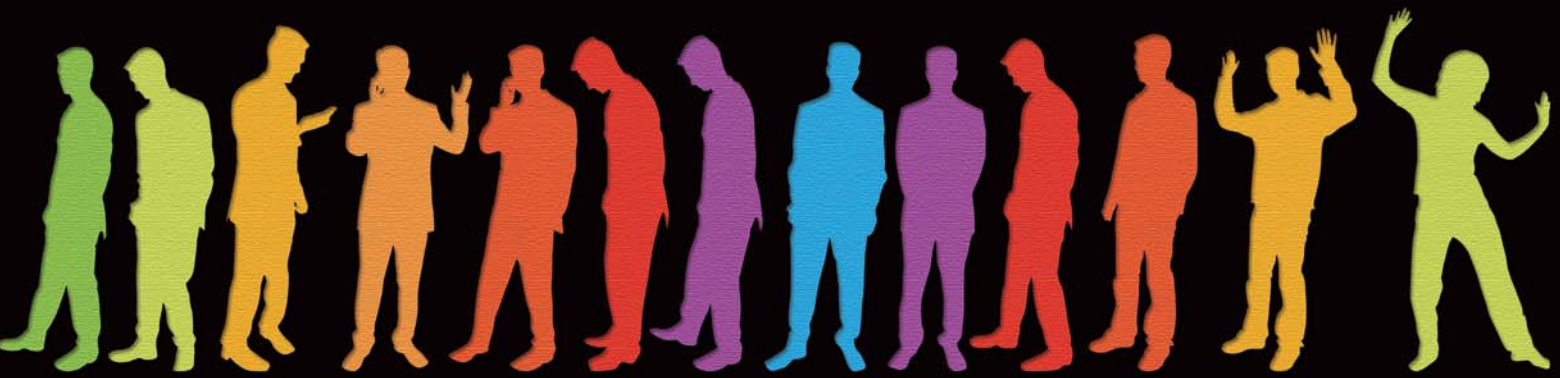


# Second Opinions



2009

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

Have your voice heard... for a change



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# Second Opinions

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

2009

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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 know and to validate the service user perspective. Service users have a unique insight and expertise to contribute to the development of quality mental health services and also to the development of measures which promote positive mental well-being. This comes from their personal understanding of psychological/ emotional distress, 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 already 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.

