to the question:

Do you think your local services have improved in the last three years?

Best local response - Most Improved Service



*Best Local Response
Most Improved Service*

- Yes
- No
- Don't Know

Appendix 1

NATIONAL SERVICE USERS EXECUTIVE QUESTIONNAIRE - October 2010

Name (optional) _____ HSE Region _____

If you would like to say more about your answers, please write below

Q.1 Do you know about the mental health policy, A Vision for Change?

- Yes No Don't Know

Q.2 Are you aware of function of The Commission?

- Yes No Don't Know

Q.3 Do you think your local services have improved in the last 3 years?

- Yes No Don't Know

Q.4 Do you think local staff attitudes have changed for the better?

- Yes No Don't Know

Q.5 Do you feel you have enough information on medication?

- Yes No Don't Know

Q.6 Are you asked to agree when discussing care and treatment options?

- Yes No Don't Know

Q.7 Do you feel treated with dignity and respect at all times?

- Yes No Don't Know

Q.8 Are you hopeful that improvements in your local service will happen?

- Yes No Don't Know

Q.9 Are good supports available in your locality (for example, home-based treatment, key worker system, self-help and voluntary support groups)?

- Yes No Don't Know

Q.10 Are you happy overall with the services provided?

- Yes No Don't Know

Q.11 Do you feel that recovery is promoted by your service?

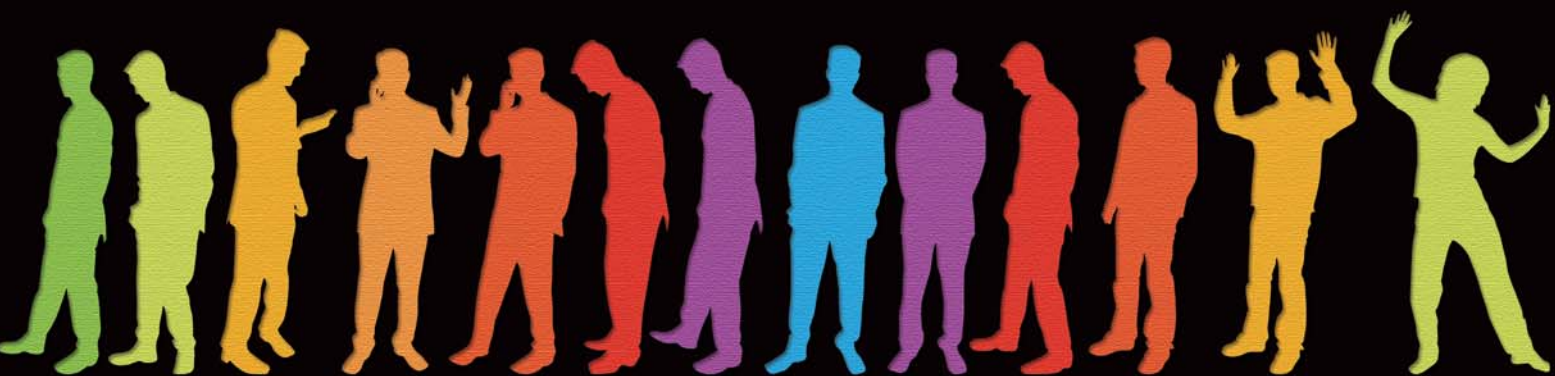
- Yes No

Q.12 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"/> Choices of treatment (not just choices of medication) |
| <input type="checkbox"/> Better staff attitudes | <input type="checkbox"/> Involvement of family and friends |
| <input type="checkbox"/> Less medication | <input type="checkbox"/> Secure housing and accommodation |
| <input type="checkbox"/> More social activities | <input type="checkbox"/> Better employment prospects |
| <input type="checkbox"/> Being listened to | <input type="checkbox"/> More counseling services |
| <input type="checkbox"/> Being asked what you want | <input type="checkbox"/> Less stigma and discrimination |
| <input type="checkbox"/> Being included in decisions | <input type="checkbox"/> More information on what is available |
| <input type="checkbox"/> Continuity of care (being seen by the same person) | <input type="checkbox"/> Other (Please specify) |

Thanks for your time and expertise. Please return to:

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2010

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