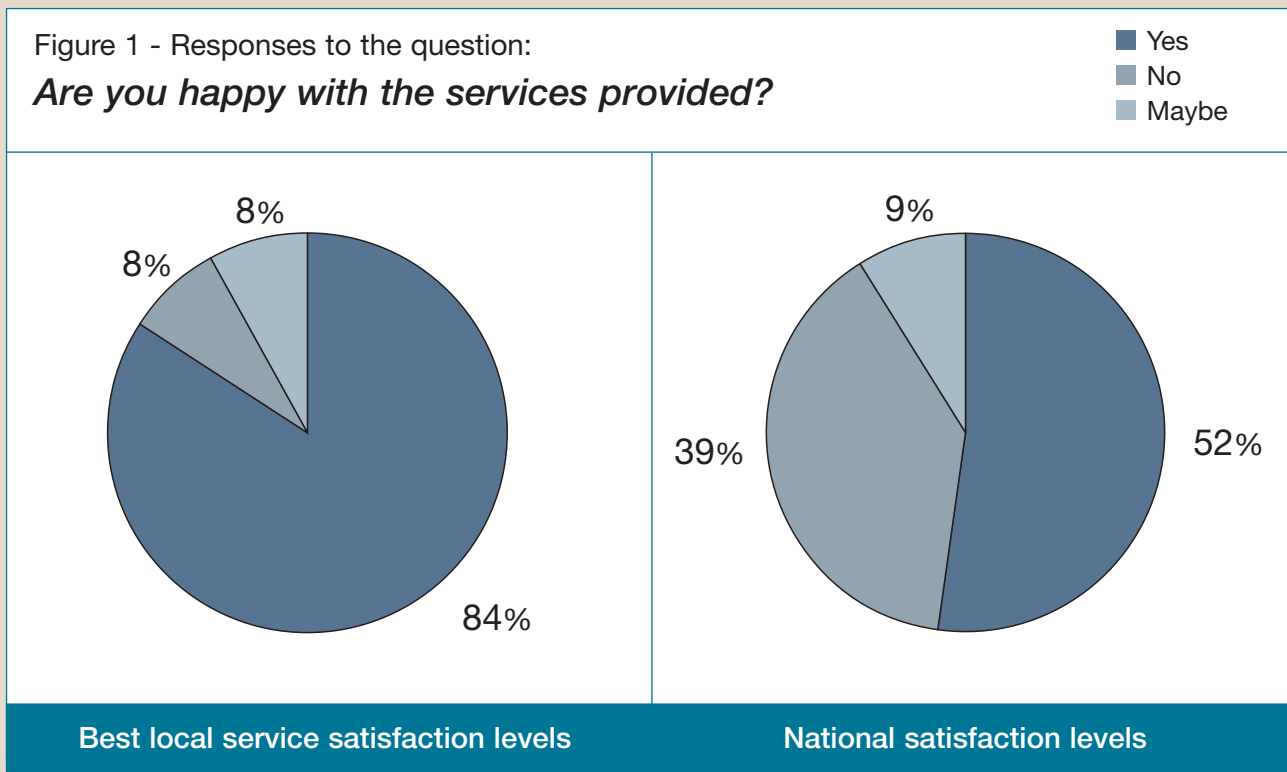
We chose questions that we felt were appropriate both in regard to the progress of vision for change and also essential to establish a recovery ethos in service delivery. We also asked people to nominate their priorities for change.

Regional and local meetings were held in order to inform people of our intentions, and at which some people partook 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 hugely encouraging. People welcomed being given the opportunity to comment. We received 536 completed surveys, containing both quantitative and qualitative data. It should be remembered that this is not 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

The results are authentic because they 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 result is encouraging, but even more heartening is the results from some local service areas, where satisfaction levels with the services are extremely high. Figure 1 below illustrates this.



As can be clearly seen, some local services are really meeting the needs of the individuals who use those services. This means, of course, that some services also are performing at levels below the national average, but these results can only be positive news for the HSE mental health services, as a majority of respondents were happy with the services being provided, in contrast to the position that is often reported by the media. Moreover, success in one part of the country should be possible to replicate elsewhere. Some services had unacceptably low satisfaction results, but we believe that if we can identify the factors that led to positive results elsewhere, then it should be possible to create an atmosphere of constant improvement.

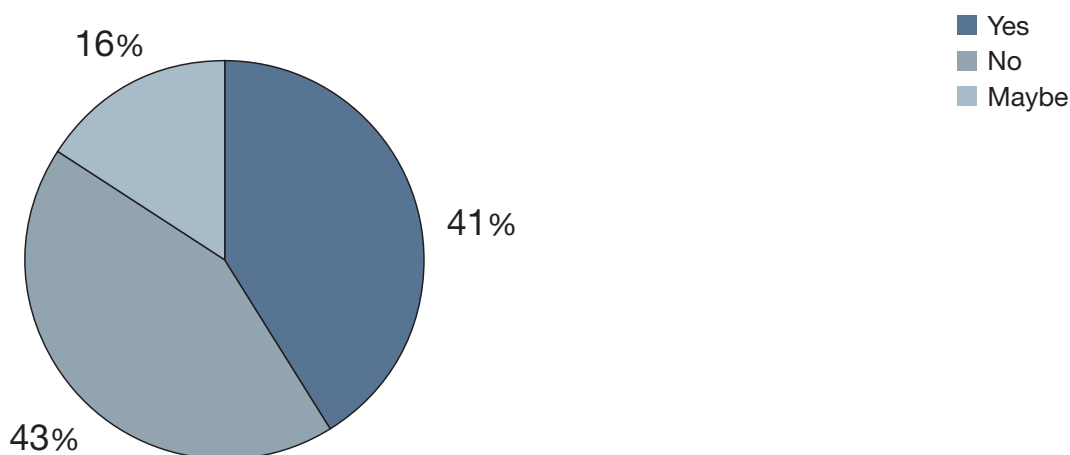
Some of the comments were qualified: *“Excellent service, but still room for improvement”*; *“yes, but I would like to see more patient participation”*; other contributors gave a ringing endorsement, *“Every aspect of my care is spot on for me”*; *“I have been treated very well here”*.

Naturally, there were concerns about possible reductions in service levels with the impending budget in mind, and other respondents were not happy with the service at all, or with particular aspects or specific policies in operation at a local level. We intend to engage with the services identified in order to try and resolve some of these issues.

Another question provoked an encouraging number of positive responses, as seen in figure 2. Although not a majority response, it clearly shows that a significant level of improvement has been recognised. The task ahead includes both maintaining this improvement and encouraging its spread.

Figure 2 - Responses to the question:

***Do you think services locally have improved in the last two years?***



National HSE Response

Once again, some local services had higher positive responses, and some lower. Significantly, many respondents identified who or what had influenced the improvements: *“Led by clinical director and director of nursing”*; *“Yes, they have improved a lot, staff are much better”*; *“My doctors are brilliant”*; *“I have a brilliant nurse”*. Not all respondents were so complimentary, and staff of all disciplines also received some adverse comment, which may need to be addressed through targeted proposals and inventive engagement at a local level, or perhaps via the new expanded catchment areas.

# Information Deficits

High numbers of individuals who did not know about either the Vision for Change (Q.1 48%) or community-based services (Q.9, also 48%) gave rise to some concerns. We feel that better information is vital if people are to realise exactly what they can expect from their mental health services. NSUE has a role to play in providing this information, much of which is available on our website, and indeed on the websites of the HSE and the Mental Health Commission. A large majority of our members, though, do not have access to the internet, and some local initiatives will be necessary. For those who were in receipt of community-based care, the key worker system was continually given praiseworthy mention. It seems clear that this is one area of practice that should be encouraged.

## Self-Advocacy Issues?

Two of the questions (Q.5 & 6) were clearly linked. The responses to these and the response to Q.7 suggested that there is a need for individuals to be prepared to challenge some of the current practice and behaviour.

Figures 3 and 4 below address the first issue: Are people listened to and are their views and wishes given priority afterwards?

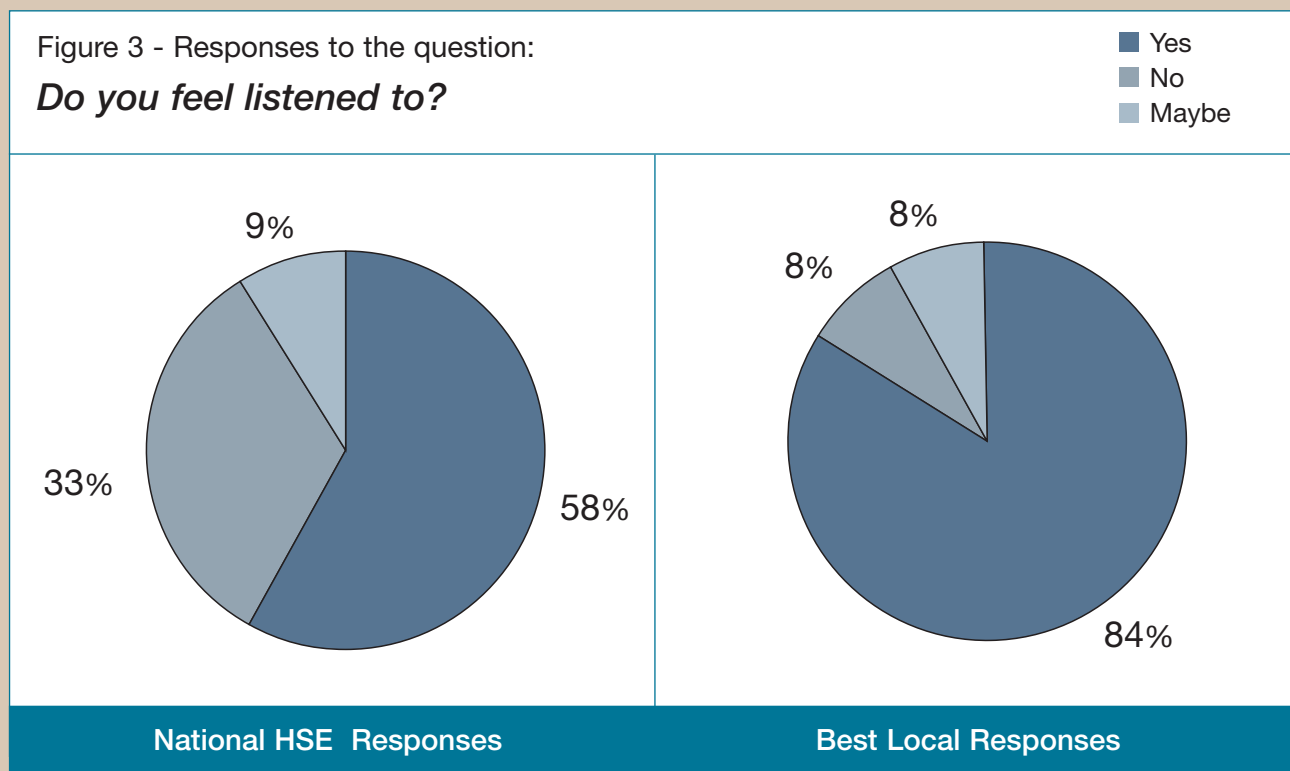
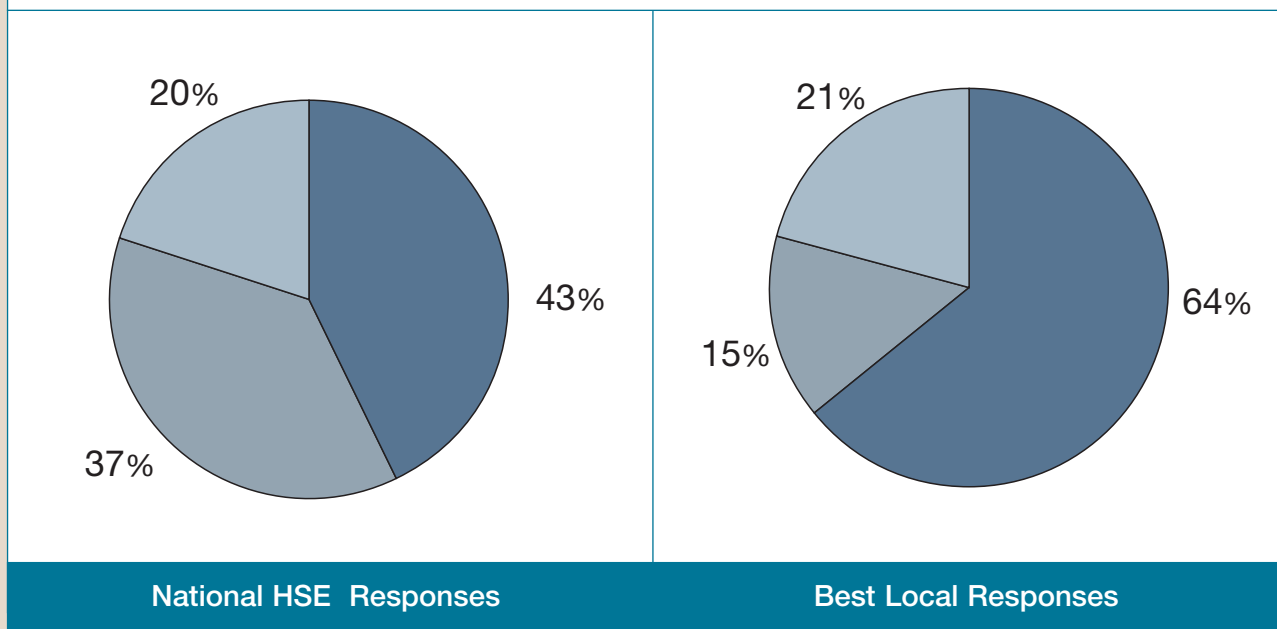


Figure 4 - Responses to the question:

***Are your views and wishes given priority?***

■ Yes  
■ No  
■ Maybe



In both cases, the level of priority given to people's views and wishes is significantly less than the apparent levels of attention. Passively receiving services is not generally a good indicator for recovery.

Several individuals recognized this in their answers, particularly to question 6: *"I have to be a strong self-advocate"*; *"When I ask that my medication be reviewed, it is done"*; *"Sometimes I just feel humoured"*; *"Not always, treatment and medication changes are often decided at team meetings and carried out regardless"*; *"course of action is often manipulated"*

Younger respondents felt that their own views and wishes were not given the same attention as those of older people. As one young person noted, *"The doctors and nurses seem to listen more to people of their own age and background"*

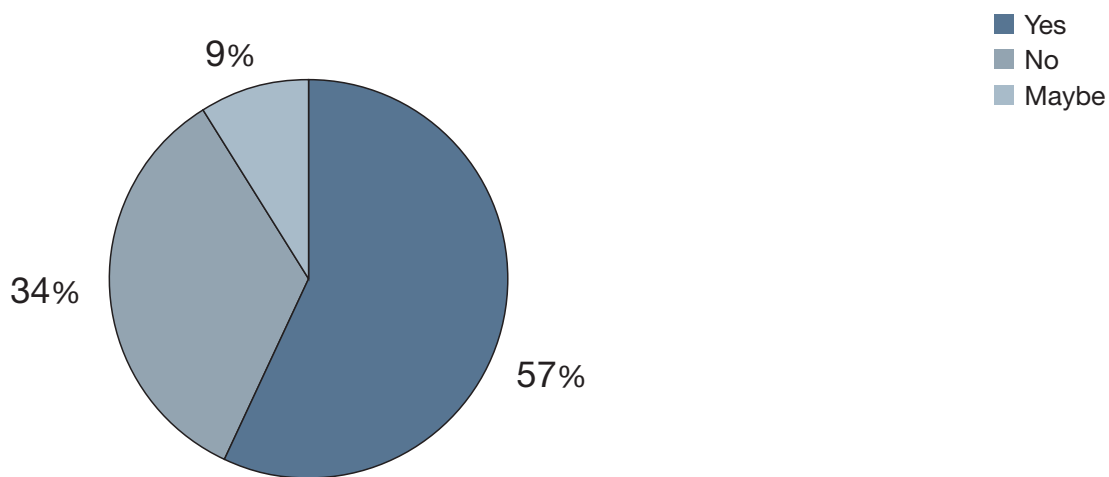
There seems a clear need for people to be more actively involved in decisions made about them, and either self-advocacy, or asking someone trusted to come along as a chosen advocate may lead to greater satisfaction levels. The "Quality framework for mental health services" produced by the mental health commission, may also be of assistance here.

# Self-Advocacy Issues?

Rather disappointingly, question 7 showed a further area where self advocacy or support of an advocate of choice may be necessary.

Figure 5 - Responses to the question:

***Do you feel treated with dignity and respect at all times?***



National HSE Response

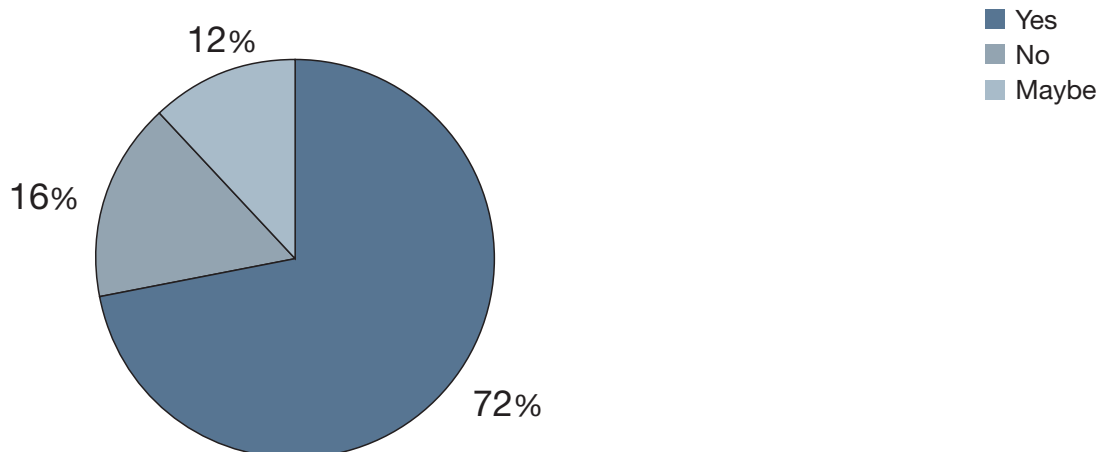
Whilst acknowledging that there is a positive response from a majority of respondents, this is far too low for such a basic human right, and given the customary trends of some services achieving high satisfaction levels and others very low, it is clear that there are pockets of highly unacceptable behaviour.

Advocacy and strong self-advocacy are part of the possible solution, but NSUE also intends to address this matter with the relevant professional bodies. Some respondents reported that there was a lack of basic common courtesy, which ought to be a prerequisite for any individual who is asked to deliver services of any kind, at any time, anywhere.

# Hope for the future

Figure 6 - Responses to the question:

***Are you hopeful that improvements will happen?***



National HSE Response

This was the most refreshing result in the whole survey. Despite the current economic chaos, which was quoted by many as a reason for why they felt improvements might not occur, there was an overwhelming vote of confidence that things would improve.

Many respondents attributed to this to the establishment of NSUE: *"More power to your elbow"* being typical of the positive comments; others reported in more general terms about the spread of the service user movement in general, *"The service-user movement is gaining pace"* The HSE came in for some favourable comment also. Most striking, perhaps, and a measure of the increasing sophistication of those engaging with mental health services, was the confidence expressed in the current Minister of State for mental health and disability. One comment that stands out here was: *"Moloney will best the vested interests"*.

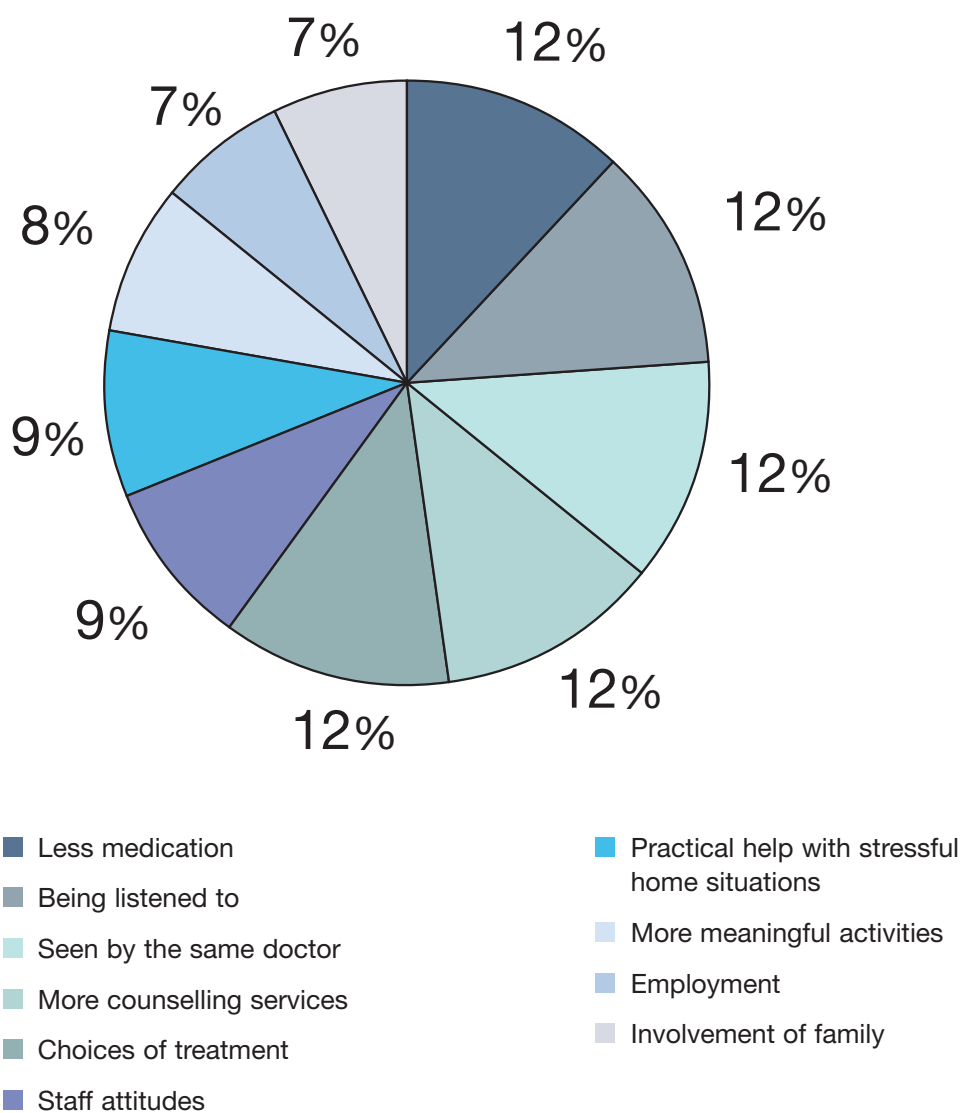
Perhaps there are some votes in mental health, after all.


# Priorities for Change

People were asked to give their three main priorities for change. Figure 7 shows the top ten priorities in descending order.

Figure 7

## *Priorities for Change*





In the current economic turmoil, this wish list can be seen as very encouraging, as at least half of them, arguably, can be said to require no extra financial resources. One of the main five priorities, less medication, could produce some savings if addressed in a collaborative framework of informed consent, which empowers the individual as a participant in their own treatment.

There are no external resources required to make people feel that they are listened to, and while the other main priorities may seem problematic, there may be scope for some innovative thinking or novel arrangements in order to make progress. All the priorities listed will form the basis for our engagement with the relevant stakeholders into the foreseeable future.

# Future Action

We intend to use the results of this survey to set an agenda for positive commitment 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.

It ought to be noted that “best local response” charts are not all from the same service. There are several current centres of excellence, and it is to be hoped that their practice will become highly infectious; a best-practice pandemic would be warmly welcomed.

The narrative that many individuals attached to the survey document allows us to identify specific locations, policies and personnel where best practice exists and also those to where and to whom it needs to be transmitted.

It is clear that the continuance of the moratorium on recruitment will continue to hinder progress, particularly when linked to comment such as: *“The younger doctors and nurses are better “*, *“I’m sure he is doing his best, but he is a bit old-fashioned”*, which suggests that one avenue of possible improvement is an incoming stream of younger staff. Whatever the reality turns out to be in terms of new recruitment, we should continue to push for change within the current workforce.

We have already engaged with the assistant national care group manager for mental health and will have 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. We intend to float the idea of an awards ceremony for mental health services, so that the undoubted hard work and positive commitment of high-performing services can be formally recognised 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, 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

# Appendix 1

NATIONAL SERVICE USERS EXECUTIVE QUESTIONNAIRE - October 2009

Name (optional) \_\_\_\_\_ HSE Region \_\_\_\_\_

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

**Q.1 Do you know about the Vision for Change?**

- Yes                       No                       Don't Know

**Q.2 Have you noticed any changes in your mental health service?**

- Yes                       No                       Don't Know

**Q.3 Do you think services locally have improved in the last 2 years?**

- Yes                       No                       Don't Know

**Q.4 Do you think staff attitudes have changed?**

- Yes                       No                       Don't Know

**Q.5 Do you feel listened to?**

- Yes                       No                       Don't Know

**Q.6 Are your views and wishes given priority?**

- 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 will happen?**

- Yes                       No                       Don't Know

**Q.9 Are services available in your community (for example, home-based treatment, outreach services or a key worker)?**

- Yes                       No                       Don't Know

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

- Yes                       No                       Don't Know

**Q.11 Do you attend a voluntary group?**

- Yes                       No

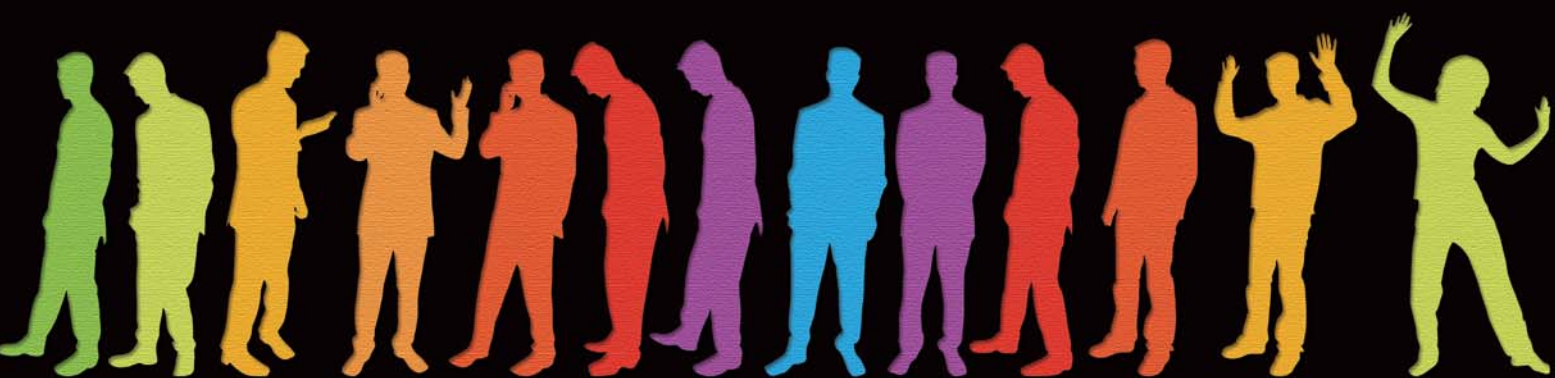
**Q.12 Tick your three main priorities for change.**

- |   |  |
|---|--|
| <input type="checkbox"/> Less Medication            | <input type="checkbox"/> Being listened to                                     |
| <input type="checkbox"/> Set appointment time       | <input type="checkbox"/> More counseling services                              |
| <input type="checkbox"/> Staff attitudes            | <input type="checkbox"/> More information on treatment and consent             |
| <input type="checkbox"/> Involvement of family      | <input type="checkbox"/> Information on where and how to complain              |
| <input type="checkbox"/> Being seen by same doctor  | <input type="checkbox"/> Practical help with stressful home situations         |
| <input type="checkbox"/> Housing                    | <input type="checkbox"/> Choices of treatment (not just choices of medication) |
| <input type="checkbox"/> More meaningful activities | <input type="checkbox"/> Other (please specify)                                |
| <input type="checkbox"/> Employment                 |  |

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*Thanks for your time and expertise. Please return to:*

*National Service Users Executive, 91 Leopardstown Avenue, Blackrock, Co Dublin*



2009

